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# The Past and Future of Deinstitutionalization Litigation

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**THE PAST AND FUTURE OF DEINSTITUTIONALIZATION LITIGATION**

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## THE PAST AND FUTURE OF DEINSTITUTIONALIZATION LITIGATION

### I. INTRODUCTION

Two conflicting stories have consumed the academic debate regarding the impact of deinstitutionalization litigation. The first, which has risen almost to the level of conventional wisdom, is that deinstitutionalization was a “disaster.”<sup>1</sup> A leading critic, Dr. E. Fuller Torrey, described its results as “a psychiatric *Titanic*”<sup>2</sup>—an evocative phrase quoted with approval by two Supreme Court justices<sup>3</sup>—and as “one of the great social disasters of recent American history.”<sup>4</sup> Another leading critic, Professor Paul Appelbaum, called deinstitutionalization a “tragedy.”<sup>5</sup> Professor Amitai Etzioni, who actually expressed cautious support for deinstitutionalization, nonetheless referred to it as a “curse[.]”<sup>6</sup> Rael Jean Isaac and Virginia Armat, in a widely cited 1990 book, wrote:

[P]atient liberation advocates, supposedly engaged in a movement of reform, left nothing in their wake but hordes of severely ill people abandoned to the vain “freedom” of the disease that enslaved them. Secure in their anti-psychiatric dogma that mental illness was a fiction, or at most an artifact of the mental institutions that made people sick, the mental health bar committed patients to the streets in the best of conscience.<sup>7</sup>

Also in 1990, two prominent commentators wrote that an “ideological consensus” was emerging “that identifies deinstitutionalization as one of the era’s most stunning public policy failures.”<sup>8</sup> Over a decade later, Professor Robert Weisberg wrote that “[i]t is now an axiom that deinstitutionalization caused the contemporary epidemic of homelessness for the mentally ill.”<sup>9</sup>

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<sup>1</sup> CHRISTOPHER JENCKS, *THE HOMELESS* 39 (1994). At least for people with psychiatric disabilities. Deinstitutionalization of people with intellectual and developmental disabilities receives much less criticism. See *infra* text accompanying notes 52-55.

<sup>2</sup> E. FULLER TORREY, *OUT OF THE SHADOWS: CONFRONTING AMERICA’S MENTAL ILLNESS CRISIS* 11 (1997).

<sup>3</sup> *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 609 (Kennedy, J., joined by Breyer, J., concurring in the judgment).

<sup>4</sup> E. FULLER TORREY, *THE INSANITY OFFENSE: HOW AMERICA’S FAILURE TO TREAT THE SERIOUSLY MENTALLY ILL ENDANGERS ITS CITIZENS* 1 (2008).

<sup>5</sup> Paul S. Appelbaum, *Crazy in the Streets*, COMMENTARY, May 1987, at 34, 39.

<sup>6</sup> Amitai Etzioni, “*Deinstitutionalization*”: *A Public Policy Fashion*, 3 EVALUATION Nos. 1-2, at 9 (1976).

<sup>7</sup> RAELE JEAN ISAAC & VIRGINIA C. ARMAT, *MADNESS IN THE STREETS: HOW PSYCHIATRY AND THE LAW ABANDONED THE MENTALLY ILL* 141 (1990).

<sup>8</sup> David Mechanic & David A. Rochefort, *Deinstitutionalization: An Appraisal of Reform*, 16 ANN. REV. SOCIOL. 301, 302 (1990).

<sup>9</sup> Robert Weisberg, *Restorative Justice and the Danger of “Community,”* 2003 UTAH L. REV. 343, 364. Against this backdrop, Professors Gerald Grob and Howard Goldman come across as amusingly understated when they say: “Although not necessarily a complete failure, deinstitutionalization can hardly be characterized as a policy tri-

Although the trope of deinstitutionalization-as-disaster has taken on the aura of conventional wisdom, a contrary position exists. Those who defend deinstitutionalization are much more ambivalent than the critics, which is perhaps why their voices have not been as widely heard. Professor David Rothman, whose work both inspired and chronicled an important episode of the early deinstitutionalization movement,<sup>10</sup> provides a good example of this ambivalence: “That deinstitutionalization has generally failed to deliver appropriate services to ex-mental patients or other persons in need of them is hardly debatable,” he writes, but “[t]he question is why the outcome of deinstitutionalization should have been so grim, and what should be done to remedy the situation.”<sup>11</sup> But Professor Rothman and others have nonetheless offered a suitably modest defense of deinstitutionalization. That defense does not deny that the results of deinstitutionalization have in many cases been disappointing. But it challenges the suggestion that deinstitutionalization has uniformly been unsuccessful, as well as the causal link critics seek to draw with the growth of the homeless population.<sup>12</sup> Advocates of this second story argue that it was cuts to social welfare programs in the 1980s, and not deinstitutionalization itself, that proximately caused the epidemic of homelessness among those with psychiatric disabilities.<sup>13</sup> They also point to a number of examples of successful community-based programs and services that policymakers and

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umph.” GERALD N. GROB & HOWARD H. GOLDMAN, *THE DILEMMA OF FEDERAL MENTAL HEALTH POLICY: RADICAL REFORM OR INCREMENTAL CHANGE?* 15 (2006). Professor Bernard Harcourt similarly finds “the historical record . . . complex,” but suggests that the deinstitutionalization movement offers at least a qualified success story to which advocates of reducing mass penal incarceration should attend. Bernard E. Harcourt, *Reducing Mass Incarceration: Lessons from the Deinstitutionalization of Mental Hospitals in the 1960s*, 9 OHIO ST. J. CRIM. L. 53, 54 (2011).

<sup>10</sup> See DAVID J. ROTHMAN, *THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC* (1971); DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS: BRINGING THE MENTALLY DISABLED INTO THE COMMUNITY* (1984).

<sup>11</sup> David J. Rothman, *The Rehabilitation of the Asylum*, AM. PROSPECT, Sept. 21, 1991.

<sup>12</sup> See, e.g., Rothman, *supra* note 11 (“[A] process that reached its peak in the 1970s cannot be the root cause of homelessness in the 1990s.”)

<sup>13</sup> See Mechanic & Rochefort, *supra* note 8, at 316 (“[T]he large waves of deinstitutionalization occurred with the expansion of social welfare activities in the late 1960s and 1970s, particularly Medicaid, SSI and SSDI, housing programs, and food stamps. These programs provided the subsistence base essential for relocating patients to the community. This subsistence base was not maintained relative to the growing numbers of seriously mentally ill persons, and in many instances it substantially shrank.”); Michael L. Perlin, Book Review, 8 N.Y.L. SCH. J. HUM. RTS. 557, 568 (1991) (“SSI had allowed (encouraged) states to release patients, since the entitlement program ensured a disability-based, federally-funded grant to provide for the ex-patients’ support in community settings. When these payments suddenly and dramatically dried up, it should not have been a real surprise to policymakers, behavioralists (or editorial writers) that some former patients would now be without homes.”).

practitioners developed in the wake of deinstitutionalization.<sup>14</sup> They argue that it was the failure of federal and state governments to invest in these programs and services that led to the disappointing results that occurred.<sup>15</sup>

Heated rhetoric to the contrary, what divides these two stories is not a disagreement about the facts so much as a disagreement about how to characterize and interpret those facts. Notwithstanding their broad pronouncements, both supporters and opponents will agree that deinstitutionalization has caused significant positive results for a large number of people who would otherwise have been set apart from their communities and denied the basic interactions of civic life.<sup>16</sup> This includes many people with psychiatric disabilities—as well as people with intellectual and developmental disabilities, whose deinstitutionalization has been far less controversial. But there is also little doubt that, in the wake of deinstitutionalization, a significant number of people with psychiatric disabilities were left to fend for themselves.

This dispute is not simply a matter of historical interest. The Supreme Court's 1999 decision in *Olmstead v. L.C.*,<sup>17</sup> which held that unjustified institutionalization can violate the Americans with Disabilities Act, was followed by a wave of new lawsuits challenging institutionalization of people with psychiatric, developmental, and/or physical disabilities.<sup>18</sup> And the Obama Administration's Community Living Initiative has led the United States Department of Justice to move aggressively into this field as well. The Department has, at last count, filed, joined, or participated in *Olmstead* suits in 21 states and obtained some significant and far-reaching settlements.<sup>19</sup> The question naturally arises whether this new round of deinstitutionalization litigation will end in the same place as the litigation of the 1970s and 1980s.

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<sup>14</sup> See, e.g., MICHAEL L. PERLIN, *THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL* 203 (2000) (“The pages of journals such as *American Psychologist* or *Psychiatric Services* are regularly filled with reports of successful deinstitutionalization programs that have ‘worked’; Fuller Torrey’s vivid heuristic should not serve to preempt the terms of this important debate.”) (footnote omitted).

<sup>15</sup> For a good example, see Michael L. Perlin, *Competency, Deinstitutionalization, and Homelessness: A Story of Marginalization*, 28 *HOUS. L. REV.* 63 (1991).

<sup>16</sup> See, e.g., GERALD N. GROB, *THE MAD AMONG US: A HISTORY OF THE CARE OF AMERICA'S MENTALLY ILL* 292 (1994) (“Whatever its contradictory and tangled origins, deinstitutionalization had positive consequences for a large part of the nation's severely and persistently mentally ill population.”); H. Richard Lamb, *Deinstitutionalization at the Beginning of the New Millennium*, in *DEINSTITUTIONALIZATION: PROMISE AND PROBLEMS* 3, 17 (H. Richard Lamb & Linda E. Weinberger, eds., 2001) (“[O]verall, most chronically and severely mentally ill persons now live in the community rather than in institutions. With adequate treatment and support, this change has greatly improved their lot, leading to a much richer life experience and a higher quality of life.”).

<sup>17</sup> 527 U.S. 581 (1999).

<sup>18</sup> See *infra* text accompanying notes 165-183.

<sup>19</sup> See *DOJ Olmstead Litigation*, [http://www.ada.gov/olmstead/olmstead\\_enforcement.htm](http://www.ada.gov/olmstead/olmstead_enforcement.htm).

In this article, I argue that things will be different this time—though not necessarily better. The outcomes of the first wave of deinstitutionalization litigation resulted, I will argue, from the interaction between the political dynamics into which advocates inserted themselves and the legal claims they employed. In particular, as many observers have noted, deinstitutionalization in the 1970s and 1980s was driven by a political alliance between civil libertarians and fiscal conservatives.<sup>20</sup> That alliance could have been expected to hold together just long enough to move people with disabilities out of expensive institutional placements but to break down when the time came to invest in community services. And, although commentators have not fully appreciated the point, the legal claims on which deinstitutionalization advocates initially relied—due process claims that were triggered by involuntary institutionalization—gave states far greater incentives to move people out of institutions than to fund adequate services in the community.

As I seek to show in this article, however, both the political dynamics and the legal claims have changed significantly, in ways that will affect deinstitutionalization litigation going forward. Precisely because the first wave of deinstitutionalization litigation was so successful in moving residents out of large state institutions for people with psychiatric and developmental disabilities, the efforts of deinstitutionalization advocates have turned to ensuring the availability of adequate services in the community. This has shifted the fiscal politics of the field. Deinstitutionalization advocates now are fighting to expand the amount of state money spent in the community—and, especially in tight budget times, to defend existing community services against cuts. While this change offers the possibility for a rapprochement between deinstitutionalization advocates and their traditional adversaries among labor unions and parents' organizations, it places the alliance with fiscal conservatives in serious jeopardy.

At the same time, deinstitutionalization advocates have moved from the due process theories on which they relied in the 1970s and 1980s to an antidiscrimination theory relying on the ADA and *Olmstead*. That theory focuses directly on state resource-allocation decisions and, far more than due process, affords states a powerful incentive to create and fund adequate community services.

All of which leaves the future of deinstitutionalization uncertain. Deinstitutionalization advocates are focused to a greater extent than ever on the goal of building up a robust community-based treatment system. And they are employing the most powerful legal tool they have ever possessed to achieve that goal. But the political partners who helped them

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<sup>20</sup> The best discussions of the political dynamics of the first two decades of the deinstitutionalization movement, in my view, are ANN BRADEN JOHNSON, *OUT OF BEDLAM: THE TRUTH ABOUT DEINSTITUTIONALIZATION* (1990), and PAUL LERMAN, *DEINSTITUTIONALIZATION AND THE WELFARE STATE* (1982). I draw on their insights throughout, though I depart significantly from their arguments in places.

achieve their great success in the first wave of deinstitutionalization will likely be the biggest obstacle to success in the next wave.

## II. EXPLAINING DEINSTITUTIONALIZATION'S PAST

From the early 1970s until the 1990s, the deinstitutionalization movement centered around two major campaigns: the campaign to close large state mental hospitals; and the campaign to close large state facilities housing people with intellectual and developmental disabilities. These campaigns were fought, among other places, in state legislatures, state executive branches, and the federal courts. These campaigns were often linked in legal and political strategy, as well as in time, though the deinstitutionalization of individuals with psychiatric disabilities became prominent in the public eye first. The rise of the deinstitutionalization movement in the 1970s and 1980s reflected and created a series of political dynamics that, until recently, structured legal and policy developments in the field.

In this Part, I argue that the deinstitutionalization movement in this period was more successful than commentators typically give it credit for. The limitations of its success, I argue, stem directly from the political dynamics into which advocates inserted themselves and the legal strategies on which they relied. Section A describes the results of the deinstitutionalization movement's advocacy—results that were profound but, in the end, did not fully reach advocates' goals. Section B argues that those results can in significant respects be attributed to the political dynamics surrounding deinstitutionalization, in which civil libertarian advocates of closing state mental hospitals and developmental disability facilities found themselves allied with fiscal conservatives in state government, and against family and union groups that argued for broader social provision. That alliance, I argue, imposed a hydraulic pressure toward downsizing institutions without providing sufficient services and supports to enable people with psychiatric or developmental disabilities to flourish in the community. And, as I argue in Section C, that pressure was exacerbated by the legal-doctrinal tools on which deinstitutionalization advocates relied in those years. Those advocates relied, in particular, on due-process-based arguments that could regulate institutionalization but afforded little purchase on the effort to promote community-based services and supports.

### A. *The Successes and Failures of Deinstitutionalization*

Notwithstanding the near-consensus that it has been a failure, in this Section I hope to show that deinstitutionalization has been a success in many significant respects, though its success has been limited. Consider first the intellectual/developmental disability context. The number of people with developmental disabilities confined to state-operated institutions

in the United States peaked at just under 200,000 in 1967.<sup>21</sup> Since that time, states have closed hundreds of their institutions, and they have downsized many others.<sup>22</sup> Institutions like the Pennhurst State School and Hospital in Pennsylvania (peak census: 3,500 in 1955), the Lincoln State School and Colony in Illinois (peak census: over 5,000 in the 1950s), and Letchworth Village in New York (peak census: over 4,000 in the mid-1960s) are now closed.<sup>23</sup> And the state-operated institutions that remain are much smaller, housing at most hundreds, not thousands, of residents.<sup>24</sup> As of June 30, 2009, according to statistics compiled by the Research and Training Center on Community Living at the University of Minnesota (RTC), “nine states had closed all state operated residential facilities with 16 or more residents” with intellectual or developmental disabilities.<sup>25</sup> And “[o]f the 354 large state operated facilities operating at any time between 1960 and 2008, only 162 facilities (45.7%) in 42 states remained open on June 30, 2009.”<sup>26</sup>

Although every state has significantly reduced its reliance on large state-operated facilities for people with intellectual disabilities, some states still have very large numbers of residents in those facilities. The RTC reports that the average daily population in these facilities across the country has dropped 74.4 percent between 1980 and 2009, from 131,345 to 33,682.<sup>27</sup> Twenty-four states and the District of Columbia have reduced the population in these facilities by more than 80 percent over this period of time. The states, which are geographically and demographically diverse, are: Alabama, Alaska, Arizona, Colorado, Delaware, Hawaii, Indiana, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, New Hampshire, New Mexico, New York, North Dakota, Oklahoma, Oregon, Pennsylvania, Utah, Vermont, West Virginia, and Wyoming.<sup>28</sup> Of the states not on this list, thirteen continued as of 2009 to confine more than 900 people in congregate, state-operated institutions: Arkansas (1,083); California (2,391); Florida (1,040); Georgia (915); Illinois (2,161); Louisiana (1,174); Mississippi (1,323); New Jersey (2,841); North Carolina (1,629); Ohio (1,455); Texas (4,629); Virginia (1,276); and Washington (936).<sup>29</sup> In Mississippi, the population of these facilities de-

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<sup>21</sup> See, e.g., Deborah S. Metzel, *Historical Social Geography*, in *MENTAL RETARDATION IN AMERICA: A HISTORICAL READER* 420, 432 (Steven Noll & James W. Trent Jr., eds., 2004).

<sup>22</sup> See K. CHARLIE LAKIN, SHERYL LARSON, PATRICIA SALMI & AMANDA WEBSTER, *RESIDENTIAL SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2009* at 17-18 (2010).

<sup>23</sup> See *id.* at 19-29.

<sup>24</sup> See *id.*

<sup>25</sup> *Id.* at iii.

<sup>26</sup> *Id.* at iv. The RTC counts the District of Columbia as a “state” for these purposes, so the number of states adds up to 51.

<sup>27</sup> See *id.* at 4.

<sup>28</sup> See *id.* at 5.

<sup>29</sup> See *id.*



creased by only 20.3 percent between 1980 and 2009; in Arkansas, it decreased by only 30.1 percent.<sup>30</sup> Perhaps not surprisingly, a number of states on this list have been the targets of enforcement actions by the Department of Justice as it has stepped up its *Olmstead* program in recent years.<sup>31</sup>

In the psychiatric disability area, the numbers are even more stark. The end-of-year inpatient census in public psychiatric hospitals in the United States peaked in 1955 at just under 560,000 individuals.<sup>32</sup> By 2005, the number had decreased by more than 90 percent to just under 50,000.<sup>33</sup> As Professors Grob and Goldman point out, “[t]he decline was even more dramatic if general population growth is taken into account. Had the proportion remained stable and the mix constant, mental hospitals would have had about 950,000 patients in 2000.”<sup>34</sup> The total number of admissions to these hospitals was significantly higher than this number might suggest, as 60 percent of adults admitted to public psychiatric hospitals in 2005 were discharged within 30 days; average length of stay has gone down dramatically since the 1950s as well.<sup>35</sup> And the total number of public psychiatric hospitals in the United States also decreased substantially, from 310 as late as 1970 to 220 in 2000.<sup>36</sup> As with developmental disabilities, there is substantial variation across the states in the numbers, but the overall trend is clear.

Why, then, has a near-consensus developed that deinstitutionalization was a failure? The major reason, which relates largely to people with psychiatric and not developmental disabilities, is the belief that deinstitutionalization caused an epidemic of “homeless mentally ill.”<sup>37</sup> It is undeniable that, at the same time the population of state institutions was decreasing dramatically, estimates of the number of homeless individuals in the United States *increased* dramatically—tripling in the 182 largest American cities over the course of the 1980s.<sup>38</sup> Most analysts estimate

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<sup>30</sup> *See id.*

<sup>31</sup> *See* United States v. Virginia, No. 12-cv-059 (E.D. Va.) (settlement agreement filed Jan. 26, 2012); United States v. Arkansas, 794 F. Supp.2d 935 (E.D. Ark. 2011); United States v. Georgia, No. 1:10-cv-00249 CAP (N.D. Ga.) (settlement agreement filed October 19, 2010); Disability Rights New Jersey v. Velez, No. 05-4723 (D.N.J., Sept. 24, 2010) (United States participated as intervenor and amicus).

<sup>32</sup> *See* Ronald W. Manderscheid, Joanne E. Atay & Raquel A. Crider, *Changing Trends in State Psychiatric Hospital Use From 2002 to 2005*, 60 PSYCHIATRIC SERVICES 29 (2009).

<sup>33</sup> *See id.*

<sup>34</sup> GROB & GOLDMAN, *supra* note 9, at 14.

<sup>35</sup> JOHNSON, *supra* note 20, at 130.

<sup>36</sup> *See* GROB & GOLDMAN, *supra* note 9, at 50.

<sup>37</sup> *E.g.*, H. RICHARD LAMB, THE HOMELESS MENTALLY ILL (1984); E. FULLER TORREY, NOWHERE TO GO: THE TRAGIC ODYSSEY OF THE HOMELESS MENTALLY ILL (1989).

<sup>38</sup> *See* Martha Burt, *Causes of the Growth of Homelessness During the 1980s*, in UNDERSTANDING HOMELESSNESS: NEW POLICY AND RESEARCH PERSPECTIVES 169, 181 (Dennis P. Culhane, ed., 1997).

that between a third and a half of homeless individuals have mental illness, and that up to three-quarters of homeless individuals have substance abuse problems.<sup>39</sup> Because homelessness rose as the population of state mental hospitals fell, and a large number of homeless persons have mental illness, a wide array of commentators across the political spectrum have blamed deinstitutionalization for the rise in homelessness.<sup>40</sup> Professor Michael Perlin, one of the strongest defenders of deinstitutionalization in the legal academy, describes the argument of the critics:

The story goes something like this: nurtured by radical psychiatrists (such as Thomas Szasz and R.D. Laing), spurred on by politically-activist organizations pushing egalitarian social agendas (such as the ACLU), a cadre of brilliant but diabolical patients' rights lawyers dazzled sympathetic and out-of-touch judges with their legal *legerdemain*—abetted by woolly-headed social theories, inapposite constitutional arguments, some oh-my-god worst-case anecdotes about institutional conditions, and a smattering of “heartwarming successful [deinstitutionalization] cases”—as a result of which courts entered orders “emptying out the mental institutions” so that patients could “die with their rights on.” When cynical bureaucrats read the judicial handwriting on the hospital walls, they *then* joined the stampede, and the hospitals were emptied. Ergo deinstitutionalization. Ergo homelessness. Endgame.<sup>41</sup>

Professor Perlin argues that this story is “all wrong. Dead wrong. Obscenely wrong.”<sup>42</sup> And the critics' argument is, indeed, far too simplistic. As the sociologist Peter Rossi explained in his landmark study of homelessness, “there were already mentally ill persons among the homeless” before deinstitutionalization, and the prevalence of psychiatric disability among homeless people may therefore “simply reflect continuity with the past.”<sup>43</sup> And as the economist Brendan O'Flaherty explained in

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<sup>39</sup> See, e.g., LITA JANS, SUSAN STODDARD & LEWIS KRAUS, CHARTBOOK ON MENTAL HEALTH AND DISABILITY IN THE UNITED STATES § 4.10 (2004).

<sup>40</sup> See, e.g., MICHAEL DEAR & JENNIFER WOLCH, LANDSCAPES OF DESPAIR: FROM DEINSTITUTIONALIZATION TO HOMELESSNESS 175 (1987) (“In some respects, an even more disturbing outcome of deinstitutionalization is the recent and widely publicized increase in the number of homeless mentally disabled.”); JENCKS, *supra* note 1, at 21 (“[C]onsiderably more than a quarter of today's homeless might have spent time in a mental hospital if we still ran the system the way we ran it in the 1950s.”); TORREY, *supra* note 37, at 6-11 (discussing increase in homelessness as a consequence of deinstitutionalization); Appelbaum, *supra* note 5, at 37 (“Many of the mentally ill, of course, have drifted away entirely from any form of care. Given the freedom to choose, they have chosen to live on the streets; according to various estimates they comprise between 40 and 60 percent of homeless persons.”); Weisberg, *supra* note 9, at 364 (“It is now an axiom that deinstitutionalization caused the contemporary epidemic of homelessness for the mentally ill.”).

<sup>41</sup> Michael L. Perlin, Book Review, *supra* note 13, at 559-560.

<sup>42</sup> *Id.* at 560.

<sup>43</sup> PETER H. ROSSI, DOWN AND OUT IN AMERICA: THE ORIGINS OF HOMELESSNESS 145 (1989).

his own book-length treatment of the subject, “[a]fter 1975, the movement out of state and county mental hospitals was more than offset by the movement into nursing homes and correctional institutions, and after 1980 homelessness rose among the mentally ill because housing conditions got worse.”<sup>44</sup>

To be sure, we could solve the problem of homelessness among people with psychiatric disabilities by simply institutionalizing them for the long term.<sup>45</sup> But other policies could solve that problem just as well—notably supportive housing, in which individuals obtain tenancy in apartments linked with supportive services.<sup>46</sup> And yet, as homelessness was increasing in the 1980s, the federal and state governments were cutting SSI and housing assistance—the very programs that could pay for community-based housing for people with psychiatric disabilities.<sup>47</sup> The indictment of deinstitutionalization, as opposed to the failure to invest in community-based services and supports, does not rest on an empirical determination of what happened in the world so much as on a normative premise that institutionalization is preferable to community-based housing and supports.<sup>48</sup> Given the undoubted harms of long-term institutionalization for people with psychiatric disabilities, and the viability of evidence-based community services like supported housing and assertive community treatment, there is no good reason to prefer institutionalization as the

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<sup>44</sup> BRENDAN O’FLAHERTY, *MAKING ROOM: THE ECONOMICS OF HOMELESSNESS* 235 (1996); *see also id.* at 227 (“[T]he reason more mentally ill people are homeless is because the probability of being homeless, given that you are mentally ill and not institutionalized, has risen substantially. The rise in the number of people who are mentally ill and not institutionalized accounts for almost nothing.”).

<sup>45</sup> *See* ROSSI, *supra* note 43, at 145 (arguing that “noninstitutionalization”—the difficulty in committing people to institutions—has “strongly” affected homelessness).

<sup>46</sup> *See* sources cited *infra* note **Error! Bookmark not defined.****Error! Bookmark not defined.**

<sup>47</sup> *See* JOHNSON, *supra* note 20, at 135-154 (describing unemployment, urban housing shortages, poverty, and the Reagan Administration’s termination of SSI for many people with mental illness in the early 1980s as the crucial causes of homelessness, and concluding that “[w]ith so many compelling explanations for the increase in homelessness across the country, it seems decidedly odd that deinstitutionalization should continue to get the blame, but it does”); JENNIFER WOLCH & MICHAEL DEAR, *MALIGN NEGLECT: HOMELESSNESS IN AN AMERICAN CITY* 112-148 (1993) (discussing welfare state retrenchment as a cause of homelessness). Even Professor Jencks, who criticizes deinstitutionalization, acknowledges that “states compounded [the] problem by cutting their cash payments to the mentally ill.” JENCKS, *supra* note 1, at 34.

<sup>48</sup> *See* Lamb, *supra* note 16, at 11 (“The two American Psychiatric Association task forces on the homeless mentally ill concluded that this problem is the result not of deinstitutionalization itself but of the way it has been implemented.”) (citations omitted); Mechanic & Rochefort, *supra* note 8, at 318 (“There is little evidence to support the contention that deinstitutionalization is the primary cause of homelessness; it is one of many interacting causes.”).

solution to the homelessness problem among people with psychiatric disabilities.<sup>49</sup>

Still, the failures of the deinstitutionalization movement have been real. Even if deinstitutionalization did not cause the problem of homelessness among individuals with psychiatric disabilities, it has not provided adequate services and supports to those individuals to enable them to flourish. And, as Professor O’Flaherty’s own argument makes clear, far too many people who would have in the past been confined to psychiatric hospitals are now in jails or congregate private institutions like nursing homes and adult care homes.<sup>50</sup> Deinstitutionalization of people with psychiatric disabilities was by and large successful in opening the back doors of large state institutions so residents could leave—and in closing the front doors so that new residents could not come in. But it was less successful in promoting investments in the kind of community service infrastructure that enables people with psychiatric disabilities to thrive in the community.<sup>51</sup>

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<sup>49</sup> See, e.g., JOHNSON, *supra* note 20, at 154-155 (arguing that what homeless people with mental illness need is a home and money); Lamb, *supra* note 16, at 17 (“With adequate treatment and support, [deinstitutionalization of “most chronically and severely mentally ill persons”] has greatly improved their lot, leading to a much richer life experience and a higher quality of life.”).

<sup>50</sup> See, e.g., CHRIS KOYANAGI, *LEARNING FROM HISTORY: DEINSTITUTIONALIZATION OF PEOPLE WITH MENTAL ILLNESS AS PRECURSOR TO LONG-TERM CARE REFORM 6* (2007) (“[B]y 1980, 750,000 people with serious mental illness lived in nursing homes, representing 44 percent of the nursing home population.”); M. Gregg Bloche & Francine Cournos, *Mental Health Policy for the 1990s: Tinkering in the Interstices*, in *HEALTH POLICY AND THE DISADVANTAGED* 143, 147 (Lawrence D. Brown, ed., 1991) (“The presence of 750,000 mentally disabled persons in nursing homes at the start of the 1980s suggests that there has been large-scale *transinstitutionalization*.”) (citations omitted); E. Fuller Torrey, *Jails and Prisons—America’s New Mental Hospitals*, 85 *AM. J. PUB. HEALTH* 1611 (1995) (“Quietly but steadily, jails and prisons are replacing public mental hospitals as the primary purveyors of public psychiatric services for individuals with serious mental illnesses in the United States.”). On people with psychiatric disabilities in adult care homes, see *Disability Advocates, Inc. v. Paterson*, 653 F. Supp.2d 184, 187 (E.D.N.Y. 2009) (“DAI has proven by a preponderance of the evidence that its constituents, approximately 4,300 individuals with mental illness, are not receiving services in the most integrated setting appropriate to their needs. The adult homes at issue are institutions that segregate residents from the community and impede residents’ interactions with people who do not have disabilities. “); Letter from Thomas E. Perez, Assistant Attorney General for Civil Rights, United States Department of Justice, to Roy Cooper, Attorney General, State of North Carolina 1 (July 28, 2011) (finding that North Carolina “plans, structures, and administers its mental health service system to deliver services to thousands of persons with mental illness in large, segregated adult care homes, and to allocate funding to serve individuals in adult care homes rather than in integrated settings”).

<sup>51</sup> See H. Richard Lamb & Leona L. Bachrach, *Some Perspectives on Deinstitutionalization*, 52 *PSYCHIAT. SERVS.* 1039, 1039-1040 (2001) (“[H]ospital censuses throughout the country have been drastically reduced, and many would-be admissions to those hospitals have been blocked, but the critical third process of supplying adequate

When they have considered it at all, commentators have generally seen deinstitutionalization of people with intellectual and developmental disabilities as more successful than deinstitutionalization of people with psychiatric disabilities. People with developmental disabilities do not make up a significant proportion of homeless persons.<sup>52</sup> And studies of the individuals who left large state developmental disability institutions like Pennhurst and Willowbrook showed that even people who had been thought the most impaired could thrive in the community.<sup>53</sup> Still, there remains some controversy regarding deinstitutionalization of people with developmental disabilities.<sup>54</sup> And, in a number of states, large numbers of people with developmental disabilities live in nursing homes because of the lack of sufficient community services.<sup>55</sup>

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and accessible community alternatives to hospitalization has frequently lagged far behind.”). For a thoughtful discussion of the problem, see KOYANAGI, *supra* note 50, at 2.

<sup>52</sup> *But cf.* Thomas Earl Backer & Elizabeth A. Howard, *Cognitive Impairments and the Prevention of Homelessness: Research and Practice Review*, 28 J. PRIMARY PREVENTION 375, 379 (2007) (“People with developmental disabilities are more vulnerable to becoming homeless at two critical junctures. The first occurs when a young person ages out of the care system designed for children . . . . The second juncture occurs when parents of a developmentally disabled person are no longer living.”).

<sup>53</sup> See JAMES W. CONROY & VALERIE J. BRADLEY, THE PENNHURST LONGITUDINAL STUDY: A REPORT OF FIVE YEARS OF RESEARCH AND ANALYSIS 313-319 (1985); ROTHMAN & ROTHMAN, *supra* note 10, at 220-253. For more recent reviews of the evidence, which demonstrate that moving from institutions to the community has led to positive outcomes for people with developmental disabilities, see Agnes Kozma, Jim Mansell, Julie Beadle-Brown & Eric Emerson, *Outcomes in Different Residential Settings for People With Intellectual Disability: A Systematic Review*, 114 AM. J. INTELLECTUAL & DEVELOPMENTAL DISABILITIES 193 (2009); Shannon Kim, Sheryl A. Larson & K. Charlie Lakin, *Behavioural Outcomes of Deinstitutionalisation for People with Intellectual Disability: A Review of US Studies Conducted Between 1980 and 1999*, 26 J. INTELLECTUAL & DEVELOPMENTAL DISABILITY 35 (2001).

<sup>54</sup> See, for example, the controversy over whether mortality rates are higher in institutions or the community, as discussed in Mary F. Hayden, *Mortality Among People with Mental Retardation Living in the United States: Research Review and Policy Application*, 36 MENTAL RETARDATION 345 (1998) (reviewing literature and finding it inconclusive); David Strauss, Theodore A. Kastner & Robert Shavelle, *Mortality of Adults with Developmental Disabilities Living in California Institutions and Community Care, 1985-1994*, 36 MENTAL RETARDATION 360 (1998) (finding significantly higher risk-adjusted mortality rates in the community); Kevin F. O’Brien & E.S. Zaharia, *Recent Mortality Patterns in California*, 36 MENTAL RETARDATION 372 (1998) (finding a trend of declining mortality rates in the community, but not in institutions, such that the rate was lower in the community than in the institutions by the end of the 1991-1995 study); James W. Conroy & Miriam Adler, *Mortality Among Pennhurst Class Members, 1978-1989: A Brief Report*, 36 MENTAL RETARDATION 380 (1998) (finding that former Pennhurst residents died at significantly lower rates than they would have if they had not moved to community residences); K. Charlie Lakin, *Observations on the California Mortality Studies*, 36 MENTAL RETARDATION 395 (1998) (noting that Strauss *et al.*, *supra*, reported lower death rates in California’s institutions than California itself did).

<sup>55</sup> See, e.g., Aman Batheja, *Many with Developmental Disabilities “Trapped” in Nursing Homes, Lawsuit Contends*, FT. WORTH STAR-TELEGRAM, Dec. 20, 2010 (describing lawsuit alleging that “[m]ore than 4,500 people with intellectual and develop-

### B. *The Old Politics of Deinstitutionalization*

Civil rights litigation against government agencies often causes extensive social change only indirectly, by organizing and mobilizing constituencies outside of government that influence the political process,<sup>56</sup> and by empowering constituencies within government that are tasked with responding to or implementing the judgments in litigation.<sup>57</sup> To understand the results of deinstitutionalization litigation in the 1970s, 1980s, and 1990s, I contend, one must understand the political goals of the lawyers who brought that litigation and the political dynamics into which they inserted themselves.<sup>58</sup> In this section, I intend to show that it was those political dynamics that led to the deinstitutionalization movement's great success in reducing the population of state institutions—and their lesser success in building the robust system of services and supports that enable people with disabilities to flourish in the community.

Advocates of deinstitutionalization had two principal goals. The first was to move people out of—and keep people from going into—state institutions. That is the goal I referred to above as opening the back door and closing the front door. To many civil libertarians at the time, involuntary commitment (particularly of people with psychiatric disabilities), looked like nothing more than incarceration, a perception that was only fed by reports of the horrific and nontherapeutic conditions in many institutions.<sup>59</sup> But while a substantial (and, in the 1960s, expanding) array of

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mental disabilities” in Texas “are ‘trapped’ in nursing homes providing inadequate care”).

<sup>56</sup> See STUART A. SCHEINGOLD, *THE POLITICS OF RIGHTS: LAWYERS, PUBLIC POLICY, AND POLITICAL CHANGE* 131-148 (1974), for the classic expression of this point.

<sup>57</sup> See JAMES Q. WILSON, *BUREAUCRACY: WHAT GOVERNMENT AGENCIES DO AND WHY THEY DO IT* 285-286 (1989). For the point as to litigation generally, see Margo Schlanger, *Operationalizing Deterrence: Claims Management (In Hospitals, a Large Retailer, and Jails and Prisons)*, 2 J. TORT L. 1 (2008).

<sup>58</sup> On the importance of the goals and strategies of lawyers in institutional reform litigation, see Margo Schlanger, *Beyond the Hero Judge: Institutional Reform Litigation as Litigation*, 97 MICH. L. REV. 1994 (1999).

<sup>59</sup> For a leading expression of the point at the time, see BRUCE J. ENNIS, *PRISONERS OF PSYCHIATRY: MENTAL PATIENTS, PSYCHIATRISTS, AND THE LAW* (1972); see also Appelbaum, *supra* note 5 at 36 (“Mentally ill persons seemed particularly appropriate targets for a crusade against governmental power, for the state was depriving them of liberty—with ostensibly benevolent aims, yet in conditions that belied the goal of treatment.”). Albert Deutsch’s 1948 book, ALBERT DEUTSCH, *THE SHAME OF THE STATES* (1948), documented the horrific conditions in state mental hospitals. Burton Blatt and Fred Kaplan’s *Christmas in Purgatory* similarly documented horrific conditions in developmental disability institutions nearly two decades later. See BURTON BLATT & FRED KAPLAN, *CHRISTMAS IN PURGATORY: A PHOTOGRAPHIC ESSAY ON MENTAL RETARDATION* (1966). And civil libertarian lawyers began to challenge the allegedly therapeutic nature of confinement. For example, state psychiatric hospitals often claimed that they provided “milieu therapy,” which advocates claimed was too often in practice simply a euphemism for custodial confinement. See, e.g., *O’Connor v. Donaldson*, 422 U.S. 563, 569 (1975) (“O’Connor described Donaldson’s treatment as ‘milieu therapy.’ But witnesses from the hospital staff conceded that, in the context of this case, ‘milieu

procedural protections precede the decision to incarcerate someone in a prison, comparatively few protections then existed to precede the decision to incarcerate someone in a psychiatric or developmental disability institution. Civil libertarians saw institutionalization as an end run around the criminal procedure revolution; they sought to extend the (new) protections of the criminal process to the context of civil institutionalization.<sup>60</sup>

In the psychiatric disability context especially, these general civil libertarian ideas mixed with a specific critique, somewhat in vogue during the 1960s and 1970s, of psychiatric diagnosis as a form of social control.<sup>61</sup> A person who was persuaded that mental illness was a “myth,” or just a label placed by powerful professionals and social institutions on people they regarded as deviant, would necessarily be highly concerned with a process that attached the state’s carceral power to psychiatric diagnosis, especially without the protections of the criminal process.<sup>62</sup>

It has never been clear that many advocates of deinstitutionalization ever went all the way to believing that mental illness was a myth—and the position that developmental disabilities were mythical certainly never had any prominence.<sup>63</sup> But one did not have to take that extreme

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therapy’ was a euphemism for confinement in the ‘milieu’ of a mental hospital.”); *Rouse v. Cameron*, 373 F.2d 451, 457 (D.C. Cir. 1966) (Bazelon, J.) (“[I]t may not be assumed that confinement in a hospital is beneficial ‘environmental therapy’ for all.”) (footnotes omitted); ALAN A. STONE, LAW, PSYCHIATRY, AND MORALITY 50 (1984) (“Like the person who sees that the Emperor has no clothes, Judge Bazelon told the psychiatrists that mere confinement in the John Howard Pavilion did not constitute milieu therapy.”). Indeed, the complaint in the challenge to institutionalization at New York’s Willowbrook State School explicitly alleged “that ‘Willowbrook is not a therapeutic institution. It more closely resembles a prison . . . .’” Herbert A. Eastman, *Speaking Truth to Power: The Language of Civil Rights Litigators*, 104 YALE L.J. 763, 782 (1994) (quoting the complaint).

<sup>60</sup> An important bridging case here was *In re Gault*, 387 U.S. 1 (1967), in which the Supreme Court held that significant elements of constitutional criminal procedure must apply in juvenile delinquency proceedings—proceedings that, like civil commitment proceedings, had been justified as providing treatment and rehabilitation, not punishment. *See id.* at 15-16.

<sup>61</sup> The key texts here were THOMAS SZASZ, *THE MYTH OF MENTAL ILLNESS: FOUNDATIONS OF A THEORY OF PERSONAL CONDUCT* (1961), and R.D. LAING, *THE POLITICS OF EXPERIENCE* (1967). Many also cite ERVING GOFFMAN, *ASYLUMS: ESSAYS ON THE SOCIAL SITUATION OF MENTAL PATIENTS AND OTHER INMATES* (1961), as forming part of the same critique, but I have always read Goffman less as challenging psychiatric diagnosis itself as at describing and explaining the social interactions and responses of those who have been confined to psychiatric hospitals.

<sup>62</sup> These concerns might have also seemed to have been validated by the extreme case of the Soviet Union’s use of psychiatry to stifle dissent. *See* STONE, *supra* note 59, at 3-36.

<sup>63</sup> In recent years, by contrast, the so-called neurodiversity movement has urged something very much like a myth-of-mental-illness position in the context of autism and even, in some cases, intellectual disabilities. *See, e.g.*, THOMAS ARMSTRONG, *NEURODIVERSITY: DISCOVERING THE EXTRAORDINARY GIFTS OF AUTISM, ADHD, DYSLEXIA, AND OTHER BRAIN DIFFERENCES* (2010); Andrew Solomon, *The Autism Rights Movement*, NEW YORK, May 25, 2008; Amy Harmon, *Nominee to Disability*

view to believe that institutionalization—as it existed in the 1960s and 1970s, to be sure, and perhaps inherently—was oppressive, dehumanizing, and antitherapeutic.<sup>64</sup> Even if one did not believe that mental illness was a myth, the risk of erroneous diagnosis and the massive deprivation of liberty attending institutionalization raised serious civil libertarian concerns.<sup>65</sup>

The second goal of deinstitutionalization advocates, often ignored by critics but just as important for most of the advocates themselves, was to develop an array of services and supports in the community that would enable people with psychiatric disabilities or intellectual/developmental disabilities to flourish.<sup>66</sup> Thus, in the retainer agreement with his clients in the landmark *Willowbrook* suit, plaintiffs' attorney Bruce Ennis described the "ultimate goal" of the litigation as one of promoting "community-based alternatives (including halfway houses, hostels, group homes, community education and training programs, etc.), so that Willowbrook (and similar institutions) can be promptly and completely phased out of existence."<sup>67</sup>

In seeking to achieve these goals, deinstitutionalization advocates confronted two powerful constituencies: the parents and other family members of those who had been institutionalized (particularly in the developmental disability context); and the workers at state facilities (often represented by their unions). To be sure, these groups were not uniformly hostile to deinstitutionalization litigation, especially in the early days. Parents and family members actually played a key role in early deinstitutionalization litigation in the developmental disability context. Many parents who had sent their children to institutions before the 1970s had felt they had no choice but to do so. Frequently, their family doctors had told them that their children would be an intolerable burden if not placed in an institution.<sup>68</sup> And there was typically no network of community-based services that would have enabled these parents to keep their children at home even if they had wanted to.<sup>69</sup> Although patterns of visitation and

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*Council is Lightning Rod for Dispute on Views of Autism*, N.Y. TIMES, Mar. 28, 2010, at A16.

<sup>64</sup> See, e.g., JENCKS, *supra* note 1, at 29 ("Since many mental hospitals really did deprive patients of rights accorded almost every other human being, and since the therapeutic rationales offered for many hospital rules seemed unpersuasive, many people (including me) found these antiauthoritarian critiques quite persuasive.")

<sup>65</sup> See ENNIS, *supra* note 59, at 235-253.

<sup>66</sup> See, e.g., JENNIFER L. ERKULWATER, *DISABILITY RIGHTS AND THE AMERICAN SOCIAL SAFETY NET* (2006) ("[R]eformers sought as a final goal to replace the asylum with a community-based system of mental health care, a policy that would allow people with mental disorders to live in their home neighborhoods and to enjoy all the rights and social privileges offered to the able-bodied.")

<sup>67</sup> ROTHMAN & ROTHMAN, *supra* note 10, at 62.

<sup>68</sup> See JAMES W. TRENT, JR., *INVENTING THE FEEBLE MIND: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES* 241-242 (1994).

<sup>69</sup> Prior to early-1970s decisions like *Pennsylvania Association for Retarded Children v. Pennsylvania*, 343 F. Supp. 279 (E.D. Pa. 1972), and *Mills v. Board of Education*, 348 F. Supp. 866 (D.D.C. 1972), and Congress's passage of the Education for All



continuing connections varied, many retained a strong interest in the well being of the children they had sometimes reluctantly institutionalized.<sup>70</sup> These parents were horrified by the conditions in the institutions in which their children resided. Many came to support litigation to challenge those conditions, and perhaps give their children an opportunity to live in the community.<sup>71</sup> Individual parents, along with chapters of parents' organizations like (what was then called) the Association for Retarded Children, served as plaintiffs in the early developmental disabilities deinstitutionalization cases.<sup>72</sup> Even the parent and family associations of particular state institutions, which often took on the feel of "company unions,"<sup>73</sup> were plaintiffs in some of these cases.<sup>74</sup> In the psychiatric disability context as well, families of institutionalized persons played a key role in early-1970s efforts to improve conditions in, and move people out of, mental hospitals.<sup>75</sup>

Similarly, workers in institutions were among the drivers of some of the early deinstitutionalization litigation. The *Wyatt* case,<sup>76</sup> which resulted in the closure of most of Alabama's institutions for people with psychiatric and developmental disabilities, was originally brought by a group of employees to challenge a cut in their wages.<sup>77</sup> And it was professional employees at New York's Willowbrook State School, radicalized by the politics of the 1960s and deploring the conditions at the institution,

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Handicapped Children Act, there was no requirement that states even provide schooling for children with intellectual disabilities. See Thomas Hehir & Sue Gamm, *Special Education: From Legalism to Collaboration*, in LAW AND SCHOOL REFORM: SIX STRATEGIES FOR PROMOTING EDUCATIONAL EQUITY 205, 209-213 (Jay P. Heubert, ed., 1999).

<sup>70</sup> See ROTHMAN & ROTHMAN, *supra* note 10, at 17-22. Judith Gran, who represented the plaintiffs in a number of developmental disability deinstitutionalization cases, identified "two groups of parents who institutionalize their children": (1) "upper middle class" parents who "focus on a cure for their children's disabilities," institutionalize them when it fails, and "are angry and bitter, often feeling hopeless and reject their child"; and (2) "typically working class families, often from minority communities, who do everything they can to keep their children at home" and only "reluctantly institutionalize their children." Quoted at <http://www.mnddc.org/parallels2/one/sidebar.040a.htm>. This story seems to me a bit too pat and politically congenial. Perhaps another way of putting the point is that higher-socioeconomic-status families have generally had more resources to ensure that their children received services in the community, so that when those families have nonetheless opted for institutionalization it has more often been a true choice.

<sup>71</sup> See ROTHMAN & ROTHMAN, *supra* note 10, at 45-50.

<sup>72</sup> See *id.* at 60.

<sup>73</sup> *Id.* at 22.

<sup>74</sup> See *id.* at 60.

<sup>75</sup> See Philip R. Beard, *The Consumer Movement*, in AMERICAN PSYCHIATRY AFTER WORLD WAR II: 1944-1994 at 299, 309-313 (Roy W. Menninger & John C. Nemiah, eds., 2000).

<sup>76</sup> See *infra* text accompanying notes 120-122.

<sup>77</sup> See Jack Drake, *Drafting the Case: The Parallel Legacies of Wyatt v. Stickney and Lynch v. Baxley*, 34 LAW & PSYCHOL. REV. 167, 167 (2011).

who directed the publicity campaign (and organized the residents and their families) to challenge institutionalization there.<sup>78</sup>

But these alliances between deinstitutionalization lawyers and family and worker groups did not last. Although some family members of institutionalized persons with developmental disabilities wholeheartedly agreed with the agenda of providing their loved ones with homes and services in the community, others had originally signed up to challenge what they thought were *bad* institutions—not the idea of institutionalization itself.<sup>79</sup> Some of the parents in this latter group withdrew from the litigation—as the mother of Terri Lee Halderman, the lead plaintiff in the landmark *Pennhurst* case, did.<sup>80</sup> Others formed organizations that actively opposed deinstitutionalization. These organizations, which overlapped with the parent and guardian associations of a number of institutions, lobbied against, and intervened in litigation to oppose, deinstitutionalization in the developmental disabilities context.<sup>81</sup> Some tension existed in the psychiatric disability context as well. The National Alliance on Mental Illness, the largest group representing families of people with psychiatric disabilities, did push to “restor[e] . . . some form of involuntary commitment law,” for example, though NAMI’s advocacy of supportive housing was very much in accord with the views of deinstitutionalization advocates.<sup>82</sup>

And the unions that represented workers in institutions could not support deinstitutionalization without undermining the livelihood of their members—and, in their view, the care and treatment they provided. Jobs in state institutions have typically been unionized in this country, while most jobs in community programs have not.<sup>83</sup> Community programs are generally run not by the state itself but by private non-profit (and occasionally for-profit) agencies that contract with the state. Those private agencies are rarely unionized, and they typically pay substantially less (and have much greater turnover) than the state does for work in its insti-

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<sup>78</sup> See ROTHMAN & ROTHMAN, *supra* note 10, at 34-42.

<sup>79</sup> See Margie Peterson, *Did Suit Help Retarded? Woman Regrets Role in Pennhurst Case*, ALLENTOWN MORNING CALL, July 18, 1994.

<sup>80</sup> See Peterson, *supra* note 79.

<sup>81</sup> See Peterson, *supra* note 79; John Woestendiek, *Objections Voiced to Plan for Closing of Pennhurst*, PHILA. INQUIRER, Sept. 26, 1984, at B6. For examples of efforts by parents’ groups to intervene in litigation in order to oppose deinstitutionalization, see *Halderman v. Pennhurst State Sch. & Hosp.*, 610 F. Supp. 1221, 1229, 1231 (E.D. Pa. 1985) (granting intervention but rejecting parents’ group’s objections); *Lelsz v. Kavanagh*, 98 F.R.D. 11 (E.D. Tex. 1982) (denying intervention), *appeal dismissed*, 710 F.2d 1040 (5th Cir. 1983). For a general discussion of the phenomenon at the time, see Robinsue Frohboese & Bruce Dennis Sales, *Parental Opposition to Deinstitutionalization: A Challenge in Need of Attention and Resolution*, 4 LAW & HUMAN BEHAV. 1 (1980).

<sup>82</sup> See Beard, *supra* note 75, at 312-313.

<sup>83</sup> See STEVEN J. TAYLOR, *THE DIRECT SUPPORT WORKFORCE CRISIS: CAN UNIONS HELP RESOLVE THIS?* (2008).

tutions.<sup>84</sup> Indeed, unions have found it exceptionally difficult to organize the small, decentralized, typically non-profit and often faith-based agencies that provide community services.<sup>85</sup>

Eventually, the parent and family organizations that opposed further deinstitutionalization of people with developmental disabilities came together in a national group known as the Voice of the Retarded (now simply VOR), a group that allied closely with AFSCME and other unions representing institutional workers. VOR and its affiliates conducted a well-organized campaign that sponsored research, organized parents politically, managed public relations, and participated in litigation.<sup>86</sup> By the late 1980s, the VOR-union alliance was the most significant obstacle to further deinstitutionalization of people with developmental disabilities.<sup>87</sup>

Parents who opposed deinstitutionalization argued that, while abuses should end, institutions were the best place for their (often now adult) children. They contended that institutional placement was necessary for many people with developmental disabilities (including their children) to receive the services they needed; that their children needed protection from risk and could not be trusted with the choices they would be required to make to live life in the community; that the group homes to which many people with developmental disabilities were deinstitutionalized were even more dangerous and isolating than institutions; and that institutions could be readily overseen for abuse, while group homes could not.<sup>88</sup> As more and more people with developmental disabilities left large state institutions, these parents urged that those who remained were the hardest cases—the ones most in need of institutional care.<sup>89</sup>

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<sup>84</sup> See, e.g., Roger J. Stancliffe, K. Charlie Lakin, John R. Shea, Robert W. Prouty & Kathryn Coucouvanis, *The Economics of Deinstitutionalization*, in COSTS AND OUTCOMES OF COMMUNITY SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES 263, 295 (Roger J. Stancliffe & K. Charlie Lakin, eds., 2005).

<sup>85</sup> See, e.g., Nari Rhee & Carol Zabin, *Aggregating Dispersed Workers: Union Organizing in the “Care” Industries*, 40 GEOFORUM 969 (2009).

<sup>86</sup> See <http://www.vor.net/>.

<sup>87</sup> See, e.g., TAYLOR, *supra* note 83 (2008) (describing how the union representing California institutional employees in the late 1990s “joined with institutional parent groups in advocating for a moratorium on community placements”); Steven M. Eidelman, *Foreword*, in COSTS AND OUTCOMES, *supra* note 84, at xix, xx (“[A]n unholy alliance between certain public employee unions, institution employees, and some families has kept many public institutions open long beyond the time when they should have been closed.”).

<sup>88</sup> For parents making all of these points, see Peterson, *supra* note 79.

<sup>89</sup> For a recent example, see Southbury Training School Home & School Assn., Press Release: DDS Previously Found No Significant Savings in Closing Southbury Training School, Sept. 19, 2011, at 2 (“Intermediate Care Facilities such as STS serve a population of clients who are much more intellectually disabled, medically involved, and older on average than DDS clients in the community system, and therefore need more services.”). There is good reason to doubt this conclusion. Studies that make an apples-to-apples comparison of people with similar diagnoses and characteristics in and out of institutions have tended to find that it remains cheaper—often substantially so—to pro-

The unions that represented institutional workers echoed these points. Deinstitutionalization, they argued, represented nothing more than a conservative effort to cut public budgets and impose privatization at the expense of people who were poor and vulnerable. Like the parents' organizations, unions such as AFSCME argued that many people with psychiatric and developmental disabilities need institutionalization, and that the people who *remained* in institutions as deinstitutionalization progressed really, really needed to be there. Deinstitutionalization threw people out of caring, supportive environments onto the streets to fend for themselves. These arguments were distilled and presented in a widely circulated AFSCME report, *Out of Their Beds and Onto the Streets*.<sup>90</sup>

With such politically powerful constituencies arrayed against them, advocates of deinstitutionalization could not have reduced institutional populations so dramatically without powerful allies. They found those allies in fiscal conservatives. Large state institutions are expensive, and deinstitutionalization advocates argued that people with psychiatric and developmental disabilities could be served just as well, and far more cheaply, in the community.<sup>91</sup> Fiscal conservatives seized the opportunity to save money in the sluggish economy—and concomitantly tight fiscal environment—of the 1970s. Ronald Reagan provided the template for this left-right alliance when, as governor of California, he supported the 1967 Lanterman-Petris-Short Act, which restricted civil commitments to the State's mental hospitals, and the 1969 Lanterman Act, which expanded

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vide services in the community than in an institutional setting. See, e.g., U.S. DEPT. OF HEALTH & HUMAN SERVICES, COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED LONG-TERM CARE SERVICES 16 (2000) (studies that control for resident characteristics in the developmental disability context find that community-based services cost 75-95% of what institutional services cost).

<sup>90</sup> AMERICAN FED'N OF STATE, COUNTY & MUNICIPAL EMPLOYEES, DEINSTITUTIONALIZATION: OUT OF THEIR BEDS AND INTO THE STREETS (1976).

<sup>91</sup> For examples of early cases relying in part on the cost differences between institutions and community services in ordering deinstitutionalization, see *Halderman v. Pennhurst State Sch. & Hosp.* 446 F. Supp. 1295, 1312 (E.D. Pa. 1977), *aff'd in part and rev'd in part*, 612 F.2d 84 (3d Cir. 1979), *rev'd*, 451 U.S. 1 (1981), *judgment reinstated on other grounds on remand*, 673 F.2d 647 (3d Cir. 1982), *rev'd*, 465 U.S. 89 (1984); *Homeward Bound, Inc. v. Hissom Memorial Center*, 1987 WL 27104 at \*17 (N.D. Okla., July 24, 1987); see also ROTHMAN & ROTHMAN, *supra* note 10, at 109 ("Plaintiffs' closing point [in the second *Willowbrook* trial] was that community care would be far cheaper than institutional care and all the requisite funds were already available to the Department of Mental Hygiene."); cf. *Association for Retarded Citizens of North Dakota v. Olson*, 561 F. Supp. 473, 483 (D.N.D. 1982) (finding unpersuasive plaintiffs' claim that community services were cheaper than institutions), *aff'd*, 713 F.2d 1384 (8th Cir. 1983). For the perspective of an advocate and sometime state government official, see Eidelman, *supra* note 87, at xix ("Even when state governments did not despair over wretched conditions in their institutions, or even accept that the human rights and full citizenship promised their states' residents applied to people with disabilities, they did understand 'cheaper,' and, as this concept got us where we wanted (i.e., people with disabilities living in the community), we took it as success.").

community services for people with developmental disabilities.<sup>92</sup> The enactment of the Supplemental Security Income program in 1972, which used federal funds to provide cash benefits to, among others, people with mental disabilities living in the community, further enabled states to shift costs off of their budgets by deinstitutionalizing.<sup>93</sup> As stagflation imposed great pressure on state budgets, alliances like these—often spurred by litigation, but ultimately encapsulated in state legislation and administrative action—arose in many states.<sup>94</sup>

As many commentators have noted, it was ultimately this coalition between civil liberties lawyers and fiscal conservatives that ensured that states would close and downsize their institutions.<sup>95</sup> The strength of this coalition also explains the precise pattern of results that deinstitutionalization litigation caused. Although deinstitutionalization advocates had two basic goals—shrinking institutions and building community services—fiscal conservatives shared only the first of these goals.<sup>96</sup> It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions, but that deinstitutionalization advocates were less successful in achieving their goal of developing community services.

### C. *Due Process and the Old Law of Deinstitutionalization*

The reasons for the outcomes of deinstitutionalization were not merely political, though. They also reflected limitations in the doctrinal tools on which deinstitutionalization advocates relied in the 1970s, 1980s, and 1990s. Beginning in the 1960s, but really hitting stride in the 1970s, deinstitutionalization advocates developed a legal strategy that relied centrally on the Due Process Clause of the Fourteenth Amendment. Advo-

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<sup>92</sup> See PAUL S. APPELBAUM, *ALMOST A REVOLUTION: MENTAL HEALTH LAW AND THE LIMITS OF CHANGE* 50 (1994); EUGENE BARDACH, *THE SKILL FACTOR IN POLITICS: REPEALING THE MENTAL COMMITMENT LAWS IN CALIFORNIA* 125 (1972); JOHNSON, *supra* note 20, at 99; Andrew M. Holmes, Note, *Initiative Funding Through Targeted Taxes: Proposition 63, Mental Health, and Direct Democracy*, 59 HAST. L.J. 195, 199-200 (2007).

<sup>93</sup> See JOHNSON, *supra* note 20, at 96-100; William Gronfein, *Incentives and Intentions in Mental Health Policy: A Comparison of the Medicaid and Community Mental Health Programs*, 26 J. HEALTH & SOCIAL BEHAVIOR 192, 200-202 (1985).

<sup>94</sup> Reviewing the literature, Mechanic and Rochefort argue that the degree to which a state deinstitutionalized during this period depended in significant part on “the vigor and efficacy of the indigenous community mental health coalition, including its civil libertarian contingent” in the state, and “the amount of economic strain faced by a given state with the stagflation of the 1970s.” Mechanic & Rochefort, *supra* note 8, at 311.

<sup>95</sup> See, e.g., JENCKS, *supra* note 1, at 39 (“It was the insidious combination of liberal policies aimed at increasing personal liberty and conservative policies aimed at reducing government spending that led to catastrophe.”).

<sup>96</sup> Governor Reagan, again, epitomized this position, by supporting closure of institutional beds and then cuts to community services. See Holmes, *supra* note 92, at 200; Jackson K. Putnam, *Governor Reagan: A Reappraisal*, CALIF. HISTORY, Vol. 83, No. 4, at 24, 30-31 (2006).

cates pursued two lines of due process doctrine: (1) a line of procedural limitations on involuntary commitment and treatment; and (2) a line of substantive guarantees of treatment for people confined to state institutions.<sup>97</sup> These lines of doctrine developed relatively concurrently, though the right to treatment line gradually became more prominent as the period progressed. Each line of doctrine led to substantial gains for the deinstitutionalization movement. But each also had very serious limitations as a tool for achieving the goals of that movement.

In this Section, I discuss those gains and limitations. Subsection 1 discusses the procedural due process line of doctrine, which I label the “right-against-treatment” cases. Subsection 2 discusses the substantive due process line of doctrine, which I, like most observers, label the “right-to-treatment” cases.

*1. The Right-Against-Treatment Line*—The litigation seeking a right against unwanted commitment and treatment proceeded from straightforward civil libertarian principles. As I described in the previous section, civil libertarian lawyers were concerned that involuntary commitment incarcerated people without the protections of the criminal process. They sought to address these concerns by developing a line of doctrine that imposed significant procedural protections prior to institutionalization. The key case in this line was *Lessard v. Schmidt*,<sup>98</sup> which adopted something very close to a criminal-procedure model for the involuntary commitment process. *Lessard* held that individuals subject to civil commitment must receive a “judicial hearing to determine whether or not probable cause exists” regarding their committability if they were detained in excess of 48 hours<sup>99</sup>; that they are entitled to “the privilege against self-

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<sup>97</sup> These two due process theories did not exhaust the theories on which plaintiffs relied in early deinstitutionalization cases, but none of the others played as crucial a role. For example, in the landmark *Pennhurst* case, the district court found a violation not just of the due process right to treatment but also of the Equal Protection Clause. Its equal protection holding, however, relied more or less entirely on its conclusion that the state had denied Pennhurst residents the right to adequate treatment. See *Halderman*, 446 F. Supp. at 1322 (“As we have heretofore discussed in this opinion, the retarded at Pennhurst have been segregated in an institution in which they have been and are being denied minimally adequate habilitation. Thus, on the basis of this record we find that the retarded at Pennhurst have been and presently are being denied their Equal Protection Rights as guaranteed by the Fourteenth Amendment to the Constitution.”). Plaintiffs in these cases also relied on federal statutes, such as the predecessor to the ADA, Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794. But these statutory claims had mixed success and played little ultimate role in the deinstitutionalization litigation of the 1970s and 1980s. See *Olmstead*, 527 U.S. at 600 n.11.

<sup>98</sup> 349 F. Supp. 1078 (E.D. Wis. 1972), *vacated and remanded*, 414 U.S. 473 (1974), *judgment reinstated on remand*, 379 F. Supp. 1376 (E.D. Wis. 1974), *vacated and remanded*, 421 U.S. 957 (1975), *judgment reinstated on remand*, 413 F. Supp. 1318 (E.D. Wis. 1976).

<sup>99</sup> *Lessard*, 379 F. Supp. at 1379; cf. *Gerstein v. Pugh*, 420 U.S. 103 (1975) (imposing same requirement in criminal context).

incrimination”<sup>100</sup>; that they have the right to counsel in commitment hearings, including court-appointed counsel if they are indigent<sup>101</sup>; that “the rules of evidence including the hearsay rule” must apply in commitment hearings<sup>102</sup>; and, most important, that a person could not be committed without “a finding *beyond reasonable doubt*” that:

(a) the subjects of the hearing are mentally ill; (b) the subjects of the hearing are dangerous to themselves or others based at a minimum upon *a recent act, attempt, or threat* to do substantial harm; (c) *all available less drastic alternatives* to commitment to a mental hospital or institution have been investigated; and (d) *all available less drastic alternatives* to commitment to a mental hospital or institution are unavailable.<sup>103</sup>

*Lessard*'s least restrictive alternative principle, in particular, was extremely influential.<sup>104</sup> The *Lessard* doctrine, as adopted across the Nation, succeeded in reducing involuntary commitments and, ultimately, the population of state mental hospitals.<sup>105</sup> But the right-against-treatment principles that *Lessard* adopted had substantial drawbacks for deinstitutionalization advocates. The biggest problem was that the right against treatment was a purely negative right. Where people were institutionalized not because of state compulsion through involuntary commitment but because they had no other effective options for obtaining treatment, the doctrine offered little purchase. More important, the doctrine could keep states from committing people to mental hospitals, but it provided no resources for obtaining necessary mental health services in the community.

Relatedly, the right-against-treatment doctrine reflected an undue skepticism regarding the value of treatment for psychiatric disabilities. To be sure, the treatment provided at state institutions offered ample reason to be skeptical. In many cases, that treatment was merely custodial, more concerned with achieving quiescence and control than in promoting re-

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<sup>100</sup> *Lessard*, 379 F. Supp. at 1379.

<sup>101</sup> *Id.*

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

<sup>103</sup> *Id.* (emphasis added).

<sup>104</sup> See Stephen J. Morse, *A Preference for Liberty: The Case Against Involuntary Commitment of the Mentally Disordered*, 70 CALIF. L. REV. 54, 55 (1982) (“[F]ollowing *Lessard*, numerous cases found state commitment laws unconstitutional and applied stringent substantive and procedural due process protections to the involuntary commitment process.”); Michael L. Perlin, “*The Promises of Paradise*”: *Will Olmstead v. L.C. Resuscitate the Constitutional “Least Restrictive Alternative” Principle in Mental Disability Law?*, 37 HOUS. L. REV. 999, 1014-1018 (2000) (explaining how courts, commentators, and legislators in the majority of states endorsed this principle for civil commitment).

<sup>105</sup> See APPELBAUM, *supra* note 92, at 28; JOHN Q. LAFOND & MARY L. DURHAM, *BACK TO THE ASYLUM: THE FUTURE OF MENTAL HEALTH LAW AND POLICY IN THE UNITED STATES* 90 (1992).

covery.<sup>106</sup> And institutionalization itself deprives institutionalized persons of liberty, agency, and the opportunity to participate in the life of the community.<sup>107</sup> But later developments have demonstrated the value of various forms of community-based treatment even for people with serious mental illness.<sup>108</sup> By viewing treatment as something to be avoided and restricted, the right-against-treatment doctrine tended to deprive people with psychiatric disabilities of services that would have promoted their happiness and flourishing.

In the end, the right-against-treatment doctrine was largely domesticated, if not neutered, by the Supreme Court. Although the 1975 decision in *O'Connor v. Donaldson*<sup>109</sup> contained language that suggested agreement with *Lessard*'s underpinnings,<sup>110</sup> a number of subsequent cases through the Burger and Rehnquist Courts rejected many of the key principles articulated in *Lessard*. In *Allen v. Illinois*,<sup>111</sup> the Supreme Court held that the privilege against self-incrimination does not apply in civil commitment proceedings. In *Addington v. Texas*,<sup>112</sup> the Court held that the beyond a reasonable doubt standard was not constitutionally required in those proceedings, either. And in *Youngberg v. Romeo*,<sup>113</sup> the Court held that only "reasonably nonrestrictive confinement conditions"—rather than the least restrictive such conditions—were required.<sup>114</sup> Some procedural protections remain against involuntary commitment,<sup>115</sup> though a stronger set of protections continues to guard against involuntary medication.<sup>116</sup>

2. *The Right-to-Treatment Line*—A second line of cases, developed around the same time as the right-against-treatment line (and occasionally by the same lawyers), focused on developing a right to treatment for institutionalized persons. This line of decisions, unlike the right-

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<sup>106</sup> Many of the conditions discussed in ENNIS, *supra* note 59, reflect this aim for control rather than recovery.

<sup>107</sup> This is a central point of Justice Ginsburg's opinion for the Court in *Olmstead*, 527 U.S. at 601 ("[C]onfinement 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>108</sup> See Lamb, *supra* note 16, at 7-8.

<sup>109</sup> 422 U.S. 563 (1975).

<sup>110</sup> See *id.* at 576 ("In short, a State cannot constitutionally confine, without more, a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends.").

<sup>111</sup> 478 U.S. 364, 372; accord *French v. Blackburn*, 428 F. Supp. 1351 (M.D.N.C. 1977), *summarily aff'd*, 443 U.S. 901 (1979).

<sup>112</sup> 441 U.S. 418, 431-433 (1979).

<sup>113</sup> 457 U.S. 307, 324 (1982).

<sup>114</sup> See PERLIN, *supra* note 14, at 278 (criticizing *Youngberg*'s "abandonment of the least-restrictive-alternative construction").

<sup>115</sup> These include, most notably, the requirement that the state establish committability by clear and convincing evidence. See *Addington*, 441 U.S. at 431-433.

<sup>116</sup> For discussion of the right to refuse medication in the civil context, see PERLIN, *supra* note 14, at 127-130. For discussion of that right in the criminal context, see, for example, *Sell v. United States*, 539 U.S. 166, 179 (2003).



against-treatment line, had significant implications for both people with psychiatric disabilities and those with developmental disabilities.

The right-to-treatment doctrine was rooted in substantive, rather than procedural, due process. It drew on two key ideas, one of which was in tension with the right-against-treatment line, the other of which was largely consistent with it. Both of these ideas appeared in a 1960 article in the ABA Journal by Morton Birnbaum, a medical doctor who worked as a lawyer in his spare time (really!).<sup>117</sup> The first idea rested on evolving professional notions of proper treatment for people with mental disabilities. In the emerging view of cutting-edge practitioners at the time, treatment should be designed to promote the acquisition of skills necessary to live outside of an institution.<sup>118</sup> The second idea, which in some ways was the flip side of the right-against-treatment argument, was the notion of a *quid pro quo*—if states were to confine people for care and treatment, the argument went, they were bound to actually provide that treatment.<sup>119</sup>

The key early case in the right-to-treatment line was *Wyatt v. Stickney*.<sup>120</sup> *Wyatt*, a challenge to conditions of institutionalization of people with psychiatric and developmental disabilities in Alabama, ultimately led to the closing of all of the state's large state-operated institutions. In finding a constitutional right to treatment, the *Wyatt* court relied explicitly on the *quid pro quo* theory: “The purpose of involuntary hospitalization for treatment purposes is treatment and not mere custodial care or punishment. This is the only justification, from a constitutional standpoint, that allows civil commitments to mental institutions . . . .”<sup>121</sup> Over the next thirty-plus years, the court (presided over first by Judge Frank Johnson then by Judge Myron Thompson) issued a series of orders to reform Alabama's facilities and ultimately transform its mental health and developmental disability system to one that was oriented around community rather than institutional treatment.<sup>122</sup>

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<sup>117</sup> Morton Birnbaum, *The Right to Treatment*, 46 A.B.A. J. 499 (1960). For a fascinating discussion of Dr. Birnbaum's advocacy of a right to treatment, and its connections to and tensions with the civil libertarian advocacy of others in the deinstitutionalization movement, see Rebecca Birnbaum, *My Father's Advocacy of a Right to Treatment*, 38 J. AM. ACAD. PSYCHIAT. & LAW 115 (2010).

<sup>118</sup> See Morton Birnbaum, *supra* note 117, at 500.

<sup>119</sup> See Morton Birnbaum, *supra* note 117, at 503.

<sup>120</sup> The first published opinion in *Wyatt* was *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971). The last was *Wyatt ex rel. Rawlins v. Sawyer*, 219 F.R.D. 529 (M.D. Ala. 2004).

<sup>121</sup> *Wyatt*, 325 F. Supp. 781, 784 (M.D. Ala. 1971); see also *Wyatt v. Aderholt*, 503 F.2d 1305, 1312 (5th Cir. 1974) (describing court's prior holding that “where the justification for commitment was treatment, it offended the fundamentals of due process if treatment were not in fact provided,” and “where the justification was the danger to self or others, then treatment had to be provided as the *quid pro quo* society had to pay as the price of the extra safety it derived from the denial of individuals' liberty”).

<sup>122</sup> See Drake, *supra* note 77, at 168.

The Supreme Court ultimately addressed the right to treatment in *Youngberg v. Romeo*,<sup>123</sup> one of many cases to come from the behemoth Pennhurst State School and Hospital.<sup>124</sup> The Court cut back on the right to treatment recognized by lower courts, but it still offered litigants significant tools for promoting such a right. *Youngberg* involved an individual with an intellectual disability who was then institutionalized at Pennhurst. He sought damages for injuries he had experienced in the institution, as well as for the failure to provide him “minimally adequate habilitation.”<sup>125</sup> The Court readily concluded that institutionalized persons have a liberty interest in safety and freedom from undue restraint,<sup>126</sup> and it also held that such persons have a right to “minimally adequate care and treatment” to serve those liberty interests.<sup>127</sup> But the Court held that “courts must show deference to the judgment exercised by a qualified professional” to serve those liberty interests: “the decision, if made by a professional, is presumptively valid; liability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment.”<sup>128</sup> As Professor Perlin argues, the professional judgment standard “sharply limits the need to inquire into the adequacy of a patient’s treatment.”<sup>129</sup>

A number of observers were, from the start, ambivalent about the right-to-treatment line of doctrine. Thomas Szasz, for example, explained that he thought a right to treatment could end up supporting institutionalization—and even leading to the recognition of institutionalization as an individual right and a governmental duty.<sup>130</sup> But advocates of deinstitutionalization brought a large number of cases relying on that right. The calculation they made was that implementing a right to treatment within institutions—a right that, as interpreted by *Wyatt*, required bringing conditions in those institutions up to accepted standards<sup>131</sup>—would impose such a financial burden on states that they would find it more economical to

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<sup>123</sup> 457 U.S. 307 (1982).

<sup>124</sup> The most notable case was itself a behemoth, the *Halderman* litigation. The first reported opinion in *Halderman* was *Halderman v. Pennhurst State School & Hosp.*, 446 F. Supp. 1295 (E.D. Pa. 1977). The last reported opinion in *Halderman* was *Halderman v. Pennhurst State School & Hosp.*, 9 F. Supp.2d 544 (E.D. Pa. 1998).

<sup>125</sup> *Youngberg*, 457 U.S. at 314-319.

<sup>126</sup> *See id.* at 315-316.

<sup>127</sup> *Id.* at 320 (internal quotation marks omitted).

<sup>128</sup> *Id.* at 322-323.

<sup>129</sup> PERLIN, *supra* note 14, at 122.

<sup>130</sup> *See* THOMAS SZASZ, PSYCHIATRIC SLAVERY 109-131 (1977); *see also* Thomas Szasz, *Introduction*, in ENNIS, *supra* note 59, at 17 (“[I]ndividuals incriminated as mentally ill do not need guarantees of ‘treatment,’ but protection against their enemies—the legislators, judges, and psychiatrists who persecute them in the name of mental health.”).

<sup>131</sup> *See*, for example, the famous “*Wyatt* standards,” which imposed detailed requirements for staffing and conditions throughout the institution. *Wyatt*, 344 F. Supp. at 379-386.

keep people out of institutions and eventually move institutional residents to the community.<sup>132</sup> In the developmental disability world particularly, events proved that calculation correct in many instances, as cases like *Wyatt* in Alabama and *Jackson v. Fort Stanton*<sup>133</sup> in New Mexico led to the closing of all public developmental disability institutions in those states, and other cases led to the closing of many individual developmental disability institutions.<sup>134</sup>

The right-to-treatment doctrine had some important features that showed promise for deinstitutionalization advocates. For one thing, unlike the right against treatment, the right to treatment was framed as more of an affirmative right to services—though one that, critically, still was conditioned on state commitment or custody.<sup>135</sup> The right against treatment left two possibilities: either a person could be committed involuntarily, in

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<sup>132</sup> See ERKULWATER, *supra* note 66, at 58 (“[I]f courts broadly applied the mandated reforms articulated in *Wyatt* and other patients’ rights cases, then many state mental institutions would be unable to meet the increased costs, thus forcing them to close their doors forever.”); ROTHMAN & ROTHMAN, *supra* note 10, at 54 n.\* (“Many lawyers, including Ennis, wanted to use the doctrine as a way of emptying mental hospitals; confident that the states would never be able to make the institutions therapeutic, they saw right to treatment as a tool for prying patients loose from horrendous settings.”). Writing before the Supreme Court pruned back some of the district court’s key holdings in the *Pennhurst* case, David Ferleger, the lead plaintiff’s attorney in the case, argued that the components of a right to treatment recognized by the district court added up as a *matter of doctrine* to a constitutional right to community treatment. See David Ferleger & Penelope A. Boyd, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 STAN. L. REV. 717, 731-743 (1979). But the doctrine ultimately did not move in that direction. For the Supreme Court’s decisions in *Pennhurst*, see *Pennhurst State School & Hosp. v. Halderman*, 465 U.S. 89 (1984); and *Pennhurst State School & Hosp. v. Halderman*, 451 U.S. 1 (1981).

<sup>133</sup> See *Jackson v. Fort Stanton Hosp. & Training School*, 964 F.2d 980 (10th Cir. 1992).

<sup>134</sup> See, e.g., PETER DAVID BLANCK, THE AMERICANS WITH DISABILITIES ACT AND THE EMERGING WORKFORCE 82 (1998) (“The *Hissom* litigation eventually led to a settlement between the plaintiffs and the state to close the institution in May 1994 and to place its approximately 350 to 400 residents in community settings.”); UNIV. OF MINN. RESEARCH & TRAINING CTR. ON COMMUNITY LIVING & THE LEWIN GROUP, MEDICAID HOME & COMMUNITY BASED SERVICE PROGRAM IN VERMONT: FINAL REPORT 8 (2000) (settlement in *Brace* lawsuit led to closure of Vermont’s only developmental disabilities institution); JULIE ANN RACINO, GARRITY V. GALLEN: THE ROLE OF THE COURT IN INSTITUTIONAL CLOSURE (1993) (*Garrity* case led to closure of New Hampshire’s only developmental disabilities institution); DAVID BRADDOCK & TAMAR HELLER, THE CLOSURE OF MENTAL RETARDATION INSTITUTIONS: TRENDS AND IMPLICATIONS (A WORKING PAPER) 11 (1984) (discussing closure of “Pennhurst (PA), Orient (OH), and Plymouth (MI)” after “intense and protracted litigation”); see also Steven Schwartz, *The Potential and Risks of Relying on Title II’s Integration Mandate to Close Segregated Institutions*, 26 GA. ST. U. L. REV. 855, 871-873 (2010) (citing cases that preceded institutional closure in many states).

<sup>135</sup> There is some degree of dispute in the federal courts regarding whether *Youngberg*’s right-to-treatment protections are triggered only by *involuntary* commitment or instead by the simple fact that an individual is in the state’s custody and control (even if she voluntarily submitted herself to that control). See *United States v. Tennessee*, 615 F.3d 646, 653-657 (6th Cir. 2010) (collecting cases).

which case the right against treatment was properly overcome, or the person could not be committed involuntarily, in which case the state was under no obligation to provide anything. Under the right to treatment doctrine, by contrast, the state took on a responsibility, once it institutionalized an individual, to provide treatment and services—treatment and services that in many cases would tend to enable the person to leave the institution.<sup>136</sup> And some courts took the right to treatment even further, to argue that a state continued to owe a duty to *formerly* institutionalized persons to provide them treatment in the community to make up for the failure to provide them appropriate treatment in the institution.<sup>137</sup> That principle could not readily extend to people who had never been institutionalized, however.

Although the right to treatment doctrine did promote substantial deinstitutionalization, the qualms about it were warranted. Because the right to treatment doctrine does not focus on the right to be free from institutionalization as much as on the right to receive services once institutionalized, states could theoretically satisfy that doctrine by improving conditions in institutions without reducing their populations at all. And in practice litigation over the right to treatment led many states to allocate a larger portion of their scarce mental health and developmental disabilities budgets to institutions.<sup>138</sup> Although there is a point at which such increased investments become unsustainable, rigorous enforcement of the right to treatment in institutions can slow the pace of deinstitutionalization and starve the community services system for people with disabilities.

Moreover, where the right against treatment was too hostile to the professionals who provide services to people with disabilities, the right to treatment was too deferential. The *Youngberg* “professional judgment”

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<sup>136</sup> See, e.g., *Clark v. Cohen*, 794 F.2d 79, 97 (3d Cir.) (Becker, J., concurring) (“Because it appears from the numerous, uncontradicted doctors’ reports in the record that placement in a CLA [community living arrangement] is the only or best way for Ms. Clark to receive the training that she is due, I believe that she has a right to placement in the CLA, until she has acquired the skills she would have had had she never been institutionalized.”), cert. denied, 479 U.S. 962 (1986); *Thomas S. v. Morrow*, 781 F.2d 367, 375 (4th Cir.) (affirming order requiring state to implement a treatment plan for institutionalized person, including placing him in the community, where the professionals at the hospital to which he was institutionalized “recommended treatment included transfer from the hospital to a group home in the community”), cert. denied, 476 U.S. 1124, 479 U.S. 869 (1986).

<sup>137</sup> See, e.g., *Clark*, 794 F.2d at 83 (“Having stipulated that their own professional staff members attributed Clark’s present need for supervision to her long institutionalization and having offered no contrary evidence, the Commonwealth defendants are in no position to question the trial court’s finding that the violations of her rights caused such deterioration of her ability to cope in society that she needs some form of supervised remediation if she is ever to be able to do so.”).

<sup>138</sup> See LERMAN, *supra* note 20, at 173 (“Besides being costly, it is likely that implementing a judicial policy that includes upgrading can divert scarce resources away from less traditional, more independent, living arrangements and supportive programs and services.”).

doctrine is the best example of this.<sup>139</sup> Though most deinstitutionalization advocates argue that the Court should have adopted a more skeptical standard of scrutiny in that case,<sup>140</sup> deference to treating professionals is almost inevitable in a doctrine that is designed to guarantee individuals the right to professionally appropriate treatment.

### III. CHARTING DEINSTITUTIONALIZATION'S FUTURE

As I have shown, the past of deinstitutionalization was marked by greater success than many commentators have given it credit for, but that success had significant limitations. And those limitations stemmed directly from the political dynamics into which deinstitutionalization advocates inserted themselves and the legal claims on which they relied. In this Part, I argue that the current wave of deinstitutionalization litigation is likely to lead to a different pattern of outcomes.

Two key changes help to predict the future of deinstitutionalization: First, deinstitutionalization advocates have moved from the constitutional due process theories on which they relied in the 1970s and 1980s to a more promising statutory discrimination theory based on the Americans with Disabilities Act. Second, deinstitutionalization advocates have essentially won the old battles for the closing and downsizing of large state institutions for people with psychiatric and developmental disabilities. As I discussed in Section II.A, the population of state institutions for people with developmental disabilities stands at approximately 16 percent of its peak, the population of state and local psychiatric hospitals stands at approximately 9 percent of its peak, and these numbers continue to decrease.<sup>141</sup>

But the success of deinstitutionalization advocates in moving people with psychiatric and developmental disabilities out of large state institutions has exposed new battlefronts. First, as people have moved out of large state institutions, large (though typically not *as* large) *private* institutions—private “intermediate care facilities for the mentally retarded” (ICF/MRs), adult care homes, and nursing homes, among others—have often taken their place.<sup>142</sup> As the locus of institutionalization has shifted to private facilities, deinstitutionalization advocates have increasingly focused on moving people with psychiatric and developmental disabilities out of those facilities—a task that has sharpened their understandings of what truly constitutes integration in the community.<sup>143</sup> The newfound fo-

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<sup>139</sup> See Susan Stefan, *Leaving Civil Rights to the “Experts”: From Deference to Abdication Under the Professional Judgment Standard*, 102 YALE L.J. 639 (1992).

<sup>140</sup> See *id.*

<sup>141</sup> See *supra* text accompanying notes 21-36.

<sup>142</sup> This trend was apparent by the 1980s. See Gronfein, *supra* note 93, at 200-202.

<sup>143</sup> See, e.g., *State of Connecticut Office of Protection and Advocacy for Persons with Disabilities v. Connecticut*, 706 F. Supp.2d 266 (D. Conn. 2010) (challenge to unnecessary institutionalization of people with psychiatric disabilities in private nursing

cus on private nursing homes has also led advocates to attend to an institutionalized population that had not especially benefited from the first round of deinstitutionalization—people with physical disabilities.<sup>144</sup> The new reliance on a discrimination-based theory of litigation fits well with these efforts.

Second, as people with psychiatric and developmental disabilities have moved out of institutions, the efforts of deinstitutionalization advocates have necessarily turned toward ensuring that adequate and appropriate services existed in the community. Concern about the adequacy of community services became especially acute as the widely-noted spike in homeless persons with mental illness called the public legitimacy of the entire deinstitutionalization enterprise into question.<sup>145</sup> And as state budgets moved toward retrenchment following the 2001 and 2007 recessions,<sup>146</sup> deinstitutionalization advocates have found themselves frequently challenging cuts to the services on which people with disabilities have relied to thrive in the community.<sup>147</sup> As with the increasing focus on private institutions, the reliance on a discrimination-based litigation theory has assisted deinstitutionalization advocates in promoting and defending community-based services.

In this Part, I discuss these key changes in the battlefield and chart their implications for the future of deinstitutionalization litigation. Section A analyzes the new discrimination-based theories, centered on the Supreme Court’s decision in *Olmstead v. L.C.*, on which deinstitutionalization advocates rely. As I show in Section B, deinstitutionalization advocates have shifted their demands from rights to services, and the increasing provision of services in the community has created an evidence base that has shifted professional practice to a more community-oriented model. But cracks have emerged in the alliance between deinstitutionalization advocates and fiscal conservatives. The current era has in some respects intensified the conflicts between deinstitutionalization advocates and family

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homes); *Williams v. Quinn*, No. 05-C-463 (N.D. Ill., Sept. 29, 2010) (approving consent decree requiring state to provide supportive housing or other community living arrangements with supportive services to qualified individuals currently residing in private “institutions for mental disease”); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp.2d 184 (E.D.N.Y. 2009) (challenge to unnecessary institutionalization in private “adult homes”).

<sup>144</sup> See, e.g., *Haddad v. Dudek*, 784 F. Supp.2d 1308 (M.D. Fla. 2011) (challenge to unnecessary institutionalization of individual with quadriplegia in nursing home); *Cruz v. Dudek*, 2010 WL 4284955 (S.D. Fla., Oct. 12, 2010) (challenge to inadequate community services for individuals with spinal cord injuries).

<sup>145</sup> See *supra* text accompanying notes 37-41.

<sup>146</sup> See, e.g., Suzy Khimm, *The State Budget Crisis Isn’t Over Yet*, Wonkblog, Oct. 20, 2011, available at [http://www.washingtonpost.com/blogs/ezra-klein/the-state-budget-crisis-isn't-over-yet/2011/10/20/g1QA35JE1L\\_blog.html](http://www.washingtonpost.com/blogs/ezra-klein/the-state-budget-crisis-isn't-over-yet/2011/10/20/g1QA35JE1L_blog.html) [check this link].

<sup>147</sup> See, e.g., *Pitts v. Greenstein*, 2011 WL 1897552 (M.D. La., May 18, 2011) (denying state’s motion for summary judgment in challenge to cuts in personal care services offered in the community); *V.L. v. Wagner*, 669 F. Supp.2d 1106 (N.D. Cal. 2009) (granting preliminary injunction against cuts to in-home supportive services for people with disabilities).

and union groups, as both sides see themselves fighting over a shrinking pie in an era of fiscal retrenchment. But the relentless budget cutting, with its pressure toward privatization, is a common threat to the family and union groups *and* the deinstitutionalization advocates—and it creates at least the potential for an alliance between the two sides. I also argue that the new era of deinstitutionalization has led to new conflicts with the providers of services outside of state institutions. Some of these providers, like nursing home operators, operate facilities that are clearly institutions. But others, like local chapters of the Easter Seals, have thought of themselves as part of the broad coalition of advocates for deinstitutionalization. This latter dynamic has the potential to lead to painful internal conflicts within the deinstitutionalization and disability rights movements.

#### A. *The New Law: Olmstead and Disability Discrimination*

The old due process theories continue to be litigated.<sup>148</sup> But deinstitutionalization advocates have turned since the 1990 enactment of the ADA to a distinct theory. That theory is not rooted in involuntary commitment (as is the right against treatment).<sup>149</sup> Nor is it rooted in the state taking an individual into custody (as is the broader version of the right to treatment).<sup>150</sup> Rather, it is rooted in a conception of *discrimination* that focuses on state resource-allocation decisions. Under this doctrine, the unnecessary segregation of people with disabilities constitutes a form of discrimination. The question for litigation is whether a state's resource allocation decisions promote that unnecessary segregation.

The key case in the new law of deinstitutionalization is the Supreme Court's decision in *Olmstead v. L.C.*<sup>151</sup> In *Olmstead*, the Court held that the ADA contains an integration mandate.<sup>152</sup> The case was brought by two Georgia women with psychiatric and developmental disabilities who had been voluntarily admitted to a state psychiatric hospital; each woman's treating professionals believed that she could be served in a community-based program, but each nonetheless remained institutionalized.<sup>153</sup> Addressing their claims, the Court held that the ADA's prohibition of discrimination "require[s] placement of persons with mental disabilities in community settings rather than institutions" when "the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."<sup>154</sup>

<sup>148</sup> See, e.g., *United States v. Tennessee*, 615 F.3d 646 (6th Cir. 2010).

<sup>149</sup> See *supra* text accompanying notes 98-105.

<sup>150</sup> See *supra* note 135.

<sup>151</sup> 527 U.S. 581 (1999).

<sup>152</sup> See *id.* at 597-603.

<sup>153</sup> See *id.* at 593.

<sup>154</sup> *Id.* at 587.

In reaching this conclusion, the Court applied the “integration regulation,” which the Attorney General had promulgated pursuant to his authority to issue rules implementing the ADA.<sup>155</sup> That regulation provides that a state must “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>156</sup> The Court held that “unjustified institutional isolation of persons with disabilities is a form of discrimination,” because it “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life” and it “severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, educational advancement, and cultural enrichment.”<sup>157</sup>

The Court did note some limitations on this broad principle, though. First, the Court said that “the State generally may rely on the reasonable assessments of its own professionals” in determining whether an individual is eligible for community-based services.<sup>158</sup> Second, the Court noted that there is no “federal requirement that community-based treatment be imposed on patients who do not desire it.”<sup>159</sup> Finally, a plurality of the justices concluded that a state can avoid liability if it can establish a “fundamental alteration” defense that, “in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.”<sup>160</sup> The plurality elaborated that a state could avoid liability if it could “demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.”<sup>161</sup> If a state could make such a showing, the plurality explained “a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions.”<sup>162</sup>

*Olmstead* focuses on a state’s resource-allocation decisions in two ways. First, it attaches the integration duty not just to a state’s own institutionalization of an individual with a disability but more broadly to a state’s “administration” of “service[s], program[s], and activt[ies],” which may involve services that are paid for by the state but provided directly by

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<sup>155</sup> See 42 U.S.C. § 12134.

<sup>156</sup> 28 C.F.R. § 35.130(d).

<sup>157</sup> *Olmstead*, 527 U.S. at 600-601.

<sup>158</sup> *Id.* at 602.

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

<sup>160</sup> *Id.* at 604 (plurality opinion).

<sup>161</sup> *Id.* at 605-606.

<sup>162</sup> *Id.* at 606.



private entities.<sup>163</sup> Second, the fundamental alteration defense looks explicitly to whether immediate relief for the plaintiffs would be equitable “in the allocation of available resources.”<sup>164</sup>

This focus enables advocates and courts to respond to a broader array of institutionalization problems than did the due process theories on which deinstitutionalization advocates formerly relied. The new doctrine enables challenges to institutionalization in *private* facilities (such as nursing homes, adult care homes, and ICF/MRs), for example, because state funding decisions often are the force driving people with disabilities into those facilities.<sup>165</sup> A state might, for example, pay for adult diapers for people with disabilities living in nursing homes but not for those living in the community,<sup>166</sup> it might provide a lower prescription drug reimbursement for Medicaid recipients in the community than for those in nursing homes,<sup>167</sup> or it might pay for adult care homes for people with psychiatric disabilities but not integrated supported housing, even though the two cost roughly the same.<sup>168</sup>

*Olmstead* also enables advocates to obtain high-quality community services for people with disabilities, precisely because the state’s failure to provide such services will predictably lead many individuals to become institutionalized, whether in state facilities or private nursing homes.<sup>169</sup> Recent judgments and consent decrees demonstrate the array of services courts are willing to require under the *Olmstead* doctrine. In the *Disability Advocates* case, now on appeal to the Second Circuit, the District Court for the Eastern District of New York ordered the State of New York to provide at least 1,500 integrated, scattered-site supported housing units per year to individuals currently residing in private adult homes.<sup>170</sup> And the United States Department of Justice has recently reached *Olmstead* settlements with a number of states.<sup>171</sup> Those settlements contain extensive

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<sup>163</sup> 28 C.F.R. § 35.130(d); see *Disability Advocates, Inc. v. Paterson*, 598 F. Supp.2d 289, 316-318 (E.D.N.Y. 2009).

<sup>164</sup> *Olmstead*, 527 U.S. at 604 (plurality opinion).

<sup>165</sup> See generally *Disability Advocates*, 598 F. Supp.2d at 316-318 (collecting cases).

<sup>166</sup> See *Hiltibrant v. Levy*, 793 F. Supp.2d 1108 (W.D. Mo. 2011).

<sup>167</sup> See *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175 (10th Cir. 2003).

<sup>168</sup> See *Disability Advocates*, 653 F. Supp.2d at 193-223.

<sup>169</sup> See, e.g., *Fisher*, 335 F.3d at 1182 (holding that individuals who “stand imperiled with segregation” may bring an *Olmstead* challenge “without first submitting to institutionalization”).

<sup>170</sup> See *Disability Advocates, Inc. v. Paterson*, 2010 WL 786657 at \*6 (E.D.N.Y., Mar. 10, 2010).

<sup>171</sup> See *United States v. Virginia*, No. 12-cv-059 (E.D. Va., Jan. 26, 2012) (settlement of *Olmstead* challenge to unnecessary institutionalization and risk of institutionalization of people with intellectual or developmental disabilities); *United States v. Delaware*, No. 11-CV-591 (D. Del., July 6, 2011) (settlement of *Olmstead* challenge to unnecessary institutionalization and risk of institutionalization of people with psychiatric disabilities); *United States v. Georgia*, No. 10-CV-249 (N.D. Ga., Oct. 19, 2010) (settle-

and detailed provisions governing the types of services the states must provide in the community to those who have been institutionalized or are at risk of institutionalization, the number of individuals who must receive those services, and timetables specifying when those services must be provided.

For example, the recent settlement with the Commonwealth of Virginia provides a detailed schedule according to which the state will add over 4000 home and community-based waivers for people with intellectual and developmental disabilities to its Medicaid program over nine years.<sup>172</sup> Just over 800 of these waiver slots will be dedicated to individuals currently living in state institutions; nearly 3,000 will be dedicated to individuals with intellectual disabilities who currently live outside of state institutions but who are either on the state's "urgent waitlist" for a waiver (indicating that they are at substantial risk of institutionalization) or are children who live in private nursing homes or intermediate-care facilities; and the remainder will be dedicated to individuals with other developmental disabilities who are on the state's waiting list for a waiver or who are children who live in private nursing homes or intermediate-care facilities.<sup>173</sup> The agreement also provides support for 1,000 families who are currently providing for family members with intellectual and developmental disabilities at home. These are individuals who might not need all of the services available under a Medicaid waiver but who do need some supports to prevent institutionalization.<sup>174</sup> The agreement also contains detailed provisions for a statewide crisis system for people with intellectual and developmental disabilities, so that the response to a behavioral or other crisis is not institutionalization or criminalization but instead is an intervention that ensures that the individual can remain successfully in the community.<sup>175</sup> The agreement also includes a number of provisions to ensure that "the community" is truly integrated for people receiving services under it. Those provisions require a commitment to integrated day activities and supported employment, they put a priority on ensuring that individuals receive services in their own homes or apartments or their family's home, and they erect a strong presumption against placing individuals in group homes containing more than four residents.<sup>176</sup> The agreement also contains significant provisions to ensure that community-based services meet key quality measures.<sup>177</sup>

The recent Department of Justice *Olmstead* settlements that involve services for people with psychiatric disabilities take a similar struc-

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ment of *Olmstead* challenge to unnecessary institutionalization and risk of institutionalization of people with psychiatric and/or intellectual/developmental disabilities).

<sup>172</sup> See *Virginia*, Settlement Agreement at 4-6.

<sup>173</sup> See *id.*

<sup>174</sup> See *id.* at 6.

<sup>175</sup> See *id.* at 7-9.

<sup>176</sup> See *id.* at 9-13.

<sup>177</sup> See *id.* at 20-27.

ture. They contain detailed timetables governing the specific community-based services specified numbers of people will receive to ensure that they can leave or avoid admission to institutions. In psychiatric disability cases, these services generally fall into four key categories: integrated supported housing<sup>178</sup>; intensive community-based treatment (like Assertive Community Treatment (ACT) or forms of case management)<sup>179</sup>; community-based crisis services<sup>180</sup>; and integrated supported employment.<sup>181</sup> Like the Virginia settlements, the psychiatric disability settlements also contain extensive provisions ensuring the quality of community-based services.<sup>182</sup>

Crucially in times of budget retrenchment, the *Olmstead* doctrine also enables advocates to challenge cuts to community services, because those cuts, too, will put people with disabilities at risk of institutionalization.<sup>183</sup> *Olmstead* thus offers important tools to avoid the problem of “dy-

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<sup>178</sup> See *Delaware*, Settlement Agreement at § II.I. (requiring the state to provide 500 new units of scattered-site supported housing for people with psychiatric disabilities and to provide supported housing to anyone in the target population who needs it by the end of the agreement); *Georgia*, Settlement Agreement at 18-21 (requiring the state to create 2,000 supported housing beds for people with psychiatric disabilities over 5 years, and to provide supported housing by the end of the agreement to any of the 9,000 individuals with serious and persistent mental illness in the state who need that support).

<sup>179</sup> See *Delaware*, Settlement Agreement at § II.F.-H. (requiring the state by the end of the agreement to have 11 full-fidelity ACT teams, 4 Intensive Case Management teams, and 25 case managers, all for the agreement’s target population; *Georgia*, Settlement Agreement at 12-15 (requiring the state by the end of the agreement to have 22 ACT teams, 8 Community Support Teams, and 14 Intensive Case Management teams, plus 45 Case Management providers, all for the agreement’s target population).

<sup>180</sup> See *Delaware*, Settlement Agreement at II.A.-E. (requiring the state by the end of the agreement to create a 24/7 crisis hotline, mobile crisis teams that can respond anywhere in the state within an hour (plus training of law enforcement so that police officers know how and when to call on the teams), crisis walk-in centers in the northern and southern regions of the state, crisis stabilization services, and four crisis apartments); *Georgia*, Settlement Agreement at 15-18 (requiring the state by the end of the agreement to create 6 crisis service centers, 3 crisis stabilization programs (not on state hospital grounds), 35 crisis beds in non-state community hospitals, a 24/7 crisis hotline, mobile crisis teams that can respond anywhere in the state within one hour, and 18 crisis apartments located in community settings and staffed by paraprofessionals and peer specialists).

<sup>181</sup> See *Delaware*, Settlement Agreement at § II.J. (requiring the state by the end of the agreement to provide integrated, evidence-based supported employment to 1100 individuals in the target population and to ensure that everyone receiving ACT services has an employment specialist on his or her ACT team); *Georgia*, Settlement Agreement at 21-22 (requiring the state by the end of the agreement to provide integrated, evidence-based supported employment to 500 individuals with serious and persistent mental illness).

<sup>182</sup> See *Delaware*, Settlement Agreement at § V; *Georgia*, Settlement Agreement at 25-26.

<sup>183</sup> See, e.g., *M.R. v. Dreyfus*, 663 F.3d 1100 (9th Cir. 2011) (ordering preliminary injunction against cuts to personal care services; *Pashby v. Cansler*, 2011 WL 6130819 (E.D.N.C., Dec. 8, 2011) (granting preliminary injunction against cuts to personal care services); *Pitts v. Greenstein*, 2011 WL 1897552 (M.D. La., May 18, 2011)

ing with their rights on.”<sup>184</sup> Unlike the due process doctrines, *Olmstead* does not incentivize states simply to turn people out of institutions and on to the streets. It incentivizes states to provide the array of services people need to thrive in the community (at least so long as a state remains enrolled in Medicaid, which requires states to pay for nursing home and other institutionalized placements for those individuals).<sup>185</sup>

To be sure, the *Olmstead* doctrine retains a number of limitations and ambiguities for deinstitutionalization advocates. One such ambiguity is *Olmstead*'s discussion of the determinations of the state's treating professionals. The Court said that “the State generally may rely on the reasonable assessments of its own professionals in determining whether an individual meets the essential eligibility requirements for habilitation in a community-based program.”<sup>186</sup> Professor Perlin reads this language as “implicitly endorsing a perpetuation of *Youngberg v. Romeo*'s ‘substantial professional judgment’ standard.”<sup>187</sup> To be sure, there does appear to be a difference between *Olmstead* and *Youngberg* on this score: *Olmstead*'s language of “reasonable assessments” seems to suggest a negligence standard, which *Youngberg* rejected in the due process context as too strict.<sup>188</sup> Permitting states to rely only on “reasonable assessments” of their treating professionals does appear stricter than requiring “only . . . that professional judgment was in fact exercised.”<sup>189</sup> If courts do broadly defer to the state's own professionals in *Olmstead* litigation—or, worse, *require* a decision from a state's treating professional before allowing an individual to obtain relief—then states have a ready means to circumvent the integration mandate. Professionals who work for the state can simply be directed or pressured to say that individuals cannot be properly served in community settings.<sup>190</sup> A number of lower courts have responded to these concerns by reading *Olmstead* as not limiting plaintiffs to relying on the determinations of the states' professionals. These courts have permit-

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(denying state's motion for summary judgment in challenge to cuts in personal care services); *Cota v. Maxwell-Jolly*, 688 F. Supp.2d 980 (N.D. Cal. 2010) (issuing preliminary injunction against cuts to adult day services); *V.L. v. Wagner*, 669 F. Supp.2d 1106 (N.D. Cal. 2009) (issuing preliminary injunction against cuts to in-home support services).

<sup>184</sup> See *supra* text accompanying note 41. Professor Mark Weber argues that, at least in this respect, *Olmstead* guarantees a form of “positive rights.” See Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269 (2004).

<sup>185</sup> See 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(4).

<sup>186</sup> *Olmstead*, 527 U.S. at 602 (internal quotation marks omitted).

<sup>187</sup> PERLIN, *supra* note 14, at 199.

<sup>188</sup> See *Youngberg v. Romeo*, 457 U.S. 307, 313, 321 (1982) (adopting rule articulated by Chief Judge Seitz below, which explicitly rejected a “malpractice” standard of liability).

<sup>189</sup> *Id.* at 321 (internal quotation marks omitted).

<sup>190</sup> See *Long v. Benson*, 2008 WL 4571904 at \*2 (N.D. Fla., Oct. 14, 2008) (“[T]he Secretary cannot deny the right simply by refusing to acknowledge that the individual could receive appropriate care in the community. Otherwise the right would, or at least could, become illusory.”).

ted plaintiffs to rely on a variety of other sources of evidence—including their own experts—to show that they can be served in community settings.<sup>191</sup> But it is unclear how far courts will push the point.

A second ambiguity relates to the concept of choice. *Olmstead* explains that there is no “federal requirement that community-based treatment be imposed on patients who do not desire it.”<sup>192</sup> But relying on the principle of choice in this context presents two distinct problems. First, particularly for people with mental disabilities, a large proportion of the people whose living situation will be determined by *Olmstead* litigation have been placed under guardianship.<sup>193</sup> Often these guardians are family members, but often they are not. Even under recently reformed guardianship laws, “while some guardians may actively involve their wards in decisions about their lives, legally, the decisions are vested in the guardian and are the guardian’s to make.”<sup>194</sup> Much may depend on *whose* choice *Olmstead* is interpreted as implementing: the choice of the individual with a disability herself, or the choice her guardian makes on her behalf.<sup>195</sup> *Olmstead* itself spoke of the choice of the “patient[,]”<sup>196</sup> and it relied on regulations that refer to the choice of the “individual with a disability”<sup>197</sup>—as well as the language in the preamble to those regulations that states that “persons with disabilities must be provided the option of declining to accept a particular accommodation.”<sup>198</sup> These sources would support the argument that it is the choice of the individual with a disability herself that should control, but one could argue to the contrary that they should be interpreted in the light of the background state-law principle that guardians can make decisions for their wards. The courts have not definitively resolved this question, though a number have suggested that it is the guardian’s choice that matters.<sup>199</sup>

Second, where resources are limited it may be impossible to satisfy the preferences of all individuals with disabilities (or their guardians). If some want to remain in institutions while others want supports in the

<sup>191</sup> See *Disability Advocates*, 653 F. Supp.2d at 258-259; *Joseph S. v. Hogan*, 561 F. Supp.2d 280, 291 (E.D.N.Y. 2008); *Frederick L. v. Dept. of Public Welfare*, 157 F. Supp.2d 509, 540 (E.D. Pa. 2001).

<sup>192</sup> *Olmstead*, 527 U.S. at 602.

<sup>193</sup> See, e.g., *Ricci v. Patrick*, 544 F.3d 8 (1st Cir. 2008), *cert. denied*, 129 S. Ct. 1907 (2009); *United States v. Arkansas*, 794 F. Supp.2d 935 (E.D. Ark. 2011).

<sup>194</sup> Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL’Y 279, 297 (2011).

<sup>195</sup> For a provocative argument that guardianship itself at least presumptively violates *Olmstead*, see Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decisionmaking as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

<sup>196</sup> *Olmstead*, 527 U.S. at 602.

<sup>197</sup> 28 C.F.R. § 35.130(e)(1).

<sup>198</sup> 28 CFR pt. 35, App. A.

<sup>199</sup> See, e.g., *People First of Tennessee v. Clover Bottom Development Center*, 753 F.Supp.2d 701, 713-715 (M.D. Tenn. 2010); *Ligas v. Maram*, 2010 WL 1418583 (N.D. Ill., Apr. 7, 2010).

community, the state will have a choice of how to allocate its limited funds. If enough individuals want to leave institutions and move into the community, and the state satisfies those preferences, then it might find continuing to operate the institutions for those who want to remain (or whose guardians want them to remain) too costly.<sup>200</sup> The *Olmstead* plurality's discussion of the fundamental alteration defense recognizes this tradeoff but does not make clear how it should be resolved.<sup>201</sup> These tradeoffs have led to intense conflict over *Olmstead* settlements between, on the one hand, the plaintiffs (who want to leave institutions) and the state (who wants to provide them with community services), and, on the other hand, intervening guardians who want to retain the option of institutional placement for their wards.<sup>202</sup> Given that the ADA creates a presumption in favor of integration in the community, one wonders why people with disabilities who want to and can live in the community should be forced to wait to ensure that *other* people with disabilities retain the option of living in an institution.<sup>203</sup>

Notwithstanding these limitations and ambiguities, *Olmstead* remains the most promising doctrinal tool yet for achieving the twin goals of

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<sup>200</sup> See *infra* text accompanying notes 226-227.

<sup>201</sup> See Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1448 (2007) (criticizing post-*Olmstead* law as “muddled” on this point); David Ferleger, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763, 775-776 (2010) (“Devoid of mention of compliance or enforcement, the *Olmstead* plan has such scant required content that it has been characterized as a “get out of jail free” card for states otherwise in violation of the decision's integration mandate.”) (quoting John F. Muller, Comment, *Olmstead v. L.C. and the Voluntary Cessation Doctrine: Toward a More Holistic Analysis of the “Effectively Working Plan,”* 118 YALE L.J. 1013, 1014 (2009)); Susan Stefan, *The Americans with Disabilities Act and Mental Health Law: Issues for the Twenty-First Century*, 10 J. CONTEMP. LEGAL. ISS. 131 (1999) (“Depending on how the lower courts interpret the requirement of a ‘comprehensive, effectively working plan’ and a ‘reasonable pace’ of placements, this requirement could be either sensible or fatal to any kind of progress in placement of inappropriately institutionalized people into the community.”).

<sup>202</sup> See, e.g., *Benjamin v. Dept. of Public Welfare*, 267 F.R.D. 456 (M.D. Pa. 2010) (denying intervention in case brought by individuals who wish to move to community settings to institutional residents (appearing through their parents and guardians) who wished to stay in institutional settings), *aff'd*, 432 Fed. Appx. 94 (3d Cir. 2011); *Ligas v. Maram*, 2010 WL 1418583 (N.D. Ill., Apr. 7, 2010) (granting intervention in case brought by individuals who wish to move to community settings to institutional residents (appearing through their parents and guardians) who wished to stay in institutional settings); see also *Ricci*, 544 F.3d at 15 (intervening parents and guardians relied on *Olmstead* in seeking to reopen pre-*Olmstead* case to seek an order barring the state from closing an institution for people with developmental disabilities). For a discussion of the parents-intervenor's position in cases like this, with particular emphasis on *Ricci*, see Schwartz, *supra* note 134, at 862-865.

<sup>203</sup> See Schwartz, *supra* note 134, at 865-866 (“[T]he integration mandate is a one-way street. The state is not required to provide institutional care even if none of the three *Olmstead* placement criteria is met. By its specific terms, the integration mandate requires movement from more to less restrictive settings, not the reverse.”) (footnotes omitted).

deinstitutionalization advocates: enabling people with disabilities to move out of institutional settings and promoting high-quality community services. Given the experience of the first wave of deinstitutionalization litigation, though, the important question is how *Olmstead* litigation will interact with broader political dynamics. I turn to that question in the next section.

### B. *The New Politics: Dangers and Opportunities*

At the same time that deinstitutionalization advocates have a powerful new doctrinal tool for accomplishing their goals, the politics of the field have shifted substantially. As I show in this section, the political shifts offer the potential to alleviate some of the conflicts that limited the success of deinstitutionalization advocacy in the 1970s and 1980s. But at the same time, they are likely to lead to new conflicts, which will impose new limitations.

1. *The Shifting Valence of Budget Politics*—The politics of fiscal retrenchment have, if anything, even more currency now than they did in the 1970s and 1980s.<sup>204</sup> One might, therefore, expect advocates to be in an especially good position to pursue further deinstitutionalization efforts now. And it is true that, in those states that continue to keep large numbers of people with mental disabilities in public institutions, fiscal concerns remain a powerful force for shifting the locus of services outside of those institutions.<sup>205</sup> But as those large state institutions have closed and downsized substantially, and advocates have increasingly focused on the creation of high-quality, ever-more-integrated services in the community, fiscal concerns have become more of an obstacle to their efforts.

Through the actions and experimentation of forward-thinking psychologists and psychiatrists, and through the implementation of deinstitutionalization decrees, a set of models has emerged for the successful provision of services to people with psychiatric and developmental disabilities in the community. These models include methods of providing housing. In the 1970s and 1980s, the prevalent service models provided housing largely through group homes and adult foster homes—if not board and care homes and nursing homes.<sup>206</sup> Over the years, however, advocates and

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<sup>204</sup> See, e.g., NAT'L ASSN. OF STATE BUDGET OFFICERS, 2010 STATE BUDGET REPORT: EXAMINING FISCAL 2009-2011 SPENDING 2 (2011) (“State expenditures have been severely impacted by the national recession and downturn that began in December 2007. The economic downturn created a unique and in some ways unprecedented fiscal situation for states.”).

<sup>205</sup> See, e.g., *Quinn Defends Plan to De-Institutionalize Mentally Ill, Disabled*, CBS CHICAGO (Jan. 25, 2012), available at <http://chicago.cbslocal.com/2012/01/25/quinn-defends-plan-to-de-institutionalize-mentally-ill-disabled/> (Illinois governor justifying deinstitutionalization efforts on ground that “closing facilities in Jacksonville and Tinley Park, which together employ about 550 people, would save nearly \$20 million”).

<sup>206</sup> See, e.g., ROTHMAN & ROTHMAN, *supra* note 10, at 109 (noting that the *Willowbrook* plaintiffs sought to place residents “in group homes and foster families”);

providers have shifted, particularly in the psychiatric disability context, toward supportive housing—in which a person with a disability lives alone or with a roommate in a normal apartment, often paid for with a voucher, while receiving services that are often provided by someone other than the entity that owns or operates the housing.<sup>207</sup>

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Arlene S. Kanter, *A Home of One's Own: The Fair Housing Amendments Act of 1998 and Housing Discrimination Against People with Mental Disabilities*, 43 AM. U. L. REV. 925, 932 (1994) (“Group homes and other ‘congregate living facilities’ have been viewed as the best alternative to institutionalization.”); Arlene S. Kanter, *Abandoned but Not Forgotten: The Illegal Confinement of Elderly People in State Psychiatric Institutions*, 19 N.Y.U. REV. L. & SOC. CHANGE 273, 284 (1992) (noting that elderly residents of psychiatric hospitals in particular were often “released to live in substandard board and care homes, foster homes, [and] nursing homes”).

<sup>207</sup> See Marilyn Kresky-Wolff, Mary Jo Larson, Robert W. O’Brien & Sarah A. McGraw, *Supportive Housing Approaches in the Collaborative Initiative to Help End Chronic Homelessness (CICH)*, 37 J. BEHAVIORAL HEALTH SERVICES & RESEARCH 213 (2010). For a discussion of supportive housing for people with psychiatric disabilities, see Substance Abuse & Mental Health Services Admin., *Pathways’ Housing First Program*, in NAT’L REGISTRY OF EVIDENCE-BASED PROGRAMS & PRACTICES (2007), available at <http://nrepp.samhsa.gov/ViewIntervention.aspx?id=155>. Supportive housing can also take a less integrated form, one that looks much like a service-rich group home. See, e.g., ROBERT SCHAFFER, SUPPORTIVE LIVING ENVIRONMENTS FOR THE DEVELOPMENTALLY DISABLED (1998) (describing one such model from the developmental disability context); see generally Sam Tsemberis, *Housing First: Ending Homelessness, Promoting Recovery, and Reducing Costs*, in HOW TO HOUSE THE HOMELESS 37, 39-47 (Ingrid Gould Ellen & Brendan O’Flaherty, eds., 2010) (describing choice between Housing First and linear-continuum models of supportive housing); Kresky-Wolff *et al.*, *supra*, at 216 (describing choice between scattered-site and congregate supportive housing). On the evidence supporting use of integrated, scattered-site supported housing applying a housing-first model, see Todd P. Gilmer, Ana Stefancic, Susan L. Ettner, Willard G. Manning & Sam Tsemberis, *Effect of Full-Service Partnerships on Homelessness, Use and Costs of Mental Health Services, and Quality of Life Among Adults with Serious Mental Illness*, 67 ARCH. GEN. PSYCHIATRY 645 (2010); Leyla Gulcur, Sam Tsemberis, Ana Stefancic & Ronni M. Greenwood, *Community Integration of Adults with Disabilities and Histories of Homelessness*, 43 COMMUNITY MENTAL HEALTH J. 211 (2007); Deborah K. Padgett, *There’s No Place Like (A) Home: Ontological Security Among Persons with Serious Mental Illness in the United States*, 64 SOC. SCI. & MED. 1925 (2007); Deborah K. Padgett, Leyla Gulcur & Sam Tsemberis, *Housing First Services for People who are Homeless with Co-Occurring Serious Mental Illness and Substance Abuse*, 16 RES. ON SOCIAL WORK PRAC. 74 (2006); Carole E. Siegel, Judith Samuels, Dei-In Tang, Ilyssa Berg, Kristine Jones & Kim Hopper, *Tenant Outcomes in Supported Housing and Community Residences in New York City*, 57 PSYCHIATRIC SERVS. 982 (2006); Ana Stefancic & Sam Tsemberis, *Housing First for Long-Term Shelter Dwellers with Psychiatric Disabilities in a Suburban County: A Four-Year Study of Housing Access and Retention*, 28 J. PRIMARY PREVENTION 265 (2007); Sam Tsemberis & Ronda F. Eisenberg, *Pathways to Housing: Supported Housing for Street-Dwelling Homeless Individuals With Psychiatric Disabilities*, 51 PSYCHIATRIC SERVICES 487 (2000); Sam Tsemberis, Leyla Gulcur & Maria Nakae, *Housing First, Consumer Choice, and Harm Reduction for Homeless Individuals with a Dual Diagnosis*, 94 AM. J. PUB. HEALTH 651 (2004); but cf. Sandra Newman & Howard Goldman, *Housing Policy for Persons with Severe Mental Illness*, 39 POL’Y STUD. J. 299, 310 (2009) (finding evidence more ambiguous than the foregoing studies suggest).



Effective models of community-based treatment services have also emerged. These models include Assertive Community Treatment for people with psychiatric disabilities, in which a multimember, multidisciplinary team provides a client with an array of services that promote recovery and participation in the life of the community.<sup>208</sup> They also include various other models for service coordination and intensive case management.<sup>209</sup> And they include models for integrated supported employment.<sup>210</sup> Crucially, they include models for crisis services—so that a medical or mental health crisis does not lead to institutionalization (whether in a civil facility or, in the case of many people with psychiatric disabilities, a jail) but instead prompts the provision of additional intensive services to ensure that the individual client can remain in the community.<sup>211</sup>

Over time, an evidence base has developed that has both refined and demonstrated the superiority of these service models. When deinstitutionalization lawyers prosecuted cases and negotiated agreements, they urged states to provide—and courts to require provision of—these service

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<sup>208</sup> See Michelle P. Salyers & Gary R. Bond, *Innovations and Adaptations of Assertive Community Treatment*, 12 AM. J. PSYCHIATRIC REHAB. 185 (2009). On the evidence demonstrating the effectiveness of Assertive Community Treatment, at least when implemented with fidelity to the standards of the ACT model, see Craig M. Coldwell & William S. Bender, *The Effectiveness of Assertive Community Treatment for Homeless Populations with Severe Mental Illness: A Meta-Analysis*, 164 AM. J. PSYCHIATRY 393 (2007); Robert E. Drake & Patricia E. Deegan, *Are Assertive Community Treatment and Recovery Compatible?*, 44 COMMUNITY MENTAL HEALTH J. 75 (2008); Anthony D. Mancini, Lorna L. Moser, Rob Whitley, Gregory J. McHugo, Gary R. Bond, Molly T. Finnerty & Barbara J. Burns, *Assertive Community Treatment: Facilitators and Barriers to Implementation in Routine Mental Health Settings*, 60 PSYCHIATRIC SERVS. 189 (2009); Susan D. Phillips, Barbara J. Burns, Elizabeth R. Edgar, Kim T. Mueser, Karen W. Linkins, Robert A. Rosenheck, Robert E. Drake & Elizabeth C. McDonel Herr, *Moving Assertive Community Treatment into Standard Practice*, 52 PSYCHIATRIC SERVS. 771 (2001).

<sup>209</sup> See Helen Killaspy & Alan Rosen, *Case Management and Assertive Community Treatment*, in OXFORD TEXTBOOK OF COMMUNITY MENTAL HEALTH 142 (Graham Thornicroft, George Szukler, Kim T. Mueser & Robert E. Drake, eds., 2011).

<sup>210</sup> See Deborah R. Becker, Gary R. Bond & Robert E. Drake, *Individual Placement and Support: The Evidence-Based Practice of Supported Employment*, in OXFORD TEXTBOOK OF COMMUNITY MENTAL HEALTH, *supra* note 210, at 161; Gary R. Bond, Gregory J. McHugo, Deborah R. Becker, Charles A. Rapp & Rob Whitley, *Fidelity of Supported Employment: Lessons Learned from the National Evidence-Based Practice Project*, 31 PSYCHIATRIC REHAB. J. 300 (2008).

<sup>211</sup> See TECHNICAL ASSISTANCE COLLABORATIVE, A COMMUNITY-BASED COMPREHENSIVE PSYCHIATRIC CRISIS RESPONSE SERVICE: AN INFORMATIONAL AND INSTRUCTIONAL MONOGRAPH (2005); Michael T. Compton, Masuma Bahora, Amy C. Watson & Janet R. Oliva, *A Comprehensive Review of Extant Research on Crisis Intervention Team (CIT) Programs*, 36 J. OF AM. ACAD. PSYCHIATRY & L. 47 (2008); Thomas K. Greenfield, Beth C. Stoneking, Keith Humphreys, Evan Sundby & Jason Bond, *A Randomized Trial of a Mental Health Consumer-Managed Alternative to Civil Commitment for Acute Psychiatric Crisis*, 42 AM. J. COMMUNITY PSYCHOLOGY 135 (2008); Shenyang Guo, David E. Biegel, Jeffrey A. Johnsen & Hayne Dyches, *Assessing the Impact of Community-Based Mobile Crisis Services on Preventing Hospitalization*, 52 PSYCHIATRIC SERVS. 223 (2001).

models. Indeed, as I showed above, many *Olmstead* decrees spell out in a great deal of detail what community-based services states must provide, when, and to how many individuals.<sup>212</sup> This itself reflects a shift from many earlier deinstitutionalization decrees, which imposed detailed requirements on the *process* by which a state must determine what sorts of treatment an individual needed but did not specify how many individuals should receive what particular treatments.<sup>213</sup> The shift responds to the critique that 1970s and 1980s deinstitutionalization litigation did a better job of protecting people's right to avoid living in institutions than of creating a robust system of services in the community. Advocates are now focusing, first and foremost, on building that system of services.

It is a commonplace in discussions of institutional reform litigation that such litigation has important effects in redistributing power *within* the government agencies being sued.<sup>214</sup> Professional and other constituencies within the agencies who embrace a decree's principles or are given authority or responsibility under a decree gain power and often displace or eclipse other individuals and groups who had previously held sway within the institution. That process has been on clear display in deinstitutionalization litigation.<sup>215</sup> In part as a result of the litigation itself, professional constituencies within state government that support institutional care and treatment have been significantly displaced by other professional constituencies who have embraced and fostered the new community-based models.

Although there remain some exceptions,<sup>216</sup> litigation today seeking to move people with psychiatric and developmental disabilities from large state institutions rarely involves the 1970s-typical clash between legal rights and professional judgment. To the contrary, the official position of the professional leadership of most states' developmental disability and mental health agencies is that the overwhelming majority of people with those disabilities do *not* need to live in institutions. The fight in most cases challenging confinement in large state institutions today is over pace and budgets—how quickly, and at what expense, people with psychiatric and developmental disabilities can move into the community—not over whether the plaintiffs belong in the community in the first place.<sup>217</sup>

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<sup>212</sup> See *supra* text accompanying notes 170-182.

<sup>213</sup> See, e.g., *Halderman v. Pennhurst State School & Hosp.*, 610 F.Supp. 1221, 1227 (E.D. Pa. 1985) (describing and approving *Pennhurst* settlement).

<sup>214</sup> See *supra* note 57.

<sup>215</sup> See, for example, Professor Phillip Cooper's discussion of the *Wyatt* litigation in PHILLIP J. COOPER, *HARD JUDICIAL CHOICES: FEDERAL DISTRICT COURT JUDGES AND STATE AND LOCAL OFFICIALS* 163-200 (1988).

<sup>216</sup> For an example of such an exception, see *United States v. Arkansas*, 794 F. Supp.2d 935 (E.D. Ark. 2011).

<sup>217</sup> See, e.g., *Arc of Washington State Inc. v. Braddock*, 427 F.3d 615, 620-622 (9th Cir. 2005); *Sanchez v. Johnson*, 416 F.3d 1051, 1067-1068 (9th Cir. 2005); *Benjamin v. Dept. of Public Welfare*, 768 F.Supp.2d 747, 755 (M.D. Pa. 2011).

The valence of the budget fight highlights an important respect in which the politics of deinstitutionalization have turned. In the 1970s and 1980s, fiscal conservatives often allied with deinstitutionalization advocates, because moving people out of institutions led to quick and significant budget savings.<sup>218</sup> But as deinstitutionalization advocates shifted their goals from rights to services, the cost gap between institutional and community services narrowed. Although studies of deinstitutionalization have found that people who move from institutions to the community can achieve better outcomes at lower cost,<sup>219</sup> it is reasonable to expect that the cost gap will shrink as people in the community receive more services. This may be especially true because a significant part of the cost gap reflects differences in the wages paid to workers in institutional and community settings<sup>220</sup>—differences, as I discuss in the next subsection, that states will face increasing pressures to narrow. And where people with disabilities live in their family’s home, another part of the cost gap often simply reflects a shifting of costs onto family members—a shifting that may be unsustainable as well.<sup>221</sup> Once private settings such as nursing homes and group homes are thought of as institutions—an important development I discuss in the following subsection—the cost gap can narrow further or even in some cases reverse. Where these settings provide very few services and supports, and they serve a population that requires significant supports, providing adequate, integrated services in the community could end up being more expensive than continuing to provide services in those private settings. In many cases, these private settings will remain more expensive than truly integrated settings, however.<sup>222</sup>

Moreover, even where further deinstitutionalization will lead to significant cost savings, it will not necessarily do so right away. The creation of a sufficient community service infrastructure can entail significant start-up costs. The costs are typically not, as many assume, those involved in constructing housing.<sup>223</sup> If scattered-site apartments are used, in most cases the state need simply provide assistance in locating an apartment,

<sup>218</sup> See *supra* text accompanying notes 91-96.

<sup>219</sup> See, e.g., Stancliffe *et al.*, *supra* note 84.

<sup>220</sup> See Stancliffe *et al.*, *supra* note 84, at 295.

<sup>221</sup> See Darrell R. Lewis & David R. Johnson, *Costs of Family Care for Individuals with Intellectual Disabilities*, in COSTS AND OUTCOMES, *supra* note 84, at 63.

<sup>222</sup> See, e.g., *Haddad v. Arnold*, 784 F.Supp.2d 1284, 1293 (M.D. Fla. 2010) (“Defendants admit that, ‘[i]n most cases, when a Medicaid recipient is diverted or transitioned from a nursing facility to an [in-home services] waiver program, costs to Medicaid for providing care to that individual are reduced.’ Indeed, for budgeting purposes, Defendants assume a two-to-one savings for those diverted from nursing homes.”) (citation omitted); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp.2d 184, 282-298 (E.D.N.Y. 2009) (finding that, although the housing costs for adult homes are cheaper than those for supported housing, Medicaid costs are unnecessarily inflated in adult home settings (perhaps because of the adult homes’ profit motive), and the higher Medicaid costs in adult homes more than offset any savings in housing costs).

<sup>223</sup> See, e.g., SCHAEFER, *supra* note 207, at 6. Schaefer assumes a single-family home modified to become an accessible congregate facility with up to fifteen residents.

bridge funding to facilitate the transition into the apartment and to cover expenses until the individual begins to receive SSI, and then a voucher to help pay for the housing going forward.<sup>224</sup> But the state still will, at least for people with psychiatric and/or developmental disabilities, have to construct a system of crisis services, as well as to hire professionals and teams to provide intensive, community-based treatment and case management. And as institutional populations go down, the per-resident costs of institutions rise substantially—largely because of fixed costs that states cannot shed until they have moved a sufficient number of individuals to close a wing, a floor, or an entire facility.<sup>225</sup> Those who look only at the immediate fiscal bottom line, therefore, will not support further deinstitutionalization even if, over the medium- to long-term, it will save money.

2. *The Intensified Conflict, But Potential for Alliances, with Families and Unions*—As the process of deinstitutionalization has ground on, conflict between deinstitutionalization advocates and family and union groups has intensified. The reason is simple economics. State-run institutions have very high fixed costs of operation. As people leave those institutions and are not replaced with new people coming in, per-resident costs rise significantly and compare less and less favorably to the costs of serving current residents in the community.<sup>226</sup> Once an institution's population drops below a tipping point, closure of the entire institution becomes almost a fiscal necessity. To parents and family members who want their loved ones to remain in an institution, and to unions who want to preserve their jobs in an institution, it becomes equally imperative to keep the institution from reaching that tipping point—or, if it has already reached that point, to apply extraordinary political and legal pressure to delay or forestall what seems fiscally inevitable. In the new politics of deinstitutionalization, then, parents and unions can be expected to wage epic battles to keep states and courts from downsizing institutions—even if the downsizing efforts focus entirely on people who affirmatively want (and whose families affirmatively want them) to live in the community. In a time of fiscal retrenchment, as those who support and oppose deinstitutionalization are fighting over shares of a shrinking pie, the battles become ever so much more intense.

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<sup>224</sup> Of course, to the extent that the individuals receiving services require particular physical accessibility features, that may limit the number of available apartments or require certain physical modifications to them, which will raise costs. But it generally will not require purchasing or developing new properties.

<sup>225</sup> See Stancliffe *et al.*, *supra* note 84, at 294-295.

<sup>226</sup> See Stancliffe *et al.*, *supra* note 84, at 295-302; see also Roger J. Stancliffe & K. Charlie Lakin, *Context and Issues in Research on Expenditures and Outcomes of Community Supports*, in *COSTS AND OUTCOMES*, *supra* note 84, at 1, 5 (“In 2002, per diems in public institutions averaged \$344.51 (i.e., \$125,746 annually) as compared to raw per diems of \$270 in 1997, \$211 in 1992, and \$90 in 1982. This substantial growth in per diems was driven, in part, by diseconomies of reduced scale associated with institutional downsizing.”). Using the Consumer Price Index as a benchmark, \$90 in 1982 dollars was the equivalent of just under \$167 in 2002 dollars.

This intensified conflict has played out in deinstitutionalization litigation across the country. Parents' organizations have often intervened to oppose (sometimes successfully) agreements that would merely allow people who choose to receive services in the community to leave institutions.<sup>227</sup> In a number of these cases, such as the original settlement of the *Ligas* litigation in Illinois,<sup>228</sup> these settlements would not require an individual to leave an institution if s/he (or his or her guardian) did not want to leave. But the parents' organizations quite understandably feared that, if too many people were allowed to leave the institutions in question, the choice of keeping one's son or daughter in that institution would soon be unavailable as a practical matter. As I discussed above, the rhetoric of choice is incomplete in the context of competing claims on scarce resources.

Similar dynamics have arisen when states have proposed to close institutions outside of the context of litigation. When Massachusetts responded to fiscal concerns by seeking to close Fernald Developmental Center, its oldest institution for people with developmental disabilities—even though it offered residents and guardians a choice of transferring to another state institution—Fernald parents sought to reopen a long-closed pre-*Olmstead* case that had been settled in 1993.<sup>229</sup> The parents argued that the closure actually violated *Olmstead*, because it deprived them of the opportunity to oppose placement in the community. The district court seemed to express support for this argument: It restored the case to its active docket; required the Commonwealth to “carefully assess the needs and wishes of each resident, and provide a genuine and meaningful opportunity for their guardians to participate in their placement decisions” before closing the institution; and stated that its ruling “simply ensur[ed]” that the Commonwealth determine whether each individual’s new placement “is appropriate and whether it ‘is not opposed by the affected individual’” under *Olmstead*.<sup>230</sup> The First Circuit reversed on the ground that there was no basis for reopening the old decree; the appellate court cited *Olmstead* for the proposition that the law had in fact “moved in a direction disfavoring institutionalization of residents” since the decree was first entered.<sup>231</sup>

But the battle did not end there. Evidently blaming the Massachusetts government’s decision on the pressures caused by the threat of litigation, Rep. Barney Frank, who represented the district in which Fernald

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<sup>227</sup> See the cases cited in note 202, *supra*.

<sup>228</sup> See *Ligas v. Maram*, 2010 WL 1418583 at \*1 (N.D. Ill., Apr. 7, 2010) (describing the court’s decertification of the plaintiff class in response to guardians’ objections to the initial consent decree).

<sup>229</sup> These events are well recounted in Schwartz, *supra* note 134, at 864.

<sup>230</sup> *Ricci v. Okin*, 499 F. Supp.2d 89, 92 & n.16 (D. Mass. 2007), *rev’d*, 544 F.3d 8 (1st Cir. 2008), *cert. denied*, 129 S. Ct. 1907 (2009).

<sup>231</sup> *Ricci v. Patrick*, 544 F.3d 8, 21 (1st Cir. 2008), *cert. denied*, 129 S. Ct. 1907 (2009).

was located, responded by introducing legislation that would limit the ability of federally funded Protection and Advocacy agencies—the source of much *Olmstead* litigation—to bring cases that could lead to the closing and downsizing of institutions.<sup>232</sup> Both VOR and AFSCME have vocally supported this legislation.<sup>233</sup> Though the legislation has not moved in Congress, the support by one of its most stereotypically liberal members for a bill that would limit public interest lawsuits highlights the unusual political alliances that continue to surround deinstitutionalization litigation.

Despite the intensified conflict, the new politics of deinstitutionalization open up the possibility for alliances between parent and union groups and deinstitutionalization advocates. In a meta-analysis of studies of parental attitudes published in 1991, the researchers Sheryl Larson and Charlie Lakin found that “prior satisfaction with institutional care and reservations about community care in time turns into satisfaction with community settings for the majority of families.”<sup>234</sup> These systematic findings have been replicated in the studies of implementation of particular deinstitutionalization decrees. These studies concluded that many parents initially opposed deinstitutionalization because they believed that their children could not benefit from community services but ultimately found that their children flourished in the community.<sup>235</sup> These parents have often become vigorous advocates of deinstitutionalization.

Nor have all unions followed AFSCME’s lead in opposing deinstitutionalization. The Service Employees International Union, for example, filed an amicus brief supporting Massachusetts’s decision to close Fernald,<sup>236</sup> and it and its locals have served as plaintiffs in a number of

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<sup>232</sup> See H.R. 2032, 112th Cong., 1st. Sess. (2011); H.R. 1255, 111th Cong., 1st Sess. (2009).

<sup>233</sup> See <http://www.vor.net/images/Signonletter.pdf> (June 13, 2011).

<sup>234</sup> Sheryl A. Larson & K. Charlie Lakin, *Parent Attitudes About Residential Placement Before and After Deinstitutionalization: A Research Synthesis*, 16 J. OF THE ASS’N FOR PERSONS WITH SEVERE HANDICAPS 25, 36 (1991). Interestingly, when parents are asked *after* their adult children move to the community about what their attitudes toward institutionalization and deinstitutionalization were *before* the move, they report a much lower level of satisfaction with institutionalization—and a much higher opinion of the prospect of moving to the community—than they did at the time. See *id.*

<sup>235</sup> See, e.g., JAMES W. CONROY, SEVEN YEARS LATER: A SATISFACTION SURVEY OF THE FAMILIES OF THE FORMER RESIDENTS OF HISSOM MEMORIAL CENTER 17 (1999) (finding a “drastic change in family attitudes” to the degree that nearly all embraced deinstitutionalization after it happened, although many were initially skeptical or opposed); JAMES W. CONROY, JEFFREY X. SEIDERS & YUSKAUSKAS, PATTERNS OF COMMUNITY PLACEMENT IV: THE FOURTH ANNUAL REPORT ON THE OUTCOMES OF IMPLEMENTING THE *COFFELT* SETTLEMENT AGREEMENT 1-2 (1998) (“[F]amilies of the Movers are very highly satisfied with community living, have sharply reduced their initial skepticism and resistance, and only a handful would ever even think of seeing their relatives return to a Developmental Center.”).

<sup>236</sup> See *Ricci*, 544 F.3d at 11 n.1.

*Olmstead* cases.<sup>237</sup> Not coincidentally, it is the SEIU that has had the greatest success in organizing the dispersed workers who provide community-based services.<sup>238</sup> Advocates of deinstitutionalization can build on this alliance with an important and dynamic part of the labor movement.

In the longer term, it is the politics of fiscal retrenchment itself that could promote an alliance between deinstitutionalization advocates and parent and union groups. As states pay less for community-based services, they will make it difficult for people with disabilities to attract a stable, skilled workforce of personal assistants, which is something deinstitutionalization advocates should care about.<sup>239</sup> At the same time, they will pay workers less, which is something unions should care about.<sup>240</sup> And they will shift more costs onto families who are carrying the load of serving their family members with disabilities, which is something parent and family groups should care about.<sup>241</sup> As the recent budget cut cases show, there are limits to the use of cost savings as a justification for deinstitutionalization—and when those limits are reached, deinstitutionalization advocates share significant interests with workers and families.<sup>242</sup>

The overwhelming majority of people with disabilities are no longer served in large state institutions, and, as a practical matter, they never again will be. These trends predate and are to a large extent independent of the current wave of deinstitutionalization litigation. But what that wave of litigation can do is ensure that, when large state institutions close, there are adequate and appropriate community-based services for people who would formerly have been housed there. The sooner deinstitutionalization advocates, parent organizations, and employee groups recognize that fact—and that it means they share far more interests than disagreements—the better will be the position in which they all will be in fighting the politics of fiscal retrenchment. The question is whether they will recognize that fact in time to fight effectively for a continued social investment in services and supports for people with disabilities.

3. *The Increasing Conflict with Service Providers*—Providers of community-based services were supportive of efforts to move people with disabilities out of large state institutions, though they were not a powerful force in the early days. But as deinstitutionalization progressed, they became an important constituency to whom government officials were required to listen.<sup>243</sup> And, increasingly, they have come into conflict with advocates of deinstitutionalization.

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<sup>237</sup> See, e.g., *M.R. v. Dreyfus*, 663 F.3d 1100 (9th Cir. 2011).

<sup>238</sup> See Rhee & Zabin, *supra* note 85, at 972-973.

<sup>239</sup> See Samuel R. Bagenstos, *The Future of Disability Law*, 114 *YALE L.J.* 1, 80 (2004).

<sup>240</sup> See *supra* note 220 and accompanying text.

<sup>241</sup> See *supra* note 221 and accompanying text.

<sup>242</sup> See *supra* note 183 and accompanying text.

<sup>243</sup> See LERMAN, *supra* note 20, at 12.

This conflict arises primarily from a sharpened focus among advocates on what counts as an “institution.” When advocates targeted large state facilities, it was easy for most involved to assume that the goal was smaller and/or private facilities—that those facilities were the “community,” not “institutions.” But as people with disabilities left the large state facilities, many ended up in large private facilities: ICF/MRs, “adult care homes,” and private nursing homes. These facilities had many of the characteristics of the institutions advocates had earlier attacked: large-group congregate living, separate from the broader community; denials of choice over day-to-day activities; an attitude and policy of paternalism and protection.<sup>244</sup> Many of these facilities, too, were operated by for-profit providers.<sup>245</sup> Deinstitutionalization advocacy—in courts, legislatures, and the streets—has increasingly labeled these facilities institutions and sought to move people out of them.<sup>246</sup>

The challenges to private institutions created a new set of powerful enemies for the deinstitutionalization movement. Private, for-profit operators of nursing homes and adult care homes, in particular, are extraordinarily powerful within state legislatures.<sup>247</sup> To the extent that effective deinstitutionalization requires reallocation of Medicaid resources out of institutional settings and to community settings, those powerful interests will fight with substantial success. Perhaps that is why, although cases challenging institutionalization in large state facilities have often been resolved through settlement,<sup>248</sup> cases challenging institutionalization in these *private* facilities have typically been resolved only after hard-fought litigation.<sup>249</sup>

The increasing conflicts with private ICF/MR, nursing home, and adult care home operators merely broaden the field of battle for deinstitutionalization advocates; they do not fundamentally change it. But other developments raise the prospect that advocates of deinstitutionalization will turn against each other. In part, again, this prospect results from an evolution among some advocates in their understanding of what constitutes an institution. In the first wave of deinstitutionalization, people who left large state facilities typically moved to group homes and other, rela-

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<sup>244</sup> The district court’s findings in the *Disability Advocates* case are exemplary on this point. See *Disability Advocates, Inc. v. Paterson*, 653 F. Supp.2d 184, 198-218 (E.D.N.Y. 2009).

<sup>245</sup> See LERMAN, *supra* note 20, at 12 (“The move from the state-sponsored institutions is, therefore, primarily a tilting toward the profit sector of the economy.”).

<sup>246</sup> For the cases, see *supra* notes 165-168 and accompanying text. Professor Lerman predicted this development as early as 1982. See LERMAN, *supra* note 20, at 11 (“As the level of acceptable social-control practices is scrutinized further, many recent alternatives to traditional institutions may well be deemed new candidates for [deinstitutionalization].”).

<sup>247</sup> For a classic discussion, see BRUCE C. VLADECK, *UNLOVING CARE: THE NURSING HOME TRAGEDY* 192-201 (1980).

<sup>248</sup> See *supra* text accompanying notes 171-182.

<sup>249</sup> See *supra* text accompanying note 170.



tively small, congregate facilities.<sup>250</sup> But many advocates have come to see 10-, 8-, and even 4-bed group homes as having characteristics that are uncomfortably similar to those of the institutions they have attacked.<sup>251</sup> These advocates have promoted decree provisions that require people coming out of institutions to be served in scattered-site apartments.<sup>252</sup> Those provisions directly threaten the operational model of group home providers—providers who typically understand their jobs as working to free people with disabilities from institutions.

These tensions are likely to become even more acute as deinstitutionalization advocates move from a focus on where people with disabilities live to a focus on *how* people with disabilities live. That shift has already begun, as advocates—in determining what constitutes an institution—have looked to whether individuals in a particular setting have choice, autonomy, and the ability to live lives like everyone else.<sup>253</sup> Deinstitutionalization advocates have also begun to challenge not just segregated housing but also segregated employment for people with disabilities, such as employment offered through sheltered workshops.<sup>254</sup> But many of the entities that operate sheltered workshops—including chapters of the Arc and Easter Seals—have historically been strong supporters of deinstitutionalization and remain a key part of the broader disability rights movement. The expansion of deinstitutionalization principles to challenge these work settings is increasing the likelihood of internecine battles within the movement.

#### IV. CONCLUSION

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<sup>250</sup> See *supra* note 206 and accompanying text.

<sup>251</sup> See, e.g., Kanter, *A Home of One's Own*, *supra* note , at 932 (“[Group homes and other congregate arrangements] are often simply an extension of the institutions left behind. 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.”) (footnote omitted).

<sup>252</sup> See, e.g., *United States v. Delaware*, No. 11-cv-591 (D. Del., July 6, 2011), Settlement Agreement at §II.E.2.iv., v. (“All new housing created under this agreement will be scattered site supported housing, with no more than 20% of the units in any building to be occupied by individuals with a disability known to the State. . . . All new supported housing created under this agreement will have no more than two people in a given apartment, with a private bedroom for each person.”); *Williams v. Quinn*, No. 05-cv-4673 (N.D. Ill., Sept. 29, 2010), Settlement Agreement at 6 (“[Permanent Supportive Housing] includes scattered-site housing as well as apartments clustered in a single building, but no more than 25% of the units in one building with more than four (4) units may be used to serve PSH clients known to have Mental Illness. For buildings with two (2) to four (4) units, no more than 50% of the units may be used to serve PSH clients known to have Mental Illness.”).

<sup>253</sup> Again, the analysis in *Disability Advocates* is exemplary. See *Disability Advocates*, 653 F. Supp.2d at 198-218.

<sup>254</sup> See, e.g., *Lane v. Kitzhaber*, No. 12-cv-\_\_\_ (D. Or., complaint filed Jan. 25, 2012) (challenging, as violation of *Olmstead*, state employment services system that unduly relies on segregated sheltered workshops).

I hope I have shown that the past of deinstitutionalization litigation was, in key respects, far more successful than most observers acknowledge. The limits of that success were very real, though: Although deinstitutionalization advocates succeeded in closing the front doors of large state institutions so that few new people with developmental or psychiatric disabilities came in, and in opening the back doors of those institutions so that the vast majority of long-term residents moved out, they were less successful in building a comprehensive system of adequate and appropriate services in the community. That key failure stemmed, I have argued, from two factors: limitations in the legal-doctrinal tools on which deinstitutionalization advocates relied; and a political alignment that created pressures to close institutions without building the community-based services that would be necessary to replace them.

As we seek to predict the future of deinstitutionalization litigation, the crucial point is that both of these factors have changed. Deinstitutionalization advocates can now rely on a legal-doctrinal tool—the *Olmstead* doctrine—that provides a meaningful way to ensure that states will build and maintain a comprehensive and adequate community system. And the very fact that most states have already substantially closed and downsized their large institutions means that, in those states, fiscal pressures no longer serve the interests of deinstitutionalization advocates as well as they did in the past. Today’s state fiscal crisis is in fact moving states to cut back on the (already insufficient) community-based services that they created as they closed their institutions. This development *might* foreshadow a *rap-prochement* between deinstitutionalization advocates and their opponents among parent and union groups—if all of these players can come to understand their common interest in time. But it remains an open question whether deinstitutionalization advocates can succeed in the political arena as their support from fiscal conservatives predictably wanes.