

## Article

# Challenges to Institutionalization: The Definition of “Institution” and the Future of *Olmstead* Litigation

Jacobus tenBroek  
Disability Law Symposium

Kevin M. Cremin\*

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\* Director of Litigation for Disability and Aging Rights for MFY Legal Services, Inc., and Lecturer-in-Law at Columbia Law School. The author would like to thank Jota Borgmann, Michele Host, and Jeanette Zelhof for their helpful comments on an earlier version of this article.

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## I. INTRODUCTION

I was asked to facilitate a workshop at the 2011 Jacobus tenBroek Disability Law Symposium on “Challenges to Institutionalization.” An appropriate starting place is to ask: What is an “institution?”

There is no universally agreed-upon answer to this question. One common way of answering this question has been to contrast institutions with facilities that are located “in the community.” There is, however, widespread disagreement about what in the community means, and definitions of “community-based services” are often tautological.<sup>1</sup> Moreover, a facility that is located in the community can also be an institution.<sup>2</sup>

Another complicating factor is that our idea of what constitutes an institution is not static. When the deinstitutionalization movement began, the targets of litigation were state hospitals. But advocates, academics, and people with disabilities, over time, began to consider segregated residential settings with a wide variety of different characteristics—large or small; private or public; locked or unlocked—to be institutions.<sup>3</sup> Our

<sup>1</sup> See, e.g., DEWAYNE DAVIS ET AL., NAT’L CONF. OF STATE LEGISLATURES, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS (2000) (defining “[c]ommunity-based services” as “long-term support services for people who need help with activities of daily living outside of large state institutions or nursing homes and in their own homes and communities.”).

<sup>2</sup> See, e.g., Arlene S. Kanter, *A Home of One’s Own. The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Disabilities*, 43 AM. U. L. REV. 925, 932 (1994) (“Group homes, halfway houses, quarterway houses, and board and care homes are hardly ‘homes’ at all. Like institutions, they segregate people with disabilities and confine them with little, if any, attention to individual choice. The residents of such homes are seldom asked where or with whom they want to live.”) (footnotes omitted); Sarah Light, Note, *Rejecting the Logic of Confinement: Care Relationships and the Mentally Disabled Under Tort Law*, 109 YALE L.J. 381, 381 n.3 (1999) (“The concepts of the ‘community’ and ‘confinement,’ or ‘institutionalization,’ are loaded and are hardly discrete and dichotomous categories.”).

<sup>3</sup> See, e.g., William A. Kraus, Note, *The Incompetent Developmentally Disabled Person’s Right of Self-Determination: Right-to-Die, Sterilization and Institutionalization*, 15 AM. J.L. & MED. 333, 359 n.134 (1989) (“Institutionalization can mean any one of a number of living conditions. Currently, the term can refer to group adult homes, half-way houses or respite homes. The term should no longer connote the ominous images of years ago, when institutionalization largely meant commitment in an insane asylum without treatment.”); David Ferleger and Penelope A. Body, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 STAN. L. REV. 717, 721 n.11 (1979) (“No single definition of ‘institution’ can suffice for all purposes. The word is typically invoked to reflect the historic use of facilities, public and private, providing residential and other services on a full-time basis to the mentally disabled. As times change, so do the words used to denote such facilities—asylums, madhouses, state schools, training schools, colonies, centers, hospitals, farms, homes. Among the common characteristics of what we term ‘institution’ for the purpose of this article are: (1) congregate living in a group larger than an above-average family, (2) maintenance of most activities of life (residential, social, vocational, leisure, educational, creative) within one administrative entity, and (3) some degree of isolation or separation from the ebb and flow of

conception of what constitutes an institution can and should continue to evolve, much in the same way that our conception of what constitutes cruel and unusual punishment under the Eighth Amendment has evolved.<sup>4</sup>

With regard to litigation that is brought pursuant to the integration mandate<sup>5</sup> of the Americans with Disabilities Act (ADA),<sup>6</sup> asking whether a given facility is an institution is also arguably the wrong question or, at the very least, a secondary question. In *Olmstead v. L.C.*, two plaintiffs with disabilities challenged Georgia's decision to provide them with services in a mental hospital even though their "needs could be met appropriately in one of the community-based programs the State supported."<sup>7</sup> The Supreme Court held that, under the ADA, "unjustified isolation . . . is properly regarded as discrimination based on disability."<sup>8</sup> Many cases that invoke the ADA's integration mandate and the *Olmstead* precedent have involved institutions, such as mental hospitals. However, the fundamental question in these so-called *Olmstead* cases is not whether the person is receiving services in an institution, but whether the person with a disability is receiving services in the most integrated setting that is appropriate to his or her needs.<sup>9</sup>

The term institution, however, continues to be invoked in *Olmstead* cases. There are at least two reasons for this. First, the term "institutionalization" has strong rhetorical value. It is effective, powerful short-hand for a long history of discrimination and exclusion. Second, there is an undeniable relationship between institutionalization and segregation.<sup>10</sup> The two are, at the very least, highly correlated. But it is important to remember that segregation can and does occur outside of institutions. Using the term "deinstitutionalization" connects current efforts to a valiant history, but it can also lead to unnecessary obstacles to future success. One does not have to prove that a particular setting is an institution to succeed in proving that a public entity has failed to provide a service in the most integrated setting appropriate to the needs of a person with a disability.

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community life. The third characteristic merely represents the effect of the second; by definition, when one's activities are carried on in one place, one becomes isolated from community life.").

<sup>4</sup> See, e.g., *Roper v. Simmons*, 543 U.S. 551, 560–61 (2005) (noting that the Supreme Court has "established the propriety and affirmed the necessity of referring to 'the evolving standards of decency that mark the progress of a maturing society' to determine which punishments are so disproportionate as to be 'cruel and unusual'" (citing *Trop v. Dulles*, 356 U.S. 86, 100–01 (1958) (plurality opinion))).

<sup>5</sup> 28 C.F.R. § 35.130(d) (2011) ("A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."). See discussion *infra* Part III.A.1.

<sup>6</sup> 42 U.S.C. §§ 12101–12213 (2006). See discussion *infra* Part III.A.1.

<sup>7</sup> *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 593 (1999). See discussion *infra* Part III.A.2.

<sup>8</sup> *Id.* at 597.

<sup>9</sup> See *id.* at 591–92.

<sup>10</sup> See *id.* at 620 (noting that "certain congressional findings contained within the ADA . . . appear to equate institutional isolation with segregation") (Thomas, J., dissenting). See also 42 U.S.C. § 12101(a)(2), (3), (5) (2006).

Different definitions of institution emphasize different characteristics. But generally, characteristics such as who owns the facility; how many residents there are; and what services are provided, are not intrinsically significant. Instead, the different definitions appear to use these characteristics as objective proxies for a more subjective inquiry about unnecessary segregation. Under *Olmstead*, the key question is whether individuals with disabilities are being unnecessarily segregated from the community.

This Article attempts to shed light on the future of *Olmstead* litigation. Part II examines the characteristics of facilities that have historically been targeted by deinstitutionalization efforts. Building on this history, Part III looks at potential definitions of the term institution. It begins with an in-depth examination of *Disability Advocates, Inc. v. Paterson*,<sup>11</sup> which is the only *Olmstead* case that has explicitly grappled with the question of what constitutes an institution. Drawing on common usage; other federal laws; and international law, Part III then examines other potential definitions of institution. Part IV attempts to describe the implications of an accurate understanding of the term institution for future *Olmstead* litigation. In particular, residential settings that have not historically been considered institutions are being scrutinized by advocates and individuals with disabilities. This Part also describes how *Olmstead* is increasingly being applied to non-residential services. Part V concludes this Article.

## II. CHARACTERISTICS OF FACILITIES HISTORICALLY TARGETED BY DEINSTITUTIONALIZATION LITIGATION

Deinstitutionalization litigation began with challenges to confinement in state mental hospitals. In addition to state hospitals, nursing homes and intermediate care facilities have been commonly

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<sup>11</sup> *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289 and 653 F. Supp. 2d 184 (E.D.N.Y. 2009), *vacated by* *Disability Advocates, Inc. v. New York Coalition for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012). The Second Circuit recently held that the plaintiff organization did not have standing to bring this lawsuit on behalf of thousands of individuals with mental illness who live in adult homes in New York City. *Disability Advocates, Inc.*, 675 F.3d at 159. Although the Second Circuit vacated the trial court's decision, it did not question the trial court's findings, discussed in Part III.A *infra*, that adult homes are institutions and that New York is violating the ADA. The Second Circuit also acknowledged that its decision is unlikely to be the last word regarding New York's use of adult homes:

We are not unsympathetic to the concern that our disposition will delay the resolution of this controversy and impose substantial burdens and transaction costs on the parties, their counsel, and the courts. Should that situation arise, we are confident that the experienced and able district judge, as a consequence of his familiarity with prior proceedings, can devise ways to lessen those burdens and facilitate an appropriate, efficient resolution.

*Id.* at 162.

targeted by deinstitutionalization lawsuits.<sup>12</sup> Instead of focusing on the procedural histories or even the outcomes of these cases, this Part examines the characteristics of the facilities that have been targeted by deinstitutionalization litigation.<sup>13</sup>

### A. State Mental Hospitals

Approximately 40,000 Americans reside in mental hospitals or general hospital psychiatric units today.<sup>14</sup> State mental hospitals were the first targets of deinstitutionalization litigation. Early lawsuits included *Wyatt v. Stickney*, a 1970 class action filed by guardians of patients at Bryce Hospital in Tuscaloosa, Alabama.<sup>15</sup> Bryce Hospital had approximately 5,000 patients.<sup>16</sup> Of these patients, between 1,500 and 1,600 were “geriatric patients who [were] provided custodial care but no treatment.”<sup>17</sup> Custodial care was also provided to the “approximately 1,000 mental retardates” who were confined at Bryce.<sup>18</sup>

The complaint was later amended to include patients at “the Searcy Hospital at Mount Vernon, Alabama, [which was] the one other state hospital for the mentally ill in Alabama, and the Partlow State School and Hospital, Alabama’s state facility for the mentally retarded.”<sup>19</sup> Patients in these hospitals “were afforded virtually no privacy: the wards were overcrowded; there was no furniture where patients could keep clothing; [and] there were no partitions between commodes in the bathrooms.”<sup>20</sup> At Partlow State School, patients were frequently put in seclusion “or under physical restraints, including straitjackets, without physicians’ orders.”<sup>21</sup> The hospitals did not have adequate staffing, and

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<sup>12</sup> These institutions are also the target of the overwhelming majority of administrative complaints filed about institutionalization. See Sara Rosenbaum, Joel Teitelbaum & Alexandra Stewart, *Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 116 (2002) (noting that, of all the administrative complaints filed between 1996–2000, “nursing homes were the single most common institutional setting among complainants, accounting for 60% of all complaints filed by institutionalized persons. Another 30% arose in psychiatric facilities”).

<sup>13</sup> Approximately 89 *Olmstead* lawsuits have been filed in 35 states. TERENCE NG, ALICE WONG & CHARLENE HARRINGTON, HOME AND COMMUNITY-BASED SERVICES: INTRODUCTION TO OLMS TED LAWSUITS AND OLMS TED PLANS 11 (2011), [http://www.pascenter.org/olmstead/downloads/Olmstead\\_report\\_2011.pdf](http://www.pascenter.org/olmstead/downloads/Olmstead_report_2011.pdf).

<sup>14</sup> U.S. CENSUS BUREAU, 2010 CENSUS, TABLE PCT20: GROUP QUARTERS POPULATION BY GROUP QUARTERS TYPE, available at [http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC\\_10\\_SF1\\_PCT20&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_SF1_PCT20&prodType=table) (showing that 42,035 people reside in “[m]ental (psychiatric) hospitals and psychiatric units in other hospitals”) [hereinafter U.S. CENSUS BUREAU].

<sup>15</sup> *Wyatt v. Stickney*, 325 F. Supp. 781, 782 (M.D. Ala. 1971).

<sup>16</sup> *Id.*

<sup>17</sup> *Id.* at 784.

<sup>18</sup> *Id.*

<sup>19</sup> *Wyatt v. Aderholt*, 503 F.2d 1305, 1308 (5th Cir. 1974).

<sup>20</sup> *Id.* at 1310.

<sup>21</sup> *Id.* at 1310–11.

they did not provide the patients with “individualized treatment programs.”<sup>22</sup> The District Court held that “civilly committed mental patients have a constitutional right to treatment,” and the Fifth Circuit affirmed that holding.<sup>23</sup> But that was not the end of the case. *Wyatt* was ultimately settled thirty years after it was filed.<sup>24</sup>

## B. Nursing Homes

Almost 1.5 million Americans live in nursing homes.<sup>25</sup> Nursing homes are increasingly the subject of deinstitutionalization litigation. In 2000, a class of residents of Laguna Honda Hospital and Rehabilitation Center (LHH), operated by the City of San Francisco, filed an *Olmstead* case against the city.<sup>26</sup> The lawsuit was filed in the wake of a Department of Justice (DOJ) finding that San Francisco was “failing to ensure that LHH residents [were] being served in the most integrated setting pursuant to the ADA.”<sup>27</sup> In particular, the DOJ found that residents who “have spinal cord injuries and use wheelchairs . . . could live in the community independently or with some supportive services.”<sup>28</sup>

At the time the DOJ investigated LHH, the hospital had almost 1,200 residents.<sup>29</sup> Most of these residents lived in “large, open wards that house[d] up to 37 residents per ward, with multiple beds in close proximity, separated, at most, by hospital curtains.”<sup>30</sup> This living

<sup>22</sup> *Id.* at 1311.

<sup>23</sup> *Id.* at 1313–14. See generally Note, *The Wyatt Case. Implementation of a Judicial Decree Ordering Institutional Change*, 84 YALE L.J. 1338 (1975).

<sup>24</sup> *Wyatt v. Sawyer*, 105 F. Supp. 2d 1234, 1238 (M.D. Ala. 2000) (approving the settlement that included, *inter alia*, a requirement that Alabama “reduce by a total of 300 the number of extended-care mental-illness beds at Bryce Hospital, Searcy Hospital, and Thomasville Mental Health Rehabilitation Center and by a total of 300 the number of extended-care mental-retardation beds at Partlow Developmental Center, Albert P. Brewer Developmental Center, J.S. Tarwater Developmental Center, and Lurleen B. Wallace Developmental Center”). The court retained jurisdiction until 2004, when it granted a joint motion “for a declaration that the Alabama Department of Mental Health and Mental Retardation . . . complied with a 2000 settlement agreement.” *Wyatt v. Sawyer*, 219 F.R.D. 529, 531 (M.D. Ala. 2004).

<sup>25</sup> U.S. CENSUS BUREAU, *supra* note 14 (showing that 1,502,264 people reside in “Nursing facilities/Skilled-nursing facilities”). But see CENTERS FOR MEDICARE & MEDICAID SERVICES, NURSING HOME DATA COMPENDIUM at i (2010), available at [https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/downloads/nursinghomedatacompendium\\_508.pdf](https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/downloads/nursinghomedatacompendium_508.pdf) (“Almost 3.3 million Americans resided in our nation’s nursing homes during 2009.”).

<sup>26</sup> See *Davis v. Cal. Health and Human Servs. Agency*, No. C 00-CV-2532 SBA ADR, 2001 WL 1772763, at \*1 (N.D. Cal. Aug. 21, 2001) (granting San Francisco’s motion to dismiss to the extent the plaintiffs’ claims were “intended to or may be interpreted as requiring San Francisco to create new programs or services,” but denying it to the extent that those claims were “seeking that San Francisco make modifications to programs or services”).

<sup>27</sup> Letter from Bill Lann Lee, Assistant Attorney General of Civil Rights Division, to The Honorable Willie L. Brown, Jr., Mayor of San Francisco at 14 (May 6, 1998), available at [http://www.ada.gov/olmstead/documents/laguna\\_findings.pdf](http://www.ada.gov/olmstead/documents/laguna_findings.pdf) [hereinafter Letter].

<sup>28</sup> *Id.*

<sup>29</sup> *Id.* at 1.

<sup>30</sup> *Id.* See also *id.* at 13 (noting that “at least two wards did not even have these curtains”).

arrangement, as well as the constant traffic through the ward, “ma[de] privacy almost impossible.”<sup>31</sup>

The DOJ concluded that conditions at LHH violated the residents’ statutory and constitutional rights.<sup>32</sup> For example, the nursing home did not “provide residents with adequate, individualized health care assessments necessary to develop a comprehensive plan of care.”<sup>33</sup> The care provided was custodial: “only approximately 50 residents were receiving physical, occupational or speech therapy services.”<sup>34</sup> The DOJ also found that Laguna Honda used “restraints on its residents in violation of accepted standards of practice and in ways that threaten[ed] the health and safety of residents.”<sup>35</sup>

Like *Wyatt*, the story of LHH is a long one. It was not until 2011 that the DOJ ended its fourteen years of oversight of the nursing home.<sup>36</sup> Today, LHH states that it provides a “person-centered approach [that] promotes well-being and independence” for its 780 residents.<sup>37</sup>

### C. Intermediate Care Facilities

In 1989, a lawsuit was filed against the State of Ohio on behalf of a class of over 9,000 people with “mental retardation or developmental disabilities” alleging that they were unnecessarily institutionalized or faced the risk of unnecessary institutionalization.<sup>38</sup> One of the named plaintiffs was Nancy Martin, who had resided in an intermediate care facility (ICF) for her entire adult life.<sup>39</sup> Mount Vernon Developmental Center, in which Ms. Martin lived for approximately twenty-five years, had more than 300 residents.<sup>40</sup> Mount Vernon staff acknowledged that “Ms. Martin’s placement at the facility was inappropriate and recommended that Ms. Martin be moved to a community setting.” However, when she was finally transferred out of the facility, she was sent to yet another ICF.<sup>41</sup> In 2004, a potential settlement agreement was

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<sup>31</sup> Letter, *supra* note 27, at 13.

<sup>32</sup> *Id.* at 2.

<sup>33</sup> *Id.* at 7.

<sup>34</sup> *Id.* at 11.

<sup>35</sup> Letter, *supra* note 27, at 12.

<sup>36</sup> Heather Knight, *Laguna Honda Hospital nears end of U.S. oversight*, S.F. CHRONICLE, June 13, 2011, at C1, available at <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2011/06/13/BA7G1JRCU1.DTL>.

<sup>37</sup> *Our Values*, LAGUNA HONDA HOSPITAL AND REHABILITATION CENTER, <http://lagunahonda.org> (last visited Mar. 29, 2012).

<sup>38</sup> *Martin v. Voinovich*, 840 F. Supp. 1175, 1181 (S.D. Ohio 1993).

<sup>39</sup> See *id.* at 1181–82 (Ms. Martin lived in one of those ICFs, Mount Vernon Developmental Center, from March 30, 1966 through October 9, 1991). See also *Martin v. Taft*, 222 F. Supp. 2d 940, 948–49 (S.D. Ohio 2002) (noting that Ms. Martin was still living in an ICF when the relevant motion was filed in 2000).

<sup>40</sup> *Martin*, 222 F. Supp. 2d at 948.

<sup>41</sup> *Id.* at 949.

reached that would have eliminated ICF care “as a [Medicaid] state plan service and ma[de] it a waived service that individuals could choose as an alternative to community services.”<sup>42</sup> The settlement was “not accepted due to public outcry from people arguing that it would undermine entitlement to [ICF] services.”<sup>43</sup> The case is currently heading to trial, over twenty years after it was filed.<sup>44</sup>

More recently, a class action was brought on behalf of people who reside in ICFs in Pennsylvania, but who “could reside in the community with appropriate services and supports.”<sup>45</sup> More than 1,200 people with disabilities live in Pennsylvania’s five ICFs.<sup>46</sup> Two of the named plaintiffs lived at one of these facilities, the Ebensburg Center, for over forty years.<sup>47</sup> The court found that the residents of ICFs were more segregated than people with disabilities who were receiving community-based services:

[M]ost state ICFs/MR are in more rural parts of the state; most state ICF/MR residents live in units ranging from about 16 to 20 people; day services are usually provided on the grounds of the facilities; and residents do not have as much opportunity to interact with a wide range of people and to have access to community activities.<sup>48</sup>

Because plaintiffs “established that Defendants ha[d] violated the integration mandates of Section II of the ADA and Section 504 of the Rehabilitation Act by unnecessarily institutionalizing Plaintiffs,”<sup>49</sup> the court granted plaintiffs’ motion for summary judgment.<sup>50</sup>

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<sup>42</sup> Marshall B. Kapp, *Deinstitutionalizing Long-Term Care: Making Legal Strides, Avoiding Policy Errors*, 11 ETHICS, L., & AGING REV. 53 (Marshall B. Kapp ed. 2005). See also Elizabeth Prialux, *Docket of Cases Related to Access to Community Based Services for People with Disabilities*, NATIONAL DISABILITY RIGHTS NETWORK (2004), <http://www.napas.org/en/issues/community-integration/345-dockets-for-community-based-services.html>.

<sup>43</sup> CTR. FOR PERSONAL ASSISTANCE SERVS., *Ohio Olmstead and Olmstead Related Cases*, 2011, [http://www.pascenter.org/olmstead/olmstead\\_cases.php?state=ohio](http://www.pascenter.org/olmstead/olmstead_cases.php?state=ohio) (last visited Feb. 26, 2012). See also Kapp, *supra* note 42, at 54 (“In response to the proposed settlement, the federal court with jurisdiction over the case received more than 5,600 objections. Of these objections, 80% were on forms created by the ICF industry, attempting to preserve the status quo.”).

<sup>44</sup> *Id.*

<sup>45</sup> *Benjamin v. Dep’t of Pub. Welfare*, 768 F. Supp. 2d 747, 748 (M.D. Pa. 2011).

<sup>46</sup> *Id.* at 749 (citing figures from 2008 and 2009). Another approximately 2,500 people with mental retardation live in private ICFs that are funded by Pennsylvania. *Id.*

<sup>47</sup> *Id.* at 750.

<sup>48</sup> *Id.*

<sup>49</sup> *Id.* at 756.

<sup>50</sup> *Benjamin*, 768 F. Supp. 2d at 757. This lawsuit was recently settled. See CTR. FOR PERSONAL ASSISTANCE SERVS., *Pennsylvania Olmstead and Olmstead Related Cases*, 2012, [http://www.pascenter.org/olmstead/olmstead\\_cases.php?state=pennsylvania&id=146#summary](http://www.pascenter.org/olmstead/olmstead_cases.php?state=pennsylvania&id=146#summary) (last visited Feb. 26, 2012).



### III. WHAT IS AN INSTITUTION?

The word institution is often used in newspaper articles, lawsuits, and law review articles about people with disabilities. The term is not, however, defined in the ADA or in the *Olmstead* decision. In this Part, various potential definitions of institution are described and their elements are analyzed. This Part begins with how the court in *Disability Advocates, Inc. v. Paterson* (*DAI I*) attempted to define institution.<sup>51</sup> Other definitions from dictionaries, the U.S. Census Bureau, federal law, international law, and social scientific literature are also described.<sup>52</sup> These definitions demonstrate that the term institution is not used consistently, and that the most useful definitions are those that focus on the presence or absence of a cluster of characteristics in a given facility. This Part also examines attempts to define institution in the negative, i.e., by saying that it is not part of the community or that it is not a “home.”

#### A. Definition of Institution in *DAI I*

*Olmstead* claims have typically involved facilities or settings whose institutional nature was not in dispute.<sup>53</sup> In *DAI I*, however, the defendants asserted that the relevant facilities—adult homes<sup>54</sup> in New York City with more than 120 beds and in which at least twenty-five

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<sup>51</sup> *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 298 (E.D.N.Y. 2009) [hereinafter *DAI I*], *vacated by* *Disability Advocates, Inc. v. New York Coalition for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

<sup>52</sup> The term “institution” is also defined in countless state and local statutes and regulations, including licensing and zoning laws. *See, e.g.*, Brandon J. Massey, Cooper Clinic, P.A. v. Barnes: *The Arkansas Child Maltreatment Act And Its Fatal Ambiguities*, 60 ARK. L. REV. 989, 1007–09 (2008) (discussing the Arkansas Supreme Court’s attempt to define the term “institution” as it is used in the Arkansas Child Maltreatment Act and noting that, in a dissenting opinion, Justice Hickman “posed the following question: ‘What is an institution—one person or a dozen persons?’”). Like the federal government, some states define institution differently, depending on the context. *Cf.* CONN. GEN. STAT. ANN. § 19a-490 (defining institution for purposes of licensing to include, *inter alia*: “a hospital, residential care home, health care facility for the handicapped, nursing home, rest home, home health care agency, homemaker-home health aide agency, mental health facility, assisted living services agency, substance abuse treatment facility, outpatient surgical facility, an infirmary operated by an educational institution for the care of students enrolled in, and faculty and employees of, such institution . . .”) with CONN. GEN. STAT. ANN. § 9-159q (defining institution for purposes of absentee voting as “a veterans’ health care facility, residential care home, health care facility for the handicapped, nursing home, rest home, mental health facility, alcohol or drug treatment facility, an infirmary operated by an educational institution for the care of its students, faculty and employees or an assisted living facility”). An analysis of the use of the term institution in state and local laws is, however, beyond the scope of this Article.

<sup>53</sup> *DAI I*, 598 F. Supp. 2d at 320–21 (“*Olmstead* and lower courts considering *Olmstead* claims have typically confronted situations in which the ‘institutional’ or ‘community-based’ nature of particular settings was not in dispute”).

<sup>54</sup> *See* N.Y. COMP. CODES R. & REGS. tit. 18, § 485.2(b) (defining an “adult home” to be “an adult-care facility established and operated for the purpose of providing long-term residential care, room, board, housekeeping, personal care and supervision to five or more adults unrelated to the operator”).

residents have a mental illness—were not institutions and should not be subject to an *Olmstead* lawsuit.<sup>55</sup> Judge Garaufis was therefore faced with determining what constitutes an institution for the purposes of Title II of the Americans with Disabilities Act. As explained below, after examining the ADA and its regulations and *Olmstead* for answers, Judge Garaufis adopted the definition of institution proffered by one of the plaintiff's expert witnesses.<sup>56</sup>

### ***1. The Americans with Disabilities Act***

The word institutionalization appears in the ADA's findings, where it is included as one of the "critical areas" in which "discrimination against individuals with disabilities persists."<sup>57</sup> The ADA does not, however, describe what institutionalization is or explicitly define what constitutes an institution.

Instead, the ADA focuses on the broader concept of the segregation of individuals with disabilities and the right they have to participate in society. The congressional findings emphasize that "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society."<sup>58</sup> The findings also note that, "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."<sup>59</sup> The ADA explains that "the Nation's proper goals regarding individuals with disabilities" include assuring "full participation" and "independent living."<sup>60</sup> Title III, for example, emphasizes the importance of "integrated settings" by requiring public accommodations, such as stores, to offer "[g]oods, services, facilities, privileges, advantages, and accommodations [to individuals with disabilities] in the most integrated setting appropriate to the needs of the individual."<sup>61</sup>

Title II protects the rights of individuals with disabilities to participate in the services, programs, and activities of public entities.<sup>62</sup> A "public entity" is a state or local government or "any department, agency, special purpose district, or other instrumentality of a State or States or local government."<sup>63</sup> The ADA requires public entities to make "reasonable modifications to rules, policies, or practices" for qualified

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<sup>55</sup> *DAI I*, 598 F. Supp. 2d at 292–93.

<sup>56</sup> See *infra* Part III.A.4.

<sup>57</sup> 42 U.S.C. § 12101(a)(3) (2006).

<sup>58</sup> *Id.* § 12101(a)(1).

<sup>59</sup> *Id.* § 12101(a)(2).

<sup>60</sup> *Id.* § 12101(a)(7).

<sup>61</sup> 42 U.S.C. § 12182(b)(1)(B) (2006).

<sup>62</sup> 42 U.S.C. § 12132 (2006).

<sup>63</sup> 42 U.S.C. § 12131(1) (2006).

individuals with disabilities.<sup>64</sup>

The Attorney General has the responsibility to promulgate regulations for Title II.<sup>65</sup> The ADA specifies that these regulations shall be consistent with the regulations “applicable to recipients of Federal financial assistance under [Section 504 of the Rehabilitation Act].”<sup>66</sup> As the Supreme Court noted in *Olmstead*, “[o]ne of the [Section] 504 regulations requires recipients of federal funds to ‘administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.’”<sup>67</sup>

The Title II regulations flesh out the ADA’s prohibitions against discrimination by public entities.<sup>68</sup> These regulations elaborate on the ADA’s focus on the right to full and equal participation in civil society.<sup>69</sup> The regulations do not define what constitutes an institution or a community-based setting.<sup>70</sup> However, one Title II regulation echoes the above-mentioned “most integrated setting” language from Title III of the ADA and the Rehabilitation Act regulations: “A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>71</sup> The preamble to the Title II regulations explains that the “most integrated setting” for an individual is “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.”<sup>72</sup> The meaning of this regulation, which is generally referred to as the ADA’s “integration mandate,” is at the heart of the landmark *Olmstead* decision.

## 2. *Olmstead v. L.C.*

*Olmstead* involved two plaintiffs with disabilities who challenged Georgia’s decision to provide them with services in an “institutional setting” even though their “needs could be met appropriately in one of the community-based programs the State supported.”<sup>73</sup> Both plaintiffs

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<sup>64</sup> See *id.* § 12131(2).

<sup>65</sup> 42 U.S.C. § 12134(a) (2006).

<sup>66</sup> *Id.* § 12134(b).

<sup>67</sup> *Olmstead v. L.C.*, 527 U.S. at 591–92 (quoting 28 C.F.R. § 41.51(d) (1998)).

<sup>68</sup> See generally 28 C.F.R. § 35.130 (2011).

<sup>69</sup> See, e.g., *id.* § 35.130(a) (“No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity”); *id.* § 35.130(b)(2) (“A public entity may not deny a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different”).

<sup>70</sup> *DAI I*, 598 F. Supp. 2d at 320.

<sup>71</sup> 28 C.F.R. § 35.130(d) (2011).

<sup>72</sup> *Id.* app. B § 35.130(d) (2011).

<sup>73</sup> *Olmstead*, 527 U.S. at 593. This discussion of *Olmstead* will be limited to the portions of the decision that provide insights into the meaning of the terms “institution” and “community-based” under Title II of the ADA. Numerous articles provide a more comprehensive account of the

challenged their treatment in Georgia Regional Hospital at Atlanta, a mental hospital with 352 inpatient beds.<sup>74</sup> The Supreme Court noted that both plaintiffs were “currently receiving treatment in community-based programs,”<sup>75</sup> but the characteristics of those programs were not described.<sup>76</sup>

The Supreme Court noted that the ADA was the “first time” Congress “referred expressly to ‘segregation’ of persons with disabilities as a ‘for[m] of discrimination,’ and to discrimination that persists in the area of ‘institutionalization.’”<sup>77</sup> In describing the integration mandate, the Supreme Court noted that “the Attorney General concluded that unjustified placement or retention of persons in institutions, severely limiting their exposure to the outside community, constitutes a form of discrimination based on disability prohibited by Title II.”<sup>78</sup> The litigants in *Olmstead* were focused “on the proper construction and enforcement” of the Title II regulations, not their validity.<sup>79</sup>

The question presented by *Olmstead* was whether Title II of the ADA “require[d] placement of persons with mental disabilities in community settings rather than in institutions.”<sup>80</sup> The Court’s answer to that question was a “qualified yes.”<sup>81</sup> It was qualified because a community setting is required only if three conditions are met: (1) “the State’s treatment professionals have determined that community placement is appropriate”; (2) “the transfer from institutional care to a less restrictive setting is not opposed by the affected individual”; and (3) “the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”<sup>82</sup> If these three criteria are met, institutionalization of a person with a disability is discriminatory.<sup>83</sup>

In reaching this decision, the Court emphasized that the DOJ has “consistently advocated” that “undue institutionalization qualifies as

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*Olmstead* case and aspects of it that are not discussed in this article, including its procedural history and the fundamental alternation defense. See, e.g., Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after Olmstead v. L.C.*, 24 HARV. J.L. & PUB. POL’Y 695 (2001).

<sup>74</sup> GA. DEP’T OF BEHAVIORAL HEALTH & DEV. DISABILITIES, GA. REG’L-ATLANTA, <http://dbhdd.georgia.gov/portal/site/DBHDD/menuitem.2f54fa407984c51e93f35cead03036a0/?vgnextoid=b75bd8d66662f210VgnVCM100000bf01010aRCRD> (last visited Apr. 1, 2012).

<sup>75</sup> *Olmstead*, 527 U.S. at 594 n.6.

<sup>76</sup> See *DAI I*, 598 F. Supp. 2d at 321 (noting that in *Olmstead*, the “plaintiff L.C. had already been removed from the psychiatric hospital—in which she had undisputedly been ‘institutionalized’—and placed in a ‘community-based program,’ but the opinion did not describe the nature of the community-based program”).

<sup>77</sup> *Olmstead*, 527 U.S. at 589 n.1 (citing 42 U.S.C. § 12101(a)(2), (3), (5) (1990)).

<sup>78</sup> *Id.* at 596 (citing 28 C.F.R. § 35.130(d) (1998)).

<sup>79</sup> *Id.* at 592.

<sup>80</sup> *Id.* at 587.

<sup>81</sup> *Id.*

<sup>82</sup> *Olmstead*, 527 U.S. at 587.

<sup>83</sup> *Id.* at 597 (holding that “[u]njustified isolation . . . is properly regarded as discrimination based on disability”).

discrimination ‘by reason of . . . disability.’”<sup>84</sup> The Supreme Court’s decision rested on the ADA’s recognition that “unjustified ‘segregation’ of persons with disabilities [is] a ‘for[m] of discrimination.’”<sup>85</sup> The Supreme Court explained why “unjustified segregation” is discrimination:

First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.<sup>86</sup>

Unjustified isolation also discriminates against people with mental disabilities by making them choose between receiving necessary medical services and participating in community life.<sup>87</sup> The Court noted that people without mental disabilities are not asked to make this sacrifice and that people with mental disabilities would not have to either, if public entities provided them with reasonable accommodations.<sup>88</sup>

### 3. *The Motion for Summary Judgment in DAI I*

In 2003, *DAI I* was filed against the State of New York.<sup>89</sup> The

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<sup>84</sup> *Id.*

<sup>85</sup> *Id.* at 600 (citing 42 U.S.C. § 12101(a)(2), (5) (1990)).

<sup>86</sup> *Id.* at 600–01 (citations omitted). *Olmstead* has been criticized for focusing on “institutions” as opposed to “attitudes” and “programmatic structures.” See Jeffery L. Geller, *Does “In the Community” Mean Anything Anymore?*, 53 PSYCHIATRIC SERVICES 1201, 1201 (2002) (“Isn’t it time we stopped paying so much attention to the walls and started paying more attention to what happens within them?”). Dr. Geller was one of the expert witnesses for the defendants in *DAI I*, and during his testimony he directly criticized the *Olmstead* decision. *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 216–17 (E.D.N.Y. 2009) [hereinafter *DAI II*] (“Dr. Geller explicitly rejected the applicable legal standard for integration. He testified that he believes the Supreme Court’s finding in *Olmstead* that ‘confinement in an institution severely diminishes the everyday life activities of individuals’ was ‘wrong,’ and that the setting in which a person lives and receives services does not determine whether he or she is ‘integrated’”), *vacated by* *Disability Advocates, Inc. v. New York Coalition for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

<sup>87</sup> *Olmstead*, 527 U.S. at 601. See also Leshe Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 193 (2010) (“While the Court’s decision in *Olmstead* directly addressed the specific issue of institutional confinement, it was not the institutional conditions that were the focus of the Court’s concerns. Rather, the Court focused on the harms flowing from the individual’s segregation from society—namely the perpetuation of demeaning stereotypes and lost opportunities for engagement in significant aspects of community life.”) (footnotes omitted).

<sup>88</sup> *Id.*

<sup>89</sup> The plaintiff was represented by MFY Legal Services, Inc.; Disability Advocates, Inc.; the Bazelon Center for Mental Health Law; New York Lawyers for the Public Interest; the Urban Justice Center; and Paul, Weiss, Rifkind, Wharton & Garrison, LLP. *DAI I*, 598 F. Supp. 2d at 289.

lawsuit alleged that New York unnecessarily segregated people with psychiatric disabilities in large, isolated adult homes, and requested that New York reallocate the funds that it spends on adult homes to provide supported housing for adult home residents.<sup>90</sup>

Unlike *Olmstead*, the question of whether the relevant facilities were institutions was contested by the defendants in *DAI I*.<sup>91</sup> Judge Garaufis was first faced with the question of what constitutes an institution in deciding the parties' motions for summary judgment.<sup>92</sup> The defendants moved for summary judgment on the grounds that (1) Title II of the ADA did not apply "because the adult homes are privately operated and the State merely licenses and inspects them,"<sup>93</sup> and (2) "adult home residents [were] already in the 'most integrated setting,' because adult homes and supported housing are 'equally integrated' with the community."<sup>94</sup>

New York's argument focused on the ownership of the relevant facility and whether a facility can be considered an institution for purposes of Title II if the facility is owned by a private entity, as opposed to a public entity. In opposition, the plaintiff argued that it was challenging New York's policy of "relying on adult homes, rather than the more integrated setting of supported housing, to provide residential and treatment services to thousands of individuals with mental illness."<sup>95</sup> The plaintiff provided evidence that, when New York began closing state psychiatric hospitals, "the State made a 'policy decision' to serve large numbers of former patients in adult homes."<sup>96</sup> Moving people with disabilities from state mental hospitals to privately owned "board and care homes"<sup>97</sup> has been described as "transinstitutionalization."<sup>98</sup>

Judge Garaufis concluded that Title II applied because the plaintiff was challenging the state's administration of its mental health service system, and not "the conduct of any particular adult home."<sup>99</sup> The fact

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<sup>90</sup> *Id.* at 292.

<sup>91</sup> *Id.* at 320.

<sup>92</sup> *Id.*

<sup>93</sup> *Id.* at 293.

<sup>94</sup> *DAI I*, 598 F. Supp. 2d at 293. "Defendants contend that . . . adult home residents have 'virtually unlimited opportunities to interact with nondisabled persons,' and adult homes facilitate these interactions through community-based programs." *Id.* at 320.

<sup>95</sup> *Id.* at 313.

<sup>96</sup> *Id.* at 296–97. See also *id.* at 297 (summarizing evidence that "the placement of large numbers of people with mental illness into adult homes was the result of a 'conscious State policy' to discharge patients from psychiatric hospitals into these facilities 'due to the absence of other housing alternatives at a time when psychiatric centers were under pressure to downsize'").

<sup>97</sup> MEDICARE.GOV, *Types of Long-Term Care*, <http://www.medicare.gov/longtermcare/static/BoardCareHome.asp> (defining "board and care homes" as a "group living arrangement [that] provides help with activities of daily living such as eating, bathing, and using the bathroom for people who cannot live on their own but do not need nursing home services.") (last visited Apr. 1, 2012).

<sup>98</sup> See, e.g., Jennifer Mathis, *Where Are We Five Years After Olmstead?*, 38 CLEARINGHOUSE REV. 561, 581 (2005).

<sup>99</sup> *DAI I*, 598 F. Supp. 2d at 318 ("In other words, [*DAI I*] challenges the State's choice to plan and administer its mental health services in a manner that results in thousands of individuals with mental

that the state's policy decisions led to individuals with disabilities being provided with services in private facilities was therefore "immaterial."<sup>100</sup> After deciding that Title II applied, Judge Garaufis examined whether adult home residents were in the "most integrated setting."

The parties offered different interpretations of the integration mandate. Defendants asserted that "'under the regulatory definition of 'integration,' the key was 'whether persons with disabilities have opportunities for contact with nondisabled persons, rather than the number of actual contacts.'"<sup>101</sup> Disability Advocates contended that it was not enough for a setting to be integrated—"providing services in settings with some opportunities for interaction is unlawful if another appropriate setting would provide more opportunities, and the individual in question does not oppose the more integrated setting."<sup>102</sup> The court agreed with Disability Advocates' interpretation of the integration mandate and declared that "[t]he question before the court is whether the large, impacted adult homes at issue enable interactions with non-disabled persons to the fullest extent possible."<sup>103</sup>

In order to assess "whether adult home residents are in the most integrated setting appropriate to their needs," Judge Garaufis considered evidence about the characteristics of the adult homes at issue.<sup>104</sup> Both parties "submitted evidence on the extent to which the adult homes share characteristics of institutions, opportunities for adult home residents to interact with people outside the adult homes, and programs and services offered in the homes."<sup>105</sup> However, Judge Garaufis found that "the parties' expert and fact witnesses ultimately disagree as to whether the homes are akin to 'institutions.'"<sup>106</sup>

In denying New York's motion for summary judgment, Judge Garaufis held that "[a] reasonable finder of fact could conclude that adult homes do not enable residents' interactions with non-disabled individuals to the fullest extent possible."<sup>107</sup> The court noted that it "is undisputed that the adult homes share certain characteristics of medical facilities and inpatient psychiatric facilities."<sup>108</sup> New York itself "ha[d] long

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illness living and receiving services in allegedly segregated settings.").

<sup>100</sup> *Id.* at 317 (citing *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 237 (D. Mass. 1999)).

<sup>101</sup> *Id.* at 320 (emphasis in the original) (quotations omitted).

<sup>102</sup> *Id.*

<sup>103</sup> *Id.* at 321–22. See also *id.* at 296 (explaining that the term "'impacted' refers to adult homes in which at least 25% or 25 residents, whichever is fewer, have mental disabilities").

<sup>104</sup> *DAI I*, 598 F. Supp. 2d at 297.

<sup>105</sup> *Id.* at 297–98.

<sup>106</sup> *Id.* at 298.

<sup>107</sup> *Id.* at 322. See also *id.* at 330 ("DAI's evidence regarding the institutional nature of adult homes . . . is sufficient to raise an issue of disputed fact").

<sup>108</sup> *DAI I*, 598 F. Supp. 2d at 298. See also *id.* at 329 ("Numerous witnesses, including DAI's and defendants' experts, observed that adult homes share characteristics of psychiatric institutions. . . . [i]n particular, defendants' expert, Alan Kaufman, reported that the adult homes' 'provision . . . of laundry services, food services, housekeeping, and other daily living services-and the resident's lack of choice in performing these tasks him/herself-is characteristic of mental health institutional settings.' He concluded that 'a large [a]dult home setting coupled with a high proportion of residents

characterized adult homes as institutions.”<sup>109</sup> Government reports “referred to . . . adult homes as ‘de facto mental institutions’ and ‘satellite mental institutions.’”<sup>110</sup> The court found that the New York’s Office of Mental Health’s website grouped adult homes with nursing homes and state psychiatric hospitals and referred to them all as “‘institutional settings.’”<sup>111</sup> The plaintiff provided evidence that adult homes are “segregated settings akin to institutions that impede residents’ interaction with individuals without disabilities.”<sup>112</sup> This characterization was particularly true relative to another service-delivery model that New York offered to some people with disabilities—“supported housing.”<sup>113</sup>

Supported housing is “an alternative form of housing in which individuals with mental illness live in their own apartments scattered throughout the community and receive supportive services.”<sup>114</sup> New York funds the housing and the flexible, individualized services with which the housing is coupled.<sup>115</sup> These services “are designed to be flexible, so that residents may receive help with cooking, shopping, budgeting, medication management and making appointments as needed, but can do all of these things themselves if they are able to.”<sup>116</sup>

#### 4. *The Trial in DAI II*

The next phase in the *Disability Advocates, Inc. v. Paterson* lawsuit was an eighteen-day bench trial in 2009 (*DAI II*).<sup>117</sup> Based on the evidence presented at trial, Judge Garaufis concluded that adult homes are “institutions that segregate residents from the community and impede

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with mental illness can artificially limit the interactions of residents and constrict the diversity of friends and acquaintances.”) (internal citations omitted).

<sup>109</sup> *Id.* at 297.

<sup>110</sup> *Id.* (citations omitted).

<sup>111</sup> *Id.*

<sup>112</sup> *Id.* at 322. See also *id.* at 329 (“[*DAI*] has provided evidence that most aspects of the residents’ lives take place inside the adult homes, and that the residents are limited in the times they can leave the homes, given rigid schedules for meals, medications, and distribution of personal need allowances. [*DAI*] has provided evidence that the homes limit residents’ ability to interact and maintain relationships with non-disabled individuals.”) (citations omitted).

<sup>113</sup> *DAI I*, 598 F. Supp. 2d at 322.

<sup>114</sup> *Id.* at 292.

<sup>115</sup> *DAI I* also briefly discusses other types of housing programs that New York provides for individuals with psychiatric disabilities, including: “(1) congregate treatment programs (referred to as group homes or supervised community residences), (2) apartment treatment programs, and (3) community residence single-room occupancy (“CR-SRO”) programs.” *Id.* at 304. In New York group homes “are single-site facilities that provide meals, on-site rehabilitative services, and 24-hour staff coverage for up to forty-eight people.” *Id.* (noting that, in New York, “group homes average 14.6 people per home”).

<sup>116</sup> *Id.* at 304.

<sup>117</sup> *DAI II*, 653 F. Supp. 2d at 188–89 (“Twenty-nine witnesses testified, more than three hundred exhibits were admitted into evidence, and excerpts from the deposition transcripts of twenty-three additional witnesses were entered into the record, along with the 3,500 page trial transcript”). The author was part of the team of attorneys who represented Disability Advocates, Inc. during the trial.



residents' interactions with people who do not have disabilities."<sup>118</sup> Before reaching that conclusion, Judge Garaufis was faced with the challenge of defining the term institution.

Judge Garaufis had previously noted that "[n]owhere in Title II, its implementing regulations, or in *Olmstead* is there a definition of what constitutes an 'institution' or 'community-based' setting."<sup>119</sup> Judge Garaufis adopted the definition of institution that was offered during the trial by an expert witness for the plaintiff, Elizabeth Jones.<sup>120</sup>

According to Jones, an institution is "a segregated setting for a large number of people that through its restrictive practices and its controls on individualization and independence limits a person's ability to interact with other people who do not have a similar disability."<sup>121</sup> This definition set forth a number of characteristics that were relevant in evaluating whether a facility is an institution. These characteristics include the size of the facility, its practices, and whom the facility serves. But the definition makes it clear that these characteristics are important primarily because of the impact that they have on whether the facility is segregated, i.e., whether the residents have ample opportunity to interact with people who do not have disabilities.<sup>122</sup>

Judge Garaufis made it clear that "segregation" is the primary characteristic of an institution; he concluded that "the Adult Homes are institutions: *segregated settings that impede residents' community integration*."<sup>123</sup> Using Jones's definition as a framework, Judge Garaufis found that "the overwhelming weight of the evidence demonstrates that Adult Homes are institutions that impede residents' interaction with individuals in the community who do not have disabilities."<sup>124</sup> Adult home residents technically live within communities, but they are not

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<sup>118</sup> *Id.* at 187.

<sup>119</sup> *DAI I*, 598 F. Supp. 2d at 320.

<sup>120</sup> *DAI II*, 653 F. Supp. 2d at 199. In denying defendants' motion in limine "to exclude testimony and opinions of Plaintiff's experts on whether adult home residents are qualified to move to alternative settings," Judge Garaufis described Elizabeth Jones's extensive experience in the mental health field and the methodology that she employed in studying the adult homes at issue in this case. *Disability Advocates, Inc. v. Paterson*, No. 03-CV-3209 (NGG)(MDG), 2008 WL 5378365, at \*7 (E.D.N.Y. Dec. 22, 2008) ("For more than thirty years, Elizabeth Jones has overseen the discharge of thousands of patients from state institutions for people with mental disabilities"); *id.* at \*8 (noting that "Ms. Jones spent approximately 175 hours observing and talking with residents of each of the adult homes at issue in this litigation" and that she "reviewed the adult home and mental health program records for approximately 130 residents").

<sup>121</sup> *Id.* at 199 (internal quotations omitted).

<sup>122</sup> In her expert report, Jones wrote the following: "Psychiatric institutions are congregate facilities characterized by restrictive rules and practices that prohibit or severely limit opportunity for interaction with non-disabled individuals." *Disability Advocates, Inc. v. Pataki*, No. 03-CV-3209 (NGG), 2006 WL 6410335 (E.D.N.Y. Apr. 5, 2006) (Expert Report and Affidavit). Unsurprisingly, this definition of institution is more precise than the one she offered orally during trial. In particular, it avoids one potential ambiguity that is present in her oral definition—because it ends with the words "similar disability," one could interpret her oral definition of institution as not applying to facilities that provide services exclusively to people with disabilities if those people happen to have a variety of different types of disabilities.

<sup>123</sup> *DAI II*, 653 F. Supp. 2d at 202 (emphasis added).

<sup>124</sup> *Id.* at 218. *See also id.* at 199 ("[T]he evidence demonstrates that Adult Homes have the characteristics Ms. Jones described").

integrated into those communities. Defendants' own witness "described the Adult Homes located in Coney Island as 'community-based psychiatric ghettos in which smaller groups of individuals were located in a community, but never helped to become part of it.'" <sup>125</sup>

Judge Garaufis concluded that adult homes are institutions, but he noted that such a conclusion is not necessary for a finding of liability under Title II. <sup>126</sup> In other words, a facility that is not an institution can still violate the integration mandate. But "[w]hether a particular setting is an institution is nonetheless a relevant consideration in determining whether it enables interactions with nondisabled persons to the fullest extent possible." <sup>127</sup> The "institutional qualities of the Adult Homes are relevant to the issue of integration because they influence the extent to which residents can interact with individuals who do not have disabilities." <sup>128</sup>

Judge Garaufis emphasized that "Adult Homes bear little resemblance to the homes in which people without disabilities normally live." <sup>129</sup> In contrast, supported housing provides a home where "people with mental illness live much like their peers who do not have disabilities." <sup>130</sup> The court concluded that "supported housing is a far more integrated setting than an Adult Home." <sup>131</sup> One witness, who moved into supported housing after living in an adult home for sixteen years, summarized the difference between the two settings:

I can limit what I eat or I can expand my choices. I can have as much salad as I like. I can have as little grease as I like. I can eat foods that were not permitted in the home. . . . I do my own shopping. I do my own food selection. It's free. It's freedom for me. It's freedom. It's being able to actually live like a human being again. <sup>132</sup>

Judge Garaufis concluded that, unlike adult home residents, "[r]esidents of supported housing live and receive services in integrated settings." <sup>133</sup> Because Judge Garaufis found that "virtually all [Adult Home residents] are qualified for supported housing," he concluded that adult home

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<sup>125</sup> *Id.* at 218.

<sup>126</sup> *Id.* at 223 ("Under the applicable standard set forth in the regulations for what constitutes the 'most integrated setting,' a plaintiff need not prove that the setting at issue is an 'institution' to establish a violation of the integration mandate.") (citing *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003)).

<sup>127</sup> *DAI II*, 653 F. Supp. 2d at 223–24.

<sup>128</sup> *Id.* at 224.

<sup>129</sup> *Id.* at 200.

<sup>130</sup> *Id.* at 219 ("[s]cattered site supported housing is a 'normalized' residential setting. In other words, it is a setting much like where individuals without disabilities live. It is a person's home.").

<sup>131</sup> *Id.*

<sup>132</sup> *DAI II*, 653 F. Supp. 2d at 222.

<sup>133</sup> *Id.* at 223 ("Compared to Adult Home residents, residents of supported housing have far greater opportunities to interact with people who do not have disabilities and to be integrated into the larger community").

residents “are not in the most integrated setting appropriate to their needs.”<sup>134</sup> He also found that the evidence established that adult home residents were not opposed to “receiving services in a more integrated setting” and that providing services to adult home residents in supported housing would not be “a fundamental alteration of [New York’s] mental health service system.”<sup>135</sup> Based on these findings, Judge Garaufis concluded that New York “discriminated against [Disability Advocates, Inc.’s] constituents in violation of the integration mandate of the ADA and the Rehabilitation Act.”<sup>136</sup>

## B. Other Potential Definitions of Institution

In defining the term institution, Judge Garaufis had other options. Drawing on common usage, other federal laws, and international law, this Subpart examines other potential definitions of institution.

### 1. Common Usage

The definition of institution in the Oxford English Dictionary focuses on the ends or purpose of the relevant entity and the physical location or building where the work is done to achieve that end or purpose:

An establishment, organization, or association, instituted for the promotion of some object, esp. one of public or general utility, religious, charitable, educational, etc., e.g. a church, school, college, hospital, asylum, reformatory, mission, or the like; as a literary and philosophical institution, a deaf and dumb institution . . . . The name is often popularly applied to the building appropriated to the work of a benevolent or educational institution.<sup>137</sup>

The earliest printed usages of institution in this context are from the eighteenth century, and in those cases the word was used to describe charities.<sup>138</sup> Some early usages specifically pertain to the treatment of

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<sup>134</sup> *Id.* at 311.

<sup>135</sup> *Id.*

<sup>136</sup> *Id.* at 314. As discussed in note 11, *supra*, the Second Circuit recently vacated the trial court’s decision on procedural grounds. It did not, however, question Judge Garaufis’s findings that adult homes are institutions and that New York State is violating the ADA and the Rehabilitation Act. *Disability Advocates, Inc. v. New York Coalition for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012).

<sup>137</sup> THE OXFORD ENGLISH DICTIONARY 1046–47 (2d ed. 1989).

<sup>138</sup> *Id.* (quoting from a 1707 sermon, “‘Tis not necessary to plead very earnestly in behalf of these Charities . . . . These, of which you have had an account, are such Wise, such Rational, such

individuals with disabilities. A 1792 work, for example, is entitled “A Plan of a Charitable Institution intended to be established upon the Sea Coast, for the accommodation of Persons afflicted with such Diseases as are usually relieved by Sea Bathing.”<sup>139</sup> In 1864, the *Times of London* wrote about “individual Institutions . . . endowed and voluntary, for every imaginable condition of want or distress.”<sup>140</sup>

The current edition of Black’s Law Dictionary defines institution somewhat similarly by focusing on the “public character” of the “established organization.”<sup>141</sup> The only example used specifically invokes the treatment of people with mental disabilities in facilities: “[a]n established organization, esp. one of a public character, such as a facility for the treatment of mentally disabled persons.”<sup>142</sup> In a prior edition of Black’s Law Dictionary, one of the definitions of institution is a “[p]ublic institution,” or “[o]ne which is created and exists by law or public authority, for benefit of public in general; e.g., a public hospital, charity, college, university, etc.”<sup>143</sup>

When estimates are made of the number of people in the United States who are institutionalized, U.S. Census Bureau statistics are often cited. How the Census Bureau defines the relevant terms is therefore central to our conceptions of the current extent of institutionalization.

For purposes of its decennial survey, the Census Bureau defines “[i]nstitutionalized population” to include “[p]eople under formally authorized, supervised care or custody in institutions at the time of enumeration. Generally, restricted to the institution, under the care or supervision of trained staff, and classified as ‘patients’ or ‘inmates.’”<sup>144</sup> Although it is not immediately apparent from this definition, the Census Bureau does not consider people who live in group homes or halfway houses to be institutionalized. Instead, the Census Bureau makes the normative judgment that “[t]here are two types of group quarters: institutional . . . and non-institutional.”<sup>145</sup> As examples of institutional group quarters, the Census Bureau includes “correctional facilities, nursing homes, and mental hospitals.”<sup>146</sup> Non-institutional group quarters

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Beneficial Institutions,” and, from 1764, a work entitled, “Definitions and Axioms relative to Charity, Charitable Institutions, and the Poor Laws”).

<sup>139</sup> *Id.*

<sup>140</sup> *Id.*

<sup>141</sup> BLACK’S LAW DICTIONARY 869 (9th ed. 2009).

<sup>142</sup> *Id.*

<sup>143</sup> BLACK’S LAW DICTIONARY 800 (6th ed. 1990).

<sup>144</sup> U.S. CENSUS BUREAU, GLOSSARY: AMERICAN FACTFINDER, [http://factfinder2.census.gov/help/en/american\\_factfinder\\_help.htm#glossary/glossary.htm](http://factfinder2.census.gov/help/en/american_factfinder_help.htm#glossary/glossary.htm) (last visited Feb. 27, 2012) (defining “Institutionalized population”).

<sup>145</sup> See *id.* (Definition of “Group Quarters (GQ)”). The Census Bureau’s Current Population Survey defines the term “Group Quarters” differently, in part because, “[b]eginning in 1972, inmates of institutions have not been included in the Current Population Survey.” U.S. CENSUS BUREAU, CURRENT POPULATION SURVEY (CPS): DEFINITIONS AND EXPLANATIONS, <http://www.census.gov/cps/about/cpsdef.html> (last visited Feb. 27, 2012).

<sup>146</sup> *Id.* U.S. CENSUS BUREAU, GLOSSARY: AMERICAN FACTFINDER, [http://factfinder2.census.gov/help/en/american\\_factfinder\\_help.htm#glossary/glossary.htm](http://factfinder2.census.gov/help/en/american_factfinder_help.htm#glossary/glossary.htm) (last visited Feb. 27, 2012) (defining

include: “college dormitories, military barracks, group homes, missions, and shelters.”<sup>147</sup>

The Census Bureau’s 2009 American Community Survey contains more detailed descriptions of “non-institutional facilities” such as “Emergency and Transitional Shelters (with Sleeping Facilities) for People Experiencing Homelessness”;<sup>148</sup> “Group Homes Intended for Adults”;<sup>149</sup> and “Residential Treatment Centers for Adults.”<sup>150</sup> It is particularly interesting that the Census Bureau does not consider residential treatment centers to be institutions because the people who reside within them seem to fall within the parameters of its definition of an “institutionalized population.”<sup>151</sup>

The Census Bureau’s definition of institution is different from those used by some advocacy groups. For example, Self-Advocates Becoming Empowered (SABE) believes that “[a]n institution is any facility or program where people do not have control over their lives.”<sup>152</sup> Given this focus on the locus of control, SABE contends that any of the following facilities or programs can qualify as an institution: “a private or public institution, nursing home, group[] home, foster care home, day treatment program, or sheltered workshop.”<sup>153</sup>

Social-scientific understandings of the nature of an institution influence the common usages of that term. In particular, Erving Goffman’s *Asylums*,<sup>154</sup> which was one of the “seminal works on the ‘institutionalization’ movement,”<sup>155</sup> has shaped usage of the term

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“Group quarters population” and explaining, “[T]he institutionalized population . . . includes people under formally authorized supervised care or custody in institutions . . . (such as correctional institutions, nursing homes, and juvenile institutions)”).

<sup>147</sup> See *id.* (defining “Group Quarters (GQ)”). See also *id.* (defining “[G]roup quarters population” and explaining, “the noninstitutionalized population . . . includes all people who live in group quarters other than institutions (such as college dormitories, military quarters, and group homes)”); *id.* (defining “Noninstitutionalized population” and explaining that it “[i]ncludes all people who live in group quarters other than institutions. Examples: college dormitories, rooming houses, religious group homes, communes, and halfway houses”).

<sup>148</sup> U.S. CENSUS BUREAU, 2009 AMERICAN COMMUNITY SURVEY/PUERTO RICO COMMUNITY SURVEY

GROUP QUARTERS DEFINITIONS 6, available at [http://www.census.gov/acs/www/Downloads/data\\_documentation/GroupDefinitions/2009GQ\\_Definitions.pdf](http://www.census.gov/acs/www/Downloads/data_documentation/GroupDefinitions/2009GQ_Definitions.pdf) (last visited Feb. 27, 2012) (“Facilities where people experiencing homelessness stay overnight.”).

<sup>149</sup> *Id.* at 7 (“[G]roup homes are community-based group living arrangements in residential settings that are able to accommodate three or more clients of a service provider. The group home provides room and board and services, including behavioral, psychological, or social programs. Generally, clients are not related to the care giver or to each other”).

<sup>150</sup> *Id.* (defining “residential treatment centers for adults” as “[r]esidential facilities that provide treatment on-site in a highly structured live-in environment for the treatment of drug/alcohol abuse, mental illness, and emotional/behavioral disorders. They are staffed 24-hours a day. The focus of a residential treatment center is on the treatment program.”).

<sup>151</sup> See U.S. CENSUS BUREAU, GLOSSARY, *supra* note 146.

<sup>152</sup> SELF ADVOCATES BECOMING EMPOWERED, POSITION STATEMENT, [http://www.sabeusa.org/user\\_storage/File/sabeusa/Position%20Statements/32\\_%20Definition%20of%20Institutions.pdf](http://www.sabeusa.org/user_storage/File/sabeusa/Position%20Statements/32_%20Definition%20of%20Institutions.pdf) (last visited Feb. 27, 2012).

<sup>153</sup> *Id.*

<sup>154</sup> See ERVING GOFFMAN, *ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES*, Anchor Books (1961).

<sup>155</sup> David L. Bazelon, *Institutionalization, Deinstitutionalization and the Adversary Process*, 75

institution.

Goffman wrote that “[e]very institution captures something of the time and interest of its members and provides something of a world for them; in brief, every institution has encompassing tendencies.”<sup>156</sup> Goffman used the term “total institution” to describe “closed institutions,” or establishments where the “encompassing or total character is symbolized by the barrier to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests, or moors.”<sup>157</sup> This raises an important but somewhat subtle point—not all institutions are total institutions. In other words, a facility may still be an institution and have “encompassing tendencies” even if it is not locked or geographically isolated from the general community.

Goffman emphasized that total institutions create barriers to participation and integration in the community:

A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different places, with different co-participants, under different authorities, and without an over-all rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life . . . .<sup>158</sup>

The key attribute of total institutions is that they “disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world—that he is a person with ‘adult’ self-determination, autonomy and freedom of action.”<sup>159</sup> Goffman classified “diverse institutions” such as “mental hospitals, nunneries, military training camps, preparatory schools, concentration camps, orphanages and ‘old age homes’” as total institutions.<sup>160</sup>

While some have disputed Goffman’s account of total institutions,<sup>161</sup> its influence is significant. One downside of this influence is that some people limit the use of the term institution to the total institutions that Goffman described. To do so is to misread Goffman.

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COLUM. L. REV. 897, 897 n.3 (1975).

<sup>156</sup> GOFFMAN, *supra* note 154, at 4.

<sup>157</sup> *Id.*

<sup>158</sup> *Id.* at 5–6.

<sup>159</sup> *Id.* at 43.

<sup>160</sup> Charles W. Lidz & Robert M. Arnold, *Rethinking Autonomy in Long Term Care*, 47 U. MIAMI L. REV. 603, 615 (1993) (“[W]hile nursing homes do not meet every characteristic of a ‘total institution,’ they still can be classified as such”).

<sup>161</sup> See, e.g., Ralph Slovenko, *The Transinstitutionalization of the Mentally Ill*, 29 OHIO N.U. L. REV. 641, 653 (2003) (arguing that “Goffman was wrong in his condemnation of institutions”).

## 2. *Federal Law*

A number of federal statutes define the term institution. This Subpart will discuss definitions of the term institution in the Civil Rights of Institutionalized Persons Act and Medicaid and Supplemental Security Income programs that are governed by the Social Security Act.<sup>162</sup>

The Civil Rights of Institutionalized Persons Act (CRIPA) of 1980 gives the Attorney General authority to initiate civil actions when “the Attorney General has reasonable cause to believe that . . . persons residing in or confined to an institution” are being subjected to “egregious or flagrant conditions.”<sup>163</sup> CRIPA defines the term institution broadly to include facilities that fall within any of the following five categories:

- (i) for persons who are mentally ill, disabled, or retarded, or chronically ill or handicapped;
- (ii) a jail, prison, or other correctional facility;
- (iii) a pretrial detention facility;
- (iv) for juveniles—
  - (I) held awaiting trial;
  - (II) residing in such facility or institution for purposes of receiving care or treatment; or
  - (III) residing for any State purpose in such facility or institution (other than a residential facility providing only elementary or secondary education that is not an institution in which reside juveniles who are adjudicated delinquent, in need of supervision, neglected, placed in State custody, mentally ill or disabled, mentally retarded, or chronically ill or handicapped); or
- (v) providing skilled nursing, intermediate or long-term care,

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<sup>162</sup> The term institution is defined in other federal statutes and regulations, but an exhaustive analysis is beyond the scope of this Article. For example, the Patient Protection and Affordable Care Act (ACA) includes nursing homes and intermediate care facilities (for persons with mental retardation) “as examples of ‘institutional’ settings.” Leonardo Cuello, *How the Patient Protection and Affordable Care Act Shapes the Future of Home- and Community-Based Services*, 45 CLEARINGHOUSE REV. 299, 301 (citing Patient Protection and Affordable Care Act, Pub. L. No. 111–148, § 10202(f)(1), 124 Stat. 119, 926 (2010)). The implementing regulations for 18 U.S.C. § 922(g), which prohibits a person who has been committed to a mental institution from possessing a firearm, define “mental institution” to include “mental health facilities, mental hospitals, sanitariums, psychiatric facilities, and other facilities that provide diagnoses by licensed professionals of mental retardation or mental illness, including a psychiatric ward in a general hospital.” 27 C.F.R. § 478.11 (2011). In setting forth the criteria for eligibility, the regulations for the Food Stamp program define people as being “residents of an institution” if “the institution provides them with the majority of their meals (over 50 percent of three meals daily) as part of the institution’s normal services.” 7 C.F.R. § 273.1(b)(7)(vi) (2011). “Individuals who are disabled or blind and are residents of group living arrangements” are generally excluded from this category. 7 C.F.R. § 273.1(b)(7)(vii)(C).

<sup>163</sup> 42 U.S.C. § 1997(a) (2006).

or custodial or residential care.<sup>164</sup>

The Religious Land Use and Institutionalized Persons Act of 2000<sup>165</sup> has the same definition of institution as CRIPA.<sup>166</sup>

CRIPA's definition is somewhat unusual because some of the five categories focus on attributes of the people being served by the facility and others focus on the nature of the services that are provided. For example, under CRIPA, some facilities are institutions simply because they serve people with disabilities or juveniles. Other facilities are institutions, however, because of the nature of the services that they provide—for example, those that provide “skilled nursing, intermediate or long-term care, or custodial or residential care.”<sup>167</sup> Who owns or operates the facility is also important because CRIPA covers only those facilities that are “owned, operated, or managed by, or provides services on behalf of any State or political subdivision of a State.”<sup>168</sup> Private institutions are not covered unless the nexus between the institution and the government is stronger than merely licensing or receipt by the institution of Social Security, Medicare, or Medicaid payments.<sup>169</sup>

The Special Litigation Section of the Civil Rights Division enforces CRIPA. The Special Litigation Section “is generally divided into five areas: (1) Jails and Prisons, (2) Juvenile Correctional Facilities, (3) State or locally-run Mental Health Facilities, (4) State or locally-run Developmental Disability and Mental Retardation Facilities, (5) State or locally-run Nursing Homes.”<sup>170</sup> In the 30 years since CRIPA became law, the Special Litigation Section has investigated “more than 430 facilities,”<sup>171</sup> or approximately fourteen per year. Because the focus of CRIPA is to protect the civil rights of people who are institutionalized, the Special Litigation Section enforces “the rights of institutionalized persons with disabilities . . . to be served in the most integrated setting appropriate to their needs.”<sup>172</sup>

The Social Security Act also defines the term institution in ways that are significant for potential beneficiaries of public health care programs and income support. The Medicaid program, which Congress enacted in 1965, provides federal funding “for medical assistance to low-income persons who are age 65 or over, blind, disabled, or members of families with dependent children or qualified pregnant women or children.”<sup>173</sup> The definition of the term institution is central to whether a

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<sup>164</sup> *Id.* § 1997(1)(B).

<sup>165</sup> 42 U.S.C. § 2000cc-1 (2000).

<sup>166</sup> *Id.* § 2000cc-1(a).

<sup>167</sup> 42 U.S.C. § 1997(1)(B) (2006).

<sup>168</sup> *Id.* § 1997(1)(A).

<sup>169</sup> *Id.* § 1997(2).

<sup>170</sup> U.S. DEPT OF JUSTICE, SUMMARY OF CIVIL RIGHTS OF INSTITUTIONALIZED PERSONS, <http://www.justice.gov/crt/about/spl/cripa.php> (last visited Feb. 27, 2012).

<sup>171</sup> *Id.*

<sup>172</sup> *Id.*

<sup>173</sup> 42 C.F.R. § 430.0 (2011). The discussion of Medicaid in this Article is limited to those provisions



facility can be reimbursed for the services that it provides. In particular, the federal government will not provide Medicaid coverage for services provided to (1) “[i]ndividuals who are inmates of public institutions[,]” and (2) “patients in an institution for mental diseases” who are older than 21 and younger than 65.<sup>174</sup>

Medicaid defines an “[i]nstitution for mental diseases” as “a hospital, nursing facility, or other institution of more than 16 beds, that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services.”<sup>175</sup> This definition has two key elements. First, Medicaid focuses on the number of beds a facility has. If a facility has 16 or fewer beds, it is not an “institution for mental diseases,” even if it meets every other criterion. Second, Medicaid focuses on the types of services that the facility provides. A facility is an institution only if it is diagnosing, treating, or caring for people with mental disabilities.<sup>176</sup> The regulations explain that this is determined by the “overall character” of the facility, and not merely “whether or not it is licensed [as an institution for mental diseases].”<sup>177</sup>

“[I]nstitutions for the mentally retarded” are specifically excluded from the definition of “institution for mental diseases.”<sup>178</sup> Unlike an institution for mental diseases, the number of beds a facility contains is immaterial to whether it is an institution for the mentally retarded. Instead, an institution for the mentally retarded is defined as follows:

[A]n institution (or distinct part of an institution) that—

- (a) Is primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions; and
- (b) Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability.<sup>179</sup>

The Supplemental Security Income (SSI) program, which was enacted in 1972, is a federal program that provides cash benefits to individuals who are at least 65 years old or disabled and who have

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that define or have a direct impact on “institutions.”

<sup>174</sup> *Id.* § 436.1005(a). Nancy K. Rhoden, *The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L. J. 375, 384 n. 46 (1982) (“The 1965 Medicaid Act excluded state mental hospital patients except those over 65; in 1972 the Act was amended to allow benefits to state hospital patients under 21”).

<sup>175</sup> 42 U.S.C. § 1396d(i) (2006).

<sup>176</sup> 42 C.F.R. § 435.1010 (2006).

<sup>177</sup> *Id.*

<sup>178</sup> *Id.* These regulations also define a “child-care institution,” an “institution for tuberculosis,” a “medical institution,” a “public institution,” and an “institution.” An “institution” is “an establishment that furnishes (in single or multiple facilities) food, shelter, and some treatment or services to four or more persons unrelated to the proprietor.” *Id.*

<sup>179</sup> *Id.*

limited income and resources.<sup>180</sup> If a person receives SSI, she is also generally eligible to receive Medicaid. However, if an otherwise eligible individual resides in an institution, her SSI benefits might be affected.

A person is generally not eligible for SSI benefits if “he is an inmate of a public institution.”<sup>181</sup> The definition of public institution generally hinges on at least two aspects of a facility—who operates or controls it and how big it is. A public institution is one that is “operated by or controlled by the Federal government, a State, or a political subdivision of a State such as a city or county.”<sup>182</sup> The Social Security Administration (SSA) can determine that a privately-owned group home is a public institution.<sup>183</sup> An institution is public if the government exercises either direct administrative control<sup>184</sup> or indirect administrative control.<sup>185</sup> The fact that a facility is licensed or certified by a government agency or receives government grants does not, in and of itself, make a facility public.<sup>186</sup> The Social Security Act specifically excludes from the definition of public institution any “publicly operated community residence which serves no more than 16 residents.”<sup>187</sup>

Somewhat confusingly, the applicable regulations define institution, as opposed to public institution, differently with regard to the relevant size. An institution is “an establishment that makes available some treatment or services in addition to food and shelter to *four or more persons* who are not related to the proprietor.”<sup>188</sup> In determining whether an establishment is an institution, the SSA policy dictates that “[i]t is not necessary for each resident to receive any or all of the treatment or services.”<sup>189</sup>

The inconsistency regarding the relevant size is compounded by the exception to the eligibility requirements for voluntary residents who pay

<sup>180</sup> 42 U.S.C. § 1381 (2006).

<sup>181</sup> 42 U.S.C. § 1382(e)(1)(A) (2006). *See* Schweiker v. Wilson, 450 U.S. 221, 224 (1981) (“From its very inception, the [SSI] program has excluded from eligibility anyone who is an ‘inmate of a public institution’”).

<sup>182</sup> 20 C.F.R. § 416.201 (2011).

<sup>183</sup> *See, e.g.*, HHS v. Chater, 163 F.3d 1129, 1136 (9th Cir. 1998) (affirming the SSA’s determination that privately-owned group homes, which housed juvenile offenders who were under the “custody and control” of the state, were “public institutions”).

<sup>184</sup> SSA POMS SI 00520.001(C)(2)(a), 2001 WL 1936566 (2009) (“Direct administrative control exists when a governmental unit is responsible for the ongoing daily activities of an institution; e.g., when the institution’s staff members are government employees or when a governmental unit, board, or officer has the final authority (whether exercised or not) to hire and fire employees”).

<sup>185</sup> *Id.* (“Indirect administrative control exists when a governmental unit has total control of all fiscal decisions (even though it lacks the authority to hire and fire). Indirect administrative control also exists when a governmental unit establishes a contractual arrangement whereby an institution (as a facility) becomes an agent of the governmental unit”).

<sup>186</sup> SSA POMS SI 00520.001(C)(2)(c), 2001 WL 1936566 (2009).

<sup>187</sup> 42 U.S.C. § 1382(e)(1)(C) (2006). *See also* 20 C.F.R. § 416.201 (2011) (“Public institution means an institution that is operated by or controlled by the Federal government, a State, or a political subdivision of a State such as a city or county. The term public institution does not include a publicly operated community residence which serves 16 or fewer residents”); 20 C.F.R. § 416.211 (2007) (defining a publicly operated community residence and the sixteen resident threshold).

<sup>188</sup> 20 C.F.R. § 416.201 (2011) (emphasis added).

<sup>189</sup> SSA POMS SI 00520.001(B)(2), 2001 WL 1936566 (2009).

for services in public institutions within Arkansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota.<sup>190</sup> In *Levings v. Califano*, the Eighth Circuit focused on two other related characteristics of a potential facility: whether it is voluntary and whether the recipient of services pays for the services the public institution provides.<sup>191</sup> *Levings* focused on the Social Security Act's use of the term inmate and the common usage of that term.<sup>192</sup> The Eighth Circuit held that a person is not "an inmate of a public institution" if she resides within the relevant facility on a voluntary basis and pays for the services with which she is provided.<sup>193</sup>

Subsequently, the SSA amended its regulations to define inmate to include a "resident of a public institution."<sup>194</sup> The Social Security Act's general eligibility exclusion for residents of public institutions does not, however, apply to SSI applicants and beneficiaries within the Eighth Circuit. In the Eighth Circuit, individuals who live in a public facility of any size can still receive SSI as long as they are in the facility voluntarily and pay for the services that the facility provides. There is evidence that this exception has influenced the size of residential programs in these states.<sup>195</sup>

### 3. *International Law*

The Convention on the Rights of Persons with Disabilities<sup>196</sup> (CRPD) was adopted on December 13, 2006, during the sixty-first session of the United Nations General Assembly.<sup>197</sup> Pursuant to Article 42, the CRPD and its Optional Protocol was opened for signature as of March 30, 2007.<sup>198</sup> The United States is one of the 153 signatories to the CRPD.<sup>199</sup> Although the United States has not ratified the CRPD, over

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<sup>190</sup> SSAR 88-6(8), 1988 WL 236017 (Oct. 27, 1988).

<sup>191</sup> *Levings v. Califano*, 604 F.2d 591, 594 (8th Cir. 1979).

<sup>192</sup> *Id.* at 593 (noting that "[o]rdinarily, the term 'inmate' is understood to refer to persons confined in institutions under some form of restraint, not to persons who reside at facilities on a purely voluntary basis").

<sup>193</sup> *Id.* at 594.

<sup>194</sup> 20 C.F.R. § 416.201 (2011).

<sup>195</sup> See, e.g., Jeffrey L. Geller, *Excluding Institutions for Mental Diseases From Federal Reimbursement for Services: Strategy or Tragedy?*, 51 PSYCHIATRIC SERVICES 1397, 1402 (2000), (noting that, as a result of this exception, "community residential programs exceed the 16-bed limit," and that "[i]n Iowa, for example, residential care facilities for persons with mental illness have as many as 80 beds").

<sup>196</sup> G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Jan. 24, 2007) [hereinafter CRPD], available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/500/79/PDF/N0650079.pdf?OpenElement>.

<sup>197</sup> Convention on the Rights of Persons with Disabilities, U.N. GAOR, 61st Sess., 76th plen. mtg. at 5, U.N. Doc. A/61/PV.76 (Dec. 13, 2006), available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/657/07/PDF/N0665707.pdf?OpenElement>.

<sup>198</sup> CRPD, *supra* note 196, at art. 42.

<sup>199</sup> Convention and Optional Protocol Signatures and Ratifications, <http://www.un.org/disabilities/countries.asp?navid=12&pid=166> (last visited Feb. 18, 2012).

100 countries have.<sup>200</sup> The CRPD's dictates therefore represent "the overwhelming weight of international opinion."<sup>201</sup>

The purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."<sup>202</sup> "Discrimination" is broadly defined to include "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."<sup>203</sup> The CRPD specifically states that the denial of a request for a reasonable accommodation constitutes discrimination.<sup>204</sup> A "reasonable accommodation" is defined as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms."<sup>205</sup>

The CRPD does not define the word institution, but it addresses the subject of institutionalization. The CRPD prohibits "torture or . . . cruel, inhuman or degrading treatment or punishment."<sup>206</sup> States parties are required to "take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities . . . from being subjected to torture or cruel, inhuman or degrading treatment or punishment."<sup>207</sup> The CRPD also repeatedly emphasizes the right that people with disabilities have to liberty and to participate and be included in the community.<sup>208</sup>

The right to participation and inclusion in the community is paramount. The CRPD defines the term "disability" as the result of "the interaction between persons with impairments and attitudinal and

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<sup>200</sup> *Id.*

<sup>201</sup> *Cf. Roper v. Simmons*, 543 U.S. 551, 578 (2005) (acknowledging "the overwhelming weight of international opinion against the juvenile death penalty" in holding that "[t]he Eighth and Fourteenth Amendments forbid imposition of the death penalty on offenders who were under the age of 18 when their crimes were committed").

<sup>202</sup> CRPD, *supra* note 196, at art. 1.

<sup>203</sup> *Id.* at art. 2.

<sup>204</sup> *Id.*

<sup>205</sup> *Id.*

<sup>206</sup> *Id.* at art. 15, ¶ 1.

<sup>207</sup> CRPD, *supra* note 196, at art. 15 ¶ 2.

<sup>208</sup> Prior to the CRPD, "no specific binding international human rights convention exist[ed] to protect explicitly the right of people with disabilities to live in the community or to be free from indeterminate institutionalization." ERIC ROSENTHAL & ARLENE KANTER, *DISABILITY RIGHTS EDUC. & DEFENSE FUND, THE RIGHT TO COMMUNITY INTEGRATION FOR PEOPLE WITH DISABILITIES UNDER UNITED STATES AND INTERNATIONAL LAW* (2010), available at [http://www.dredf.org/international/paper\\_r-k.html](http://www.dredf.org/international/paper_r-k.html). However, "[r]eferences to community integration are found in Article 23 of the Convention on the Rights of the Child, and in instruments and documents of the UN General Assembly such as the Declaration on the Rights of Mentally Retarded Persons, the 1991 Principles for the Protection of Persons with Mental Illness, the 1993 Standard Rules on Equalization of Opportunities for Persons with Disabilities, and General Comment 5 to the International Convention on Economic, Social and Cultural Rights, as well as in the Charter of Fundamental Rights of the European Union." *Id.* (citations omitted).

environmental barriers that hinders their full and effective participation in society on an equal basis with others.”<sup>209</sup> This is just one of the four times in the preamble alone that the CRPD emphasizes the importance of participation.<sup>210</sup> The word participation, or participate, appears a total of 25 times within the CRPD. One of the CRPD’s “general principles” is “[f]ull and effective participation and inclusion in society.”<sup>211</sup> The importance of another general principle—“accessibility”—is directly tied to independent living and full participation in the community.<sup>212</sup> Article 24 also emphasizes that the right to education is essential to “[enable] persons with disabilities to participate effectively in a free society.”<sup>213</sup> People with disabilities have the right to participate on an equal basis in “political and public life”<sup>214</sup> and “cultural life, recreation, leisure and sport.”<sup>215</sup> Michael Stein and Janet Lord have written that “aspects of the Convention . . . are especially notable for their substantive and procedural inclusion of persons with disabilities and reflective of a deeply participatory model of justice.”<sup>216</sup>

Article 19 states that “all persons with disabilities” have the right “to live in the community.”<sup>217</sup> States parties are required to “take effective and appropriate measures to facilitate full enjoyment . . . of this right.”<sup>218</sup> In particular, states parties are required to ensure that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; (b) Persons with disabilities have access to a range of in-home, residential and other

<sup>209</sup> CRPD, *supra* note 196, at pmbl. (e). *See also id.*, art. 1 (“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”).

<sup>210</sup> *Id.* at pmbl. (e), (k) (“[P]ersons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”); *id.* at pmbl. (m) (“[T]he promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty”); *id.* at pmbl. and (y) (“[A] comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres . . .”).

<sup>211</sup> CRPD, *supra* note 196, at art. 3.

<sup>212</sup> *See id.* at arts. 3, 9.

<sup>213</sup> *Id.* at art. 24(1)(c). *See also id.* at art. 24(3) (“States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community”).

<sup>214</sup> *Id.* at art. 29.

<sup>215</sup> CRPD, *supra* note 196, at art. 30.

<sup>216</sup> Michael Ashley Stein & Janet E. Lord, *Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities*, 13 TEX. J. C.L. & C.R. 167, 168 (2008).

<sup>217</sup> CRPD, *supra* note 196, at art. 19. The words “community” and “communities” are used repeatedly throughout the CRPD, appearing a total of 16 times.

<sup>218</sup> *Id.*

community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; [and] (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.<sup>219</sup>

Article 25 also requires states parties to “[p]rovide . . . health services [to people with disabilities] as close as possible to [their] own communities.”<sup>220</sup> The CRPD thus implicitly defines institution in the negative; it is *not* “living independently and being included in the community.”<sup>221</sup>

To facilitate “maximum independence” and “full inclusion and participation in all aspects of life,” states parties are required to “organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.”<sup>222</sup> The CRPD specifies that “habilitation and rehabilitation services” must be voluntary and “based on the multidisciplinary assessment of individual needs and strengths.”<sup>223</sup>

Article 14 of the CRPD requires states parties to “ensure that Persons with disabilities, on an equal basis with others[,] [e]njoy the right to liberty and security of person.”<sup>224</sup> States parties must also ensure that people with disabilities “[a]re not deprived of their liberty unlawfully or arbitrarily . . . and that the existence of a disability shall in no case justify a deprivation of liberty.”<sup>225</sup> Article 14 requires that any deprivation of liberty is “in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation.”<sup>226</sup> One commentator has concluded that, although the CRPD text “neither expressly prohibits nor permits forced intervention,” the ambiguity should be construed in light of the complete document’s emphasis on the dignity and autonomy of persons with disabilities.<sup>227</sup>

Meghan Flynn has concluded that, “[t]ogether, these provisions guarantee persons with disabilities rights to enjoy freedom from institutionalization and live in the community setting of their choice.”<sup>228</sup>

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<sup>219</sup> *Id.*

<sup>220</sup> *Id.* at art. 25(c).

<sup>221</sup> *Id.* at art. 19(a).

<sup>222</sup> CRPD, *supra* note 196, at art. 26.

<sup>223</sup> *Id.* at art 26(1)(a)–(b).

<sup>224</sup> *Id.* at art. 14(1)(a).

<sup>225</sup> *Id.* at art. 14(1)(b).

<sup>226</sup> *Id.* at art. 14(2).

<sup>227</sup> Amita Dhanda, *What does the Convention on Rights of Persons with Disabilities Promise to Persons with Psychosocial Disability?*, AAINA (Ctr. for Advocacy in Mental Health, Pune, Maharashtra, India), Nov. 2006, at 17, 19.

<sup>228</sup> Meghan Flynn, *Olmstead Plans Revisited: Lessons Learned from the U.N. Convention on the Rights of Persons with Disabilities*, 28 LAW & INEQ. 407, 424 (2010).

Similarly, Michael Perlin concludes that, to comply with the CRPD, a domestic mental health law must address the “Failure to Provide Humane Care to Institutionalized Persons” and the “Lack of Coherent and Integrated Community Programs as an Alternative to Institutional Care.”<sup>229</sup>

#### IV. IMPLICATIONS FOR FUTURE *OLMSTEAD* LITIGATION

The definitions of institution found in *DAI I*, common usage, federal law, and international law shed light on the main harm that unnecessary segregation inflicts. Different definitions of institution emphasize different characteristics. But characteristics such as who owns the facility, how many residents there are, and what services are provided, are not intrinsically significant. Instead, the definitions appear to use these characteristics as objective proxies for a more subjective inquiry: are the individuals with disabilities who are being served unnecessarily segregated from the community?

By focusing on this question, the future of *Olmstead* litigation becomes more apparent. Some advocates and individuals with disabilities have begun looking beyond paradigmatic institutions—e.g., state mental hospitals, nursing homes, and intermediate care facilities—to examine whether other residential settings such as homeless shelters, board and care homes, and group homes are providing services in the most integrated setting. But this inquiry is not limited to residential facilities. Advocates and individuals with disabilities are also asking whether other services such as sheltered workshops, child protective services, assisted outpatient treatment, guardianship, and elections are being operated in a manner that violates *Olmstead*.

##### A. Residential Settings Being Questioned

Advocates and individuals with disabilities are increasingly scrutinizing whether segregated residential settings violate *Olmstead*. Challenges to institutionalization no longer focus only on state hospitals, nursing homes, and intermediate care facilities. Now, segregated “community” settings—such as homeless shelters, board and care homes, and group homes—are increasingly being examined to determine whether they are providing services in the most integrated setting. As Susan Stefan has written:

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<sup>229</sup> Michael L. Perlin, *International Human Rights Law and Comparative Mental Disability Law: The Universal Factors*, 34 SYRACUSE J. INT’L L. & COM. 333, 343, 349 (2007).

[I]n the decade following *Olmstead*, it became increasingly clear that many state mental health and developmental disability systems operated within a framework that offered “community” services in a context of control and segregation, even after discharge from formal institutional settings. People who lived in what was euphemistically called “the community” still lived regimented lives with other disabled people, had little control over the most mundane decisions of their lives, and had little or no interaction with non-disabled people.<sup>230</sup>

While the policies of some of these facilities have already drawn scrutiny under the Fair Housing Act,<sup>231</sup> they are increasingly being looked at through the lens of the ADA’s integration mandate.

Approximately 200,000 Americans reside in homeless shelters.<sup>232</sup> The similarities between homeless shelters and paradigmatic institutional settings have long been recognized.<sup>233</sup> Advocates and individuals with disabilities are now examining government policies and procedures that funnel people who are homeless with disabilities, or who have children with disabilities, into segregated shelters. In New York, for example, there is only one domestic violence shelter that is available for women or families with disabilities.<sup>234</sup> Discriminatory admission policies commonly lead to the segregation of people who are homeless and have physical or mental disabilities.<sup>235</sup> Although the ADA includes shelters as an example of public accommodations,<sup>236</sup> which are covered by Title III, it is clear that shelter systems are government programs that are subject to Title II and its integration mandate. These policies are subject to

<sup>230</sup> Susan Stefan, *Beyond Residential Segregation: The Application of Olmstead to Segregated Employment Settings*, 26 GA. ST. U. L. REV. 875, 892 (2010).

<sup>231</sup> See *Cnty. House, Inc. v. City of Boise*, 490 F.3d 1041 (9th Cir. 2007).

<sup>232</sup> U.S. CENSUS BUREAU, *supra* note 14 (showing that 209,325 people reside in “[e]mergency and transitional shelters (with sleeping facilities) for people experiencing homelessness”). *But see* U.S. DEPT. OF HOUS. AND URBAN DEV., 2010 ANN. HOMELESS ASSESSMENT REP. 5 (2010), available at <http://www.hudhre.info/documents/2010HomelessAssessmentReport.pdf> (estimating that approximately 400,000 homeless people “sleep[] either in an emergency shelter or a transitional housing program”).

<sup>233</sup> See, e.g., Rhoden, *supra* note 174, at 376 (“The New York City Men’s Shelter resembles nothing so much as a 19th century insane asylum. A large room off the lobby is filled with over 100 men. Some lie curled up on the dirty floor; a few are in various stages of undress; others gesture wildly in the air talking to themselves. Some just sit staring into space. The stench of urine and unwashed bodies is strong.”) (quoting CINDY LYNN FREIDMUTTER, OFFICE OF THE PRESIDENT OF THE NEW YORK CITY COUNCIL, FROM COUNTRY ASYLUMS TO CITY STREETS: THE CONTRADICTION BETWEEN DEINSTITUTIONALIZATION AND STATE MENTAL HEALTH FUNDING PRIORITIES 30 (1979)).

<sup>234</sup> See Fred Scaglione, *Barrier Free Living: When Disability Isn’t the Only Challenge*, N.Y. NONPROFIT PRESS, Dec. 2009, at 10, available at [http://www.nynp.biz/current/archives/nynparchives/1209\\_December\\_2009\\_Edition.pdf](http://www.nynp.biz/current/archives/nynparchives/1209_December_2009_Edition.pdf) (noting that Barrier Free Living’s “Freedom House is the sole emergency domestic violence shelter for women or families with disabilities”).

<sup>235</sup> See Greg C. Cheyne, Comment, *Facially Discriminatory Admissions Policies in Homeless Shelters and the Fair Housing Act*, 1 U. CHI. LEGAL F. 459, 463 (2009) (“Social scientists, though rarely targeting such policies for study, have long documented the existence of facially discriminatory policies in homeless shelters with respect to . . . disability”).

<sup>236</sup> 28 C.F.R. § 36.104 (2011).



scrutiny under *Olmstead*.

Similarly, the assumption that board and care homes and group homes are community-based facilities is also increasingly being questioned. Board and care homes and group homes have at times been criticized “for providing substandard living conditions and inadequate treatment.”<sup>237</sup> But, in the wake of *Olmstead*, some began to point out that “the inappropriate maintenance of a person with disabilities in a custodial group home rather than in a less restrictive independent community setting would be contrary to *Olmstead*.”<sup>238</sup> The question is whether people who live in board and care homes and group homes could, if they were provided with the opportunity, be better integrated in the community:

In a society that is moving (if, by some accounts, too slowly) away from housing people with disabilities in traditional institutions, it would be easy to miss the full importance of *Olmstead* and its requirement that states work toward providing services in the most integrated setting appropriate for each individual. However, when one acknowledges the unlawful discrimination that occurs when people spend decades living in settings that amount to “mini-institutions,” and as a result miss the opportunity to live fuller, more normal lives, the scope and potential longevity of *Olmstead* come into focus. Even if every large state institution were to eventually close its doors, *Olmstead* would provide the standard for when states must provide people with disabilities more integrated settings, both for residential and day services, in which to live their lives.<sup>239</sup>

Approximately 300,000 Americans live in group homes for adults.<sup>240</sup> There are over 2,000 state-run group homes in New York alone.<sup>241</sup> With between four and eight residents, these homes are small in comparison to state hospitals and nursing homes. In 2011, an abuse scandal involving New York’s group homes provided a chilling reminder of the costs to human dignity and lives that even small facilities can exact from their residents.<sup>242</sup> The allegations of physical and sexual

<sup>237</sup> Rhoden, *supra* note 174, at 388.

<sup>238</sup> John V. Jacobi, *Federal Power, Segregation, and Mental Disability*, 39 HOUS. L. REV. 1231, 1251 (2003) (stating, in addition, “[t]he choice among services for people with major mental illness or cognitive impairment is not binary--in the institution or out. Rather, people with mental disabilities, once they are deinstitutionalized, can be more or less integrated into society.”).

<sup>239</sup> Megan Chambers, Comment, *Integration as Discrimination Against People with Disabilities? Olmstead’s Test Shouldn’t Work Both Ways*, 46 CAL. W. L. REV. 177, 207–08 (2009).

<sup>240</sup> U.S. CENSUS BUREAU, *supra* note 14 (showing that 304,688 people reside in “[g]roup homes intended for adults.”). As discussed above, the Census Bureau does not consider group homes for adults to be “institutional” facilities. See *supra* Part III.B.1.

<sup>241</sup> Danny Hakim, *At State-Run Homes, Abuse and Impunity*, N.Y. TIMES, Mar. 12, 2011, <http://www.nytimes.com/2011/03/13/nyregion/13homes.html?scp=1&sq=At%20State-Run%20Homes,%20Abuse%20and%20Impunity&st=cse>.

<sup>242</sup> *Id.*

abuse, as well as the initial responses to those allegations, are reminiscent of the systemic problems that plagued larger institutions: “State records show that of some 13,000 allegations of abuse in 2009 within state-operated and licensed homes, fewer than 5 percent were referred to law enforcement.”<sup>243</sup> The comments of one group home worker who was interviewed by *The New York Times* compare working in a group home to working in a prison: “The job is really stressful . . . . You have residents that you work with that are attacking you, they have hepatitis, they have things that can be transferred. They bite you, they hit you, they verbally abuse you. It’s almost like working in a prison.”<sup>244</sup> If working in one of these group homes is like working in a prison, it seems appropriate to ask whether living in one of these group homes is like living in a prison. Unsurprisingly, based on accounts of group homes such as this one, advocates are increasingly questioning whether group homes—even those with as few as four residents—are institutions.<sup>245</sup>

## B. Other Services Being Questioned

The next frontier in *Olmstead* litigation is the application of its principles to non-residential services. In particular, advocates and individuals with disabilities are bringing or contemplating challenges to the segregated nature or the segregating effect of other government services such as sheltered workshops, child protective services, assisted outpatient treatment, guardianship, and elections.<sup>246</sup>

Sheltered workshops are one of the state-funded services that are being scrutinized for unnecessary segregation. Although they have been criticized as being expensive and for paying less than minimum wage, sheltered workshops are still prevalent. In New York, for example,

[t]here are currently 52,229 individuals enrolled in segregated

<sup>243</sup> *Id.*

<sup>244</sup> *Id.* The alleged behavior by residents could be interpreted as being a reaction to the setting in which they are being held.

<sup>245</sup> See, e.g., Comments from Bazelon Center for Mental Health Law on Proposed Rule for the “Medicaid Program: Community First Choice Option” to the Department of Health and Human Services (April 28, 2011), available at <http://www.bazelon.org/LinkClick.aspx?fileticket=4eBX2HXEF4%3D&tabid=349> (“Additionally, we believe that institutions other than nursing facilities, IMDs or ICF-MRs should be included among the list of institutions from which individuals must transition in order for transition costs to be provided. Many individuals with serious mental illness who are currently placed in smaller institutional settings, such as adult homes or large group homes, could, with assistance, successfully transfer to independent supported housing. . . . Paragraph (b)(1) should be amended to add ‘adult homes for people with mental illness and group homes with over four residents’ to the list of institutions so that transition costs for people in these settings moving into independent supported housing can be covered”).

<sup>246</sup> See e.g., Michael L. Perlin, *What's Good Is Bad, What's Bad Is Good, You'll Find Out When You Reach the Top, You're on the Bottom: Are the ADA (and Olmstead v. L.C.) Anything More Than “Idiot Wind?”*, 35 U. MICH. J.L. REFORM 235, 255 (2002) (“[Q]uestions of institutionalization and deinstitutionalization are far broader than simply inquiries into whether a patient is ‘behind the wall’ . . . [but] touch on virtually every aspect of interpersonal interaction.”).

employment programs, including sheltered workshops, through OMRDD [Office of Mental Retardation and Developmental Disability] alone, with a total cost to the state of more than \$1 billion. The cost per person in a segregated program is \$21,309 compared to \$5,291 per person in supported employment.<sup>247</sup>

Even before *Olmstead*, sheltered workshops were criticized for “look[ing] like an institution or a warehouse.”<sup>248</sup> One former participant in a sheltered workshop eloquently pointed out the adverse effect that shelter workshops have on the opportunity for community participation: “[i]f people work out in the community, they develop a wider range of contacts, unlike going to a segregated building every day.”<sup>249</sup> These criticisms have been heeded in Vermont, which “has prohibited the use of state funds for sheltered workshops.”<sup>250</sup>

Stefan has argued that *Olmstead* and *Disability Advocates, Inc.* “amply support the proposition that the ADA prohibits unjustified isolation of people with disabilities in segregated sheltered workshops when those people would prefer to work in the community with the aid of supported employment services and the states currently fund programs that would enable them to work in the community.”<sup>251</sup> She suggests that the integration mandate could be invoked to force states that currently provide vocational assistance to people with disabilities in sheltered workshops “to convert entirely to integrated supported employment.”<sup>252</sup> At least two such cases have already been brought, including one class action that was recently filed on behalf of thousands of people with disabilities in Oregon who “are unnecessarily segregated because of [the Oregon Department of Human Services’s] over-reliance on sheltered workshops, and its failure to timely develop and adequately fund integrated employment services, including supported employment programs.”<sup>253</sup>

Stefan has also been at the forefront of examining the applicability of the integration mandate to the child protective services that public entities provide.<sup>254</sup> Stefan points out that providing a family that is being

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<sup>247</sup> Stefan, *supra* note 230, at 905 (quoting *2009 Disability Priority Agenda*, N.Y. ASS’N ON INDEP. LIVING, <http://www.nysilc.org/caucus-bu/2009Disab-Priority-Agenda5-5-09.pdf> (last visited March 9, 2012)).

<sup>248</sup> Chambers, *supra* note 239, at 209 n.150 (quoting MICHAEL J. KENNEDY, CTR. ON HUMAN POL’Y, SYRACUSE UNIV., FROM SHELTERED WORKSHOPS TO SUPPORTED EMPLOYMENT (1988), <http://thechp.syr.edu/kdywork.htm>).

<sup>249</sup> *Id.*

<sup>250</sup> Stefan, *supra* note 230, at 878.

<sup>251</sup> *Id.* at 879.

<sup>252</sup> *Id.* at 880.

<sup>253</sup> Complaint at paragraph 2, *Lane et al. v. Kitzhaber et al.*, No. CV12-138 ST (D. Ore. filed Jan. 25, 2012). See also *Schwartz v. Jefferson County*, No. 2004CV000091 (Jefferson County Cir. Ct. Feb. 24, 2004).

<sup>254</sup> See Susan Stefan, *Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together*, 2 ST. LOUIS U. J. HEALTH L & POL’Y 135 (2008).

affected by disability with appropriate services “greatly reduce[s]” the likelihood that one of its members “will be institutionalized or placed out of the home in segregated residential placements.”<sup>255</sup> In the past, parents with disabilities have generally been unsuccessful when they have invoked the ADA to challenge a public entity’s termination of their parental rights. Stefan suggests that a systemic case that challenges, for example, “a statute precluding parents with psychiatric disabilities from receiving reunification services provided to other parents” could be successful if it emphasized that “one or more family members is at risk of institutionalization because of the absence of family-based services that the mental health agency has reason to know that the family needs.”<sup>256</sup> In 2011, a settlement was reached in *Katie A. v. Bontá*, “that will provide intensive home- and community-based mental health services for California children in foster care or at risk of removal from their families.”<sup>257</sup>

Advocates are also scrutinizing the impact that the administration of assisted outpatient treatment programs has on institutionalization. In New York, an organization brought a class action alleging that “Kendra’s Law”<sup>258</sup> violates, *inter alia*, the ADA.<sup>259</sup> Kendra’s Law “provides for court ordered “assisted” outpatient mental health treatment (‘AOT’) for persons who have been hospitalized twice within the past three years or who have acted violently towards themselves or others as a result of mental illness.”<sup>260</sup> The class action was brought on behalf of individuals with disabilities who face involuntary hospitalization because they do not meet the eligibility requirements for assisted outpatient treatment.<sup>261</sup> The plaintiffs alleged that, “by failing to authorize outpatient services to individuals who do not satisfy the criteria for [assisted outpatient treatment],” individuals with psychiatric disabilities faced unnecessary segregation in inpatient settings.<sup>262</sup>

<sup>255</sup> *Id.* at 166 (“This article argues that keeping families together is, necessarily, a key component of the integration mandate.”). *See also id.* at 140 (“This article argues that family integration is not only a natural corollary to community integration, it is a fundamental component of community integration”).

<sup>256</sup> *Id.* at 174.

<sup>257</sup> *Katie A. v. Bontá*, JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW, <http://www.bazelon.org/In-Court/Current-Cases/Katie-A.-v.-Bonta.aspx> (last visited Feb. 28, 2012); *see also* *Katie A. v. Bontá*, No. CV02-5662 (C.D. Cal. Sept. 27, 2011) (Settlement Agreement), available at <http://www.bazelon.org/LinkClick.aspx?fileticket=iyiXUKcEQH0%3d&tabid=186>.

<sup>258</sup> N.Y. Mental Hygiene Law § 9.60 (2010).

<sup>259</sup> *Mental Disability Law Clinic v. Hogan*, No. CV-06-6320 (CPS)(JO), 2008 WL 4104460 (E.D.N.Y. Aug. 29, 2008) (partially denying defendants’ motion to dismiss), *dismissed on other grounds by Order* (E.D.N.Y. April 23, 2012). Although this lawsuit portrays assisted outpatient treatment, which entails forced medication, as a desired benefit, other advocates have questioned whether that benefit comes at too high a cost to the autonomy of individuals with disabilities. *See, e.g.,* Michael L. Perlin, “*Their Promises of Paradise*”: *Will Olmstead v. L.C. Resuscitate the Constitutional “Least Restrictive Alternative” Principle in Mental Disability Law?*, 37 HOUS. L. REV. 999, 1044 (2000).

<sup>260</sup> *Mental Disability Law Clinic*, 2008 WL 4104460, at \*1.

<sup>261</sup> *Id.* at \*3.

<sup>262</sup> *Id.* at \*15.

Guardianship programs have also been criticized as potentially violating the integration mandate.<sup>263</sup> Leslie Salzman has made a compelling case that substituted decision making systems “violate the [ADA]’s mandate to provide services in the most integrated and least restrictive manner.”<sup>264</sup> Although people who have guardians might “reside in the community and are not physically segregated by the walls of an institution, guardianship creates a legal construct that parallels the isolation of institutional confinement.”<sup>265</sup> Like institutionalization, guardianship entails the loss of civic participation—“when the state appoints a guardian and restricts an individual from making his or her own decisions, the individual loses crucial opportunities for interacting with others.”<sup>266</sup> There is evidence that guardianship often leads to institutionalization.<sup>267</sup> Salzman emphasizes that less segregated options than guardianship are used by other countries and that the CRPD dictates supported—as opposed to substituted—decision making.<sup>268</sup>

Civic and political participation was also at the heart of a class action that people with mobility disabilities brought against the Philadelphia Board of Elections.<sup>269</sup> The lawsuit claimed that the Board of Elections violated the ADA and Rehabilitation Act “by denying them equal and integrated access to neighborhood polling places in Philadelphia.”<sup>270</sup> This lawsuit relied on evidence that people with disabilities “have been prevented from voting, or have been able to vote only with difficulty or with assistance, because their assigned polling places were inaccessible.”<sup>271</sup> After finding that “the evidence on the record of this Motion demonstrates that there are genuine issues of material fact as to whether Defendants select inaccessible polling places and whether they give priority to providing access to voting in the most integrated settings,” the court denied defendant’s motion for summary judgment on the plaintiffs’ integration mandate claim.<sup>272</sup> The

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<sup>263</sup> See generally Salzman, *supra* note 87.

<sup>264</sup> *Id.* at 157.

<sup>265</sup> *Id.* at 194.

<sup>266</sup> *Id.*

<sup>267</sup> See Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly: Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City*, 16 GEO. J. ON POVERTY L. & POL’Y 315, 341 (2009) (“Guardianship is certainly part of the process that results in a person being institutionalized in a nursing home, and perhaps in some cases at least part of the cause”).

<sup>268</sup> Salzman, *supra* note 87, at 161 (“[A] move to a supported decision-making paradigm is consistent with the ADA, as well as with the recently adopted U.N. Convention on the Rights of People with Disabilities”); see Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Rights of Elderly People under International Law*, 25 GA. ST. U. L. REV. 527, 563 (2009) (citing CRPD, Art. 12).

<sup>269</sup> *Kerrigan v. Phila. Bd. of Election*, No. 07-687, 2008 WL 3562521, at \*9 (E.D. Pa. Aug. 14, 2008) (“In their sixth claim, Plaintiffs maintain that Defendants have violated the ADA, 42 U.S.C. § 12132 and 28 C.F.R. § 35.130(d), and the [Rehabilitation Act], 29 U.S.C. § 794 and 28 C.F.R. § 41.51(d), by failing to provide services in the most integrated setting possible.”).

<sup>270</sup> *Id.* at \*1.

<sup>271</sup> *Id.* at \*6.

<sup>272</sup> *Id.* at \*19.

exclusionary aspects of the voting system that are being challenged in this case are not, by any means, unique to Philadelphia.

## V. CONCLUSION

Despite decades of deinstitutionalization, paradigmatic institutions persist. Millions of individuals with disabilities are still segregated from the community in psychiatric hospitals, nursing homes, and intermediate care facilities. But focusing on institutions alone understates the problem and potentially complicates the solution:

The facts of *Olmstead* specifically required the Court to decide when the ADA's proscription of discrimination in the form of unjustified segregation requires a state to move a person out of the most segregated setting possible—an "institution"—and into some less segregated setting. But whether a setting is "segregated" or "integrated" is not an all-or-nothing inquiry. Integration is not "binary;" "community-based" services fall everywhere along the spectrum in terms of how integrated they really are. *Olmstead* on its facts moves states toward minimizing the most obvious and egregious form of unnecessary segregation. However, its underlying principles also obligate a state to move an individual further along the spectrum. The "integration regulation" relied upon by the Court requires that services be provided, not merely "outside of traditional institutions," but "in the most integrated setting appropriate" to an individual's needs.<sup>273</sup>

Different definitions of institution focus on different attributes that might be present in a given facility. The presence or absence of these characteristics is important, however, mainly for the information it gives us about whether individuals with disabilities are being provided with services that are unnecessarily segregated from the community. Understanding this is the key to future *Olmstead* litigation. Advocates and individuals with disabilities are looking beyond "total institutions" to examine whether other residential settings such as homeless shelters, board and care homes, and group homes are providing services in the most integrated setting. They are also asking whether other services such as sheltered workshops, child protective services, assisted outpatient treatment, guardianship, and elections are being provided in a manner that violates *Olmstead*. The answers to these questions will shape future challenges to institutionalization.

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<sup>273</sup> Chambers, *supra* note 239, at 205.