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Community Integration of People with Disabilities: Can *Olmstead* Protect Against Retrenchment?

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Abstract: Since the passage of the Americans with Disabilities Act (ADA) in 1990, states have made significant progress in enabling Americans with disabilities to live in their communities, rather than institutions. That progress reflects the combined effect of the Supreme Court's holding in *Olmstead v. L.C. ex rel. Zimring*, that states' failure to provide services to disabled persons in the community may violate the ADA, and amendments to Medicaid that permit states to devote funding to home and community-based services (HCBS). This article considers whether *Olmstead* and its progeny could act as a check on a potential retrenchment of states' support for HCBS in the event that states face severe reductions in federal funding for Medicaid, as was threatened by Republican efforts in 2017 to "repeal and replace" the Affordable Care Act and to restructure Medicaid. The article concludes that *Olmstead* provides a strong basis for challenging a state's elimination or severe curtailment of existing HCBS programs, but that the fact-specific nature of a state's likely "fundamental alteration" defense precludes predicting the outcome of such a challenge. Despite this legal uncertainty, protests mounted by people with disabilities, in which they demanded freedom from institutionalization, may have helped cement the idea that community integration is a civil right in the public's mind.

Keywords: ADA; disability; discrimination; Medicaid; community integration; institutionalization; Olmstead

1. Introduction

Since the beginnings of the independent living movement a half century ago, people with disabilities have been moved to activism to demand the ability to live in their own homes and to participate in their communities, rather than living in the institutions to which they had been historically consigned (Bagenstos 2009; Basas 2010). The history of disability in the United States is replete with examples of the state-imposed segregation of people with disabilities (Cook 1991). By the 1990 passage of the Americans with Disabilities Act (ADA)¹, Congress recognized that institutionalization—and the resulting isolation and segregation—was one form of the pervasive discrimination that people with disabilities experienced, and that the ADA was intended to remedy.² As one disability activist wrote at the time, the ADA's "statutory findings ... make it as plain as it could be that the primary evil addressed in the ADA was the segregation that continues to impose an isolated, denigrated existence upon persons with disabilities" (Cook 1991, p. 398).

In the decades since the passage of the ADA, states have achieved significant progress in enabling Americans with disabilities to live in their homes or communities. In 2011, 80% of non-elderly people with disabilities who were enrolled in Medicaid and receiving some kind of long-term services and supports (LTSS) lived in the community, as did 50% of elderly people with disabilities (Sowers et al. 2016). That progress has resulted largely from the confluence of two forces. First,

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¹ 42 U.S.C. §§12101–12213.

² 42 U.S.C.A. §§12101.

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the Supreme Court's interpretation of Title II of the ADA in *Olmstead v. L.C. ex rel. Zimring*³ sent a strong, if not entirely clear, signal to states that their failure to provide services to disabled persons in the community could violate the ADA. Second, additions to Medicaid—the joint federal–state health insurance program covering low-income persons—have permitted state Medicaid agencies to devote funding to home and community-based services (HCBS) for disabled beneficiaries, rather than institution-based services. As a result, states increasingly have had both the legal motive (*Olmstead*) and the financial means (Medicaid funding) to support greater community integration for their disabled citizens (Rosenbaum et al. 2002).

However, this progress has been incomplete and (to the mind of disability activists) insufficient. Aspects of Medicaid program design privilege the funding of care in institutions, both historically and today. While institutional care is a mandatory coverage category under the federal Medicaid statute, states choose to cover HCBS at their option (Musumeci and Claypool 2014). Although all states have opted to cover some HCBS, they often do so via Medicaid waivers that permit them to limit enrollment. These limitations have produced long waiting lists of persons seeking to receive Medicaid-covered services in the community. In 2015, more than 640,000 people with disabilities were on waiting lists for waiver-funded HCBS, and they spent more than two years on average on those lists (Ng et al. 2016). Moreover, the optional nature of HCBS programs render them tempting targets in the event of cuts to Medicaid funding. Thus, when conservatives in Congress proposed in 2017 to impose dramatic cuts to the growth of the Medicaid program in conjunction with their effort to repeal the Affordable Care Act (ACA), people with disabilities viewed the proposed cuts as directly threatening to roll back the progress toward community integration achieved over the previous two decades. Although those proposals narrowly failed in 2017, they remain integral to conservative discussions of the future of Medicaid.

This article begins by describing briefly how the *Olmstead* decision and changes to Medicaid combined to fuel gains in opportunities for people with disabilities to live in the community or in their own homes. It then considers whether *Olmstead* and its progeny could act as a check on a potential retrenchment of states' support for HCBS in the event of drastic reductions in federal funding for Medicaid. *Olmstead* and cases interpreting it provide a strong basis for advocates for people with disabilities to mount a legal challenge to state proposals to eliminate or severely curtail HCBS programs. However, the outcome determinative questions in *Olmstead* litigation are typically fact-specific, and disability advocates cannot assume that the *Olmstead* line of cases would provide a lifeline to rescue existing Medicaid HCBS programs.

Despite this unsatisfyingly inconclusive conclusion, the article concludes by asking whether another force may tip the balance to protect people with disabilities from being re-segregated in institutions. It suggests that the 2017 political debate over the future of Medicaid and the ACA, and particularly media coverage of people with disabilities protesting proposed cuts, may have cemented the political, social, and moral capital of the disability rights movement enough to prevent future rollbacks of programs supporting community integration.

2. The Olmstead Decision

The *Olmstead* case resulted from the desire of two women in Georgia, Lois Curtis and Elaine Wilson, to move out of an institution and live in the community. Both women had mental disabilities and had received treatment in a state institution, even after their health care providers agreed that community-based treatment would meet their needs. The women challenged their continued isolation in an institution as a violation of Title II of the ADA⁴, which prohibits disability discrimination by state and local governments and their programs. When their case reached the United States Supreme Court,

³ 527 U.S. 591 (1999).

⁴ 42 U.S.C. §12132.

the Court had to address two questions: first, does the ADA's prohibition on disability discrimination extend to a state's unjustified institutionalization of persons with disabilities? And, if so, what steps to implement community-based care must a state pursue in order to meet Title II's obligations?

The Court, in an opinion by Justice Ginsberg, answered the first question clearly. The Court pointed to Congressional findings in the ADA identifying the isolation and segregation of people with disabilities as forms of discrimination and noting the persistence of discrimination in institutionalization,⁵ and held that "[u]njustified isolation . . . is properly regarded as discrimination based on disability." Justice Ginsburg bolstered this holding by pointing out that undue institutionalization simultaneously perpetuated stigma and prejudice against people with disabilities and severely diminished their ability to pursue "everyday life activities . . . including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

However, the Court emphasized that a state program's institutional isolation of persons with disabilities would violate Title II only when the institutionalization was "unjustified". So, what renders institutionalization "unjustified"? Answering that question as it relates to the plaintiffs' characteristics proved straightforward for the Court. It reasoned that if treating professionals concluded that a disabled person could benefit from community-based services and the person herself did not oppose those services, then the person should be deemed (in the language of Title II) a "qualified individual with a disability" for whom institutional placement would be unjustified. This conclusion accorded with the approach of Justice Department regulations implementing Title II, which called on public entities to administer services in "the most integrated setting appropriate to the needs of qualified individuals with disabilities".

Being attuned to the complexity of the financial and institutional arrangements involved in operating state health care and human services programs, the *Olmstead* Court did not issue a mandate that any qualified individual with a disability was immediately entitled to receive requested community-based services. Another Title II regulation (the so-called "reasonable-modifications regulation") gave states a potential defense. It provided:

"A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." ¹⁰

Georgia argued that being required to transfer persons similar to the plaintiffs to a community setting immediately would "fundamentally alter" its programs for providing services to persons with mental disabilities. The lower courts had rejected this defense. The district court had flatly ruled that disability discrimination in the form of unnecessary institutionalization could not be justified by a lack of funding.¹¹ The Eleventh Circuit was only slightly more sympathetic to the state. It concluded that a cost-based defense would succeed "only in the most limited of circumstances", such as when a state could show that providing community-based services to the plaintiffs would be unreasonable in light of its entire mental health budget.¹²

Justice Ginsburg rejected the lower courts' interpretations of the "fundamental alteration" defense and instead adopted a more "sensibl[e]" construction ¹³ that acknowledged the logistical and financial

⁵ 42 U.S.C. §§12101(a)(2),(3).

⁶ 527 U.S. at 597.

⁷ Id. at 602.

⁸ *Id.* at 601–603.

⁹ 28 CFR §35.130(d)(1998).

¹⁰ 28 CFR §35.130(b)(7)(1998).

¹¹ *Id.* at 594.

¹² *Id.* at 603.

¹³ *Id.* at 604.

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difficulties potentially facing states charged with moving qualified persons with disabilities into community settings, while continuing to operate or fund institutions for persons needing or desiring institution-based care. Writing in this part of her opinion for a plurality of the Court, she read the regulation as "allow[ing] the State to show 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 . . . disabilities."¹⁴ This ambiguous standard places on the state the burden of demonstrating the unfairness of the plaintiffs' requested remedy, without articulating clearly factors that courts should consider in determining whether a state is "administer[ing] services with an even hand"¹⁵ (Rosenbaum et al. 2002). However, the opinion suggested an example of how a state could demonstrate that it had met the reasonable modifications standard, as follows:

"If ... 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 ... " 16

In the years following *Olmstead*, the federal government, states, and the lower courts all have looked to Ginsburg's description of a "comprehensive, effectively working plan" for guidance in meeting the ADA's community integration mandate. Soon after the decision, officials from the Department of Health and Human Services issued guidance encouraging states to develop the type of deinstitutionalization plan needed to satisfy the ADA—so-called "*Olmstead* plans" (Rosenbaum 2016). A decade after *Olmstead* was decided, the Department of Justice stepped up enforcement efforts against states, with the Civil Rights Division becoming involved in more than 40 *Olmstead* cases from 2009–2012 (Musumeci and Claypool 2014). While *Olmstead* itself concerned efforts by plaintiffs with mental disabilities to get out of the state institution where they received services, its community integration mandate has been applied to protect persons with all types of disabilities (Bliss and Wells 2010).

3. Medicaid's Coverage of Home and Community-Based Services

Neither the United States (US) Constitution nor the ADA, as interpreted in *Olmstead*, creates a freestanding positive right for persons with disabilities to receive supports and services that enable them to live in their own homes or community settings (Weber 2004). Instead, Title II requires that—to the extent that the state provides services for persons with disabilities—it provides them in the most integrated setting appropriate to disabled recipients' needs. Thus, appreciating *Olmstead's* power as a tool for achieving community integration requires a basic understanding of how states fund health-related services for people with disabilities. In short, it requires some understanding of Medicaid.

In 2015, Medicaid provided health coverage for more than 10 million persons with disabilities who qualified for the program based on their disability, as well as additional people with disabilities who qualified solely because they are poor (Watts et al. 2016). Federal law requires state Medicaid programs to cover certain services ("mandatory" service categories) as a condition of participation in Medicaid and the receipt of federal funding. It also gives states the option to cover a wide range of additional services ("optional" service categories), as well as the ability to receive waivers of certain requirements of the federal law. This framework ensures that all state Medicaid programs cover mandatory services as a baseline, while giving them the flexibility to cover additional services meeting the particular needs and constraints identified by state health policy makers.

From its beginning, Medicaid was biased towards providing disabled recipients with needed medical care in institutional settings (Watson 2010)—a bias that is in tension with the ADA's

¹⁴ *Id*.

¹⁵ *Id.* at 605.

¹⁶ *Id.* at 606.

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requirement that states provide services in the most integrated appropriate setting. The distinction between mandatory and optional coverage shapes states' decisions as they attempt to comply with <code>Olmstead</code>'s integration mandate. Under the Medicaid statute, covering services provided to adult Medicaid beneficiaries in nursing facilities is mandatory. By contrast, most services that fall under the umbrella of "home and community based services" (such as personal attendant services, habilitation services, transportation support, case management, and respite services) are optional. The Medicaid statute did not originally give states the ability to include the full range of HCBS that can be covered today, but the federal government's willingness to fund HCBS as a part of Medicaid has grown in recent decades, nudging states to move their programs in that direction (Kapp 2014).

A proliferation of Medicaid waiver authorities and funding streams to encourage community-based care has eroded, but not eliminated, this historical bias. As of 2013, at least nine different paths existed permitting states to cover an expanded range of services enabling people with disabilities to live in the community, including personal attendant care, specialized therapies, and care coordination (Rosenbaum 2016). These pathways include amending Medicaid state plans to cover HCBS and receiving §1115 and §1915(c) waivers, which waive compliance with certain requirements in the federal Medicaid statute (Kapp 2014). The ACA provided further support for community-based services, offering states novel and expanded ways to offer services and providing enhanced federal funding in some cases (Kapp 2014; Musumeci and Foutz 2017). The details of this "bewildering array of programs" (Hermer 2014) are not important for this article's purposes. What matters are two critical points. First, states have used these Medicaid innovations to rebalance their long-term supports and services spending toward community-based care. In 2013, for the first time, a majority of Medicaid dollars spent on long-term services and supports went to HCBS, rather than institutional care (Sowers et al. 2016). Second, almost all of the innovations supporting this rebalancing remain optional for states. Each state decides whether to cover those benefits, and how much to spend on them. As a result, Medicaid coverage of HCBS is, in the words of one commentator, "at best a patchwork that varies substantially from state to state and is often not available for many people in need" (Hermer 2014).

Thus, Medicaid's institutional bias is partly historical, but it also continues to be structural. The federal government has offered new ways to help states provide community-based care, and all of the states have—to some degree—taken up that offer, adopting HCBS programs for disabled Medicaid recipients and moving more people with disabilities into integrated settings. However, expanding funding streams for more integrated services does not eliminate states' obligations to pay for services provided in the isolation of institutions. As long as states participate in Medicaid, they *must* cover care in nursing homes. In Medicaid, integration is optional, but segregation is mandatory.

That distinction explains why so many people with disabilities viewed the Republican proposal as an existential threat to the steady progress towards community integration that states have achieved since the *Olmstead* decision. They feared that the states facing massive cuts in federal support for Medicaid (the Congressional Budget Office estimated that the proposal would reduce federal Medicaid spending by \$880 billion over a decade) would view optional benefits such as HCBS as low-hanging fruit in the quest for savings. A report from the Center on Budget and Policy Priorities asserted that "HCBS are a likely target if states must make substantial cuts due to federal funding shortfalls, because they spend more on optional HCBS than on any other optional benefit. . . . Some states could eliminate their HCBS programs altogether" (Solomon and Schubel 2017). This response, according to an analysis by the Center for American Progress, would "risk a return to widespread institutionalization" (Vallas et al. 2017). The prospect that Medicaid cuts would cause people with disabilities to lose access to the services and supports that increasingly permitted them to live full lives in the community, and in many cases hold jobs, prompted condemnation of the proposals and widespread protests by people with disabilities, which are further discussed below.

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4. How Strong a Bulwark Is Olmstead against Retrenchment of Home and Community-Based Services?

The narrow failure of Republican proposals in 2017 averted immediate concerns about the elimination of optional HCBS programs. However, Medicaid spending remains a favorite target of conservative politicians, and further attempts to axe Medicaid spending and restructure the program seem certain. That prospect animates this article's inquiry: if states face substantial reductions in federal Medicaid funding, would *Olmstead* and its progeny serve as a check on a rollback of HCBS programs? In other words, could people with disabilities successfully argue that, by eliminating or severely curtailing existing coverage of HCBS through its Medicaid program, a state would violate Title II of the ADA?

Addressing this question would require courts to "navigate once again the murky waters between two statutory bodies," ¹⁷ this time in a scenario testing the limits of the ADA's constraints on states' administration of Medicaid. Decisions from lower courts applying *Olmstead* are not terribly numerous, but they supply some insights on how a court might answer the question. Cuts to Medicaid of the magnitude proposed in 2017 are unprecedented, but judicial evaluations of more modest cuts to HCBS and states' decisions to limit the expansion of those services are informative.

In a number of cases, disabled Medicaid recipients have relied on *Olmstead* to push back against state cuts to coverage of HCBS. *Olmstead*'s protection is not limited to persons confined to an institution. Several courts have held that disabled Medicaid recipients need not wait until the lack of covered services pushes them out of their homes and into an institution. Facing a demonstrable risk of institutionalization suffices to give a person standing to sue to enforce Title II's community integration mandate. Thus, *Olmstead* applies to disabled persons living at home or in less restrictive settings, but who may be forced into a nursing home or state institution in order to receive needed services if a state cuts HCBS programs (Weber 2004).

The key issue in an *Olmstead* challenge to a state's elimination or severe curtailment of HCBS would likely be whether the plaintiffs' requested remedy (for example, the maintenance of existing programs) would entail a "fundamental alteration" of the state's Medicaid program. Recall that Title II requires states to make "reasonable modifications" to their programs to make services available "in the most integrated setting appropriate" to the needs of service recipients, but does not demand that states take steps constituting a "fundamental alteration". Several recurring themes emerge from cases applying *Olmstead* and the fundamental alteration defense in the context of HCBS services.

Courts have emphasized that a state invoking the budgetary impact from retaining or expanding HCBS will not by itself sustain a successful fundamental alteration defense. As one court put it, "although budgetary concerns are relevant to the fundamental alteration calculus, financial constraints alone cannot sustain a fundamental alteration defense." Permitting a state to defeat an *Olmstead* claim simply by highlighting the funding required to provide services in an integrated setting would render the ADA's integration mandate "hollow indeed".²¹

The cases speak less clearly about the relevance budgetary considerations *should* have in a fundamental alteration analysis, but they offer some suggestions. For example, plaintiffs may argue that providing services to a disabled Medicaid recipient in her own home is cheaper than providing institutional care. Those per capita cost arguments are relevant, and on their face sound quite compelling. However, *Olmstead* indicates that courts should consider the program-wide cost effects of covering HCBS.²² For instance, courts may consider the "woodwork effect", which describes the

Arc of Washington State Inc. v. Braddock, 427 F.3d 615, 617 (9th Cir. 2005).

See, e.g., Fisher v. Okla. Health Care Authority, 335 F.3d 1175 (3rd Cir. 2003); M.R. v. Dreyfus, 697 F.3d 706, 734–35 (9th Cir. 2012); Pashby v. Della, 709 F.3d 307 (4th Cir. 2013).

¹⁹ 28 CFR §35.130(b)(7)(1998).

²⁰ Pashby v. Della, at 324.

²¹ Fisher, 335 F.3d at 1183.

²² 527 U.S. at 605–606.

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potential that the availability of HCBS may lead to increased costs by encouraging additional persons to seek Medicaid-covered services²³ (Weber 2004). More broadly, courts should consider evidence that the costs incurred in providing HCBS to *Olmstead* plaintiffs will require cutting other aspects of a state's Medicaid program or somehow disadvantage other disabled Medicaid recipients.²⁴

Reported cases also make evident judges' differing views on the fundamental question of how to balance the ADA's integration mandate against the policy-making discretion states properly enjoy in administering Medicaid. Striking this balance is at the core of the fundamental alteration defense. Some decisions, through emphasizing Congress's intent to address the historical segregation of people with disabilities in institutions, set a high bar for a state to show specifically how providing HCBS to the plaintiffs will harm other Medicaid recipients. Others, by contrast, stress the complexity of managing a Medicaid program, and the need for states to be able to make reasonable decisions as long as they do not facially discriminate against people with disabilities. These courts read *Olmstead* as instructing lower courts "to be sympathetic to fundamental alternation defenses, and to give states 'leeway' in administering services for the disabled". This deference to state policy decisions in administering Medicaid, even when those decisions are arguably discriminatory, calls to mind the Court's reluctance in *Alexander v. Choate*²⁸ to subject state Medicaid decisions to a disparate impact analysis (Weber, forthcoming).

The courts' reluctance to order states to provide the plaintiffs' requested remedy has been particularly strong when the state could point to its existing progress in moving disabled Medicaid recipients to integrated settings. Justice Ginsburg's language in *Olmstead* assists these states. She reckoned that the ADA's "reasonable modifications" standard might be satisfied if the state could show it had adopted "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 ... "²⁹ Through relying on this language, courts have found that forcing states to modify or "disrupt" their existing approach to rebalancing their Medicaid spending on services and supports for people with disabilities would constitute a "fundamental alteration" not demanded by the ADA, at least in cases where the state points to progress under its existing approach. As one court put it, "the ADA did not impose a requirement that the state quicken the pace of deinstitutionalization by expanding the [existing] program." This judicial willingness to bless existing state approaches has been criticized for not demanding that states provide empirical evidence on the question of access for persons with disabilities (Weber, forthcoming).

What can be gleaned from this discussion about how a court might analyze a claim that eliminating or severely curtailing Medicaid-funded HCBS would lead to the re-institutionalization of many people with disabilities, and thus violate *Olmstead's* community integration mandate? Frankly, it's hard to draw many conclusions. The decided cases typically have addressed complaints about a state's failures to expand community-based services for disabled citizens or an adjustment to its Medicaid program that caused plaintiffs to lose their access to some or all of the community-based services they had previously received. The cases do not deal with the sort of wholesale retrenchment and re-segregation

²³ Townsend v. Quasim, 328 F.3d 511, 520 (9th Cir. 2003).

Id.; A. H. R. v. Washington State Health Care Auth., No. C15-5701JLR, 2016 WL 98513, at *16 (W.D. Wash. 7 January 2016).
See, e.g., M.R. v. Dreyfus, 697 F.3d 706, 737 (9th Cir. 2012) ("The state must make a more particularized showing of harm to others in the disabled community in order to eliminate serious questions on the merits concerning the validity of the fundamental alteration defense."); cf. Steimel v. Wernert, 823 F.3d 902, 911 (7th Cir. 2016) (referring to the "integration mandate's maximalist language").

Townsend, 328 F.3d at 518 (noting that the fundamental alteration defense does not apply to cases involving facial discrimination).

²⁷ Arc of Washington State at 618 (quoting *Olmstead*, 527 U.S. at 605).

²⁸ 469 U.S. 287 (1985).

²⁹ Olmstead, 527, 736U.S. at 606.

³⁰ Sanchez v. Johnson, at 1067-68.

³¹ ARC of Washington v. Braddock, 427 F.3d at 620.

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of people with disabilities that many feared would result from 2017 proposals to slash federal Medicaid funding—and that may still lie in Medicaid's future.

Notwithstanding the peril of predicting how courts might address hypothetical future cuts, a few points emerge from the foregoing discussion. First, although courts may not read *Olmstead* to require states to add new services to their programs³², *Olmstead* arguably makes it hard for states to eliminate established services such as the home and community-based services they have increasingly offered. Both the Ninth and Tenth Circuits have observed that the "reasonable modifications" regulation suggests that the fundamental alteration defense is available only when plaintiffs demand changes to a state's program, not when they seek to preserve the status quo.³³ As a result, how can maintaining the status quo (or something that closely approximates it) amount to a fundamental alteration?

Of course, a state facing a sizable loss of federal Medicaid funding might respond that any evaluation of the fundamental alteration defense must take into account its changed budgetary reality. It might argue that, as articulated in *Olmstead* and applied in subsequent cases, courts should give states some "leeway" to adapt their Medicaid programs to this new reality. The cases recognize that states making programmatic decisions must balance the needs of a range of recipient groups and make judgments about how to equitably allocate limited resources. States forced to "make do" with diminished federal Medicaid funding will face challenging, even tragic, choices about where to make cuts. Various groups with interests in Medicaid—including not only recipient groups, such as low-income pregnant women, children, and seniors and those newly eligible under the Medicaid expansion, but also the myriad providers and managed care plans that contract with states—will all seek to minimize cuts to their interests. An argument that all groups should bear some of the pain of cuts sounds fair enough. Since Medicaid programs are required to cover nursing facility services for disabled recipients, the optional programs covering HCBS become the obvious place where people with disabilities would be expected to take their "fair share" of Medicaid cuts.

Despite the facial plausibility of these arguments, *Olmstead*'s community integration mandate provides disabled Medicaid recipients with strong footing to contest cuts to HCBS programs, even in the face of substantial federal cuts.³⁴ Title II of the ADA is not a mere suggestion that, in making complex policy choices, states should strive to provide services to people with disabilities in integrated settings. As part of the ADA's "clear and comprehensive national mandate"³⁵ to end discrimination against people with disabilities, Title II requires community integration, except in cases where a state can demonstrate that modifying its practices and programs to ensure integration would fundamentally alter those programs.

Commentators have compared *Olmstead's* mandate that state Medicaid programs provide services to disabled people in integrated settings, while simultaneously using the fundamental alteration defense to grant states leeway in achieving integration, to *Brown v. Board of Education's* ³⁶ mandate that public schools end racial segregation "with all deliberate speed" (Bliss and Wells 2010; Rosenbaum 2016). In both cases, the Court had to balance the demands of equality and antidiscrimination against notable challenges in changing the administration of complex public systems. Bliss and Wells argued in 2010 that states' ability to use the fundamental alteration defense to excuse continuing segregation of persons with disabilities dissipates over time (Bliss and Wells 2010). In short, the defense "you can't expect us

³² Rodriguez v. City of New York, 197 F.3d 611 (2nd Cir. 1999).

M.R. v. Dreyfus, 697 F.3d 706, 736 (9th Cir. 2012); Fisher v. Oklahoma Health Care Authority, 335 F.3d 1175, 1183 (stating "[n]or is it clear why the preservation of a program as it has existed for years and as approved by the federal government would fundamentally alter the nature of the program").

Of course, if a state concentrated all its cuts to HCBS and other services for people with disabilities, leaving coverage of other recipient groups unscathed, a strong argument would exist that the state was facially discriminating against people with disabilities. Disabled plaintiffs might contest those cuts as treating disabled Medicaid recipients differently from, and worse than, non-disabled recipients. This article's discussion addresses the more likely scenario in which HCBS programs are eliminated or severely cut as part of broader package of Medicaid cuts that touch the full range of recipient groups.

^{35 42} U.S.C. §12101(b)(1). 347 U.S. 483 (1954).

to achieve integration all at once"—while perhaps persuasive in the years immediately following *Olmstead*—falls flat nearly two decades later. It does take time and resources to achieve integration, but that time cannot be unlimited if the community integration mandate is to mean anything.

This premise, that full community integration of all disabled Medicaid recipients who seek to receive services in the community and can appropriately do so is a goal that states *must* achieve, means that courts should not permit states to backslide toward re-segregation. A real difference exists between requiring a state to quicken the pace of its plan for moving people into integrated settings and permitting a state to start moving disabled Medicaid recipients back into institutional settings. Under *Olmstead*, a state's rebalancing of its spending on long-term services and supports can move in only one direction. The clear expectation is that states will make *progress* in moving Medicaid recipients with disabilities into integrated settings.

This conclusion seems inescapable if disability advocates can demonstrate that eliminating or harshly cutting back on optional HCBS programs, while maintaining coverage for institution-based services, will not in fact save the state money over the long term (Weber 2004). Although proving the cost effects of a particular state's proposed cuts would entail case-specific factual development, plaintiffs in *Olmstead* litigation regularly present such evidence. Some empirical research (Wiener et al. 2017; Felix et al. 2011) and statistical modeling (Kaye 2012) suggest that providing community-based services as part of Medicaid may save states money on a program-wide, and not simply individual, level. When the question is whether the ADA requires maintenance of an existing level of HCBS, rather than the adoption of new avenues for covering HCBS, concerns about a potential "woodwork effect" are less pertinent. Presumably, the persons who emerged from the woodwork when the state began offering new community-based services are already availing themselves of those services. Thus, states should have a good idea of what it costs to provide HCBS to disabled Medicaid recipients under existing pathways, and should not face additional new enrollees if they are simply maintaining existing coverage. Concerns about the costs of transitioning towards new or expanded community-based services are simply not at issue in a lawsuit aiming to prevent retrenchment.

Still, states may argue, as Georgia did in *Olmstead*, that they must be able to fund institutional care for Medicaid beneficiaries who require or desire it, which includes overhead costs associated with supporting institutions that are not fully occupied. Justice Ginsburg's opinion in *Olmstead* gave that argument credence, but only to a point. Although she construed the fundamental alteration defense as operating at a program-wide cost level rather than a per capita cost level (Rosenbaum et al. 2002), Ginsburg cautioned that a state's desire to keep its institutions full could not control the pace of moving people with disabilities into integrated settings.³⁷ In the event of significant cuts to federal Medicaid funding, the powerful nursing home industry is likely to lobby states heavily to forestall further shifting of beneficiaries into community settings as a way of managing those cuts (Bagenstos 2009). However, maintaining institutional settings for care beyond what disabled Medicaid recipients need or seek, even when doing so is shown not to be cost effective for the state, could itself be evidence of a state's segregationist bias (Rosenbaum et al. 2002).

Finally, a state may argue that forcing it to maintain existing HCBS coverage in the face of draconian federal cuts would wreak a fundamental alteration in its allocation of state Medicaid funding across different eligibility groups. In other words, if a court interprets the ADA to prohibit the elimination of optional HCBS programs, the state will be forced to make deep cuts elsewhere that will fundamentally alter its Medicaid program. If framed as an argument that maintaining optional HCBS coverage will compel the state to drastically cut covered services for pregnant women and children or to eliminate coverage of the ACA expansion population, this response will doubtless evoke sympathy from the public, and perhaps from the courts. To repeat, though, this argument rests on a belief that resurrecting Medicaid's bias toward institution-based services for people with

³⁷ 527 U.S. at 605–606.

disabilities will save money that the state can then allocate toward other Medicaid recipient groups. *Olmstead* places on the state the burden of proving that premise. Recent research shows most states that expanded Medicaid coverage under the ACA to include childless adults and persons just above the poverty line actually experienced a decrease in any waiting list they had for HCBS waiver services (Musumeci 2017). This research suggests that HCBS services for disabled recipients and services for the expansion population do not compete in a zero-sum game.

5. Conclusion: The Power of Protest

The foregoing discussion concludes that relying on the ADA and *Olmstead* to prevent states from eliminating or severely curtailing existing pathways for Medicaid coverage of HCBS for people with disabilities, while by no means a sure bet, could well prove successful. The fate of a legal challenge to a state's proposed cuts to coverage of integrated services would likely depend on proof of facts regarding the costs of HCBS programming as one component of the state's broader obligations to provide funding for the full universe of Medicaid beneficiaries. It might also depend on how the judges hearing a challenge strike the balance between the ADA's integrationist mandate and the deference that courts regularly give to state Medicaid administrators' policy decisions.

Just months before the 2016 election, Sara Rosenbaum published an article that noted both how socially consequential *Olmstead* has proven, and the decision's limits (Rosenbaum 2016). Despite the decision's vital role in pushing states to rebalance their Medicaid long-term care spending, it could only push states so far. According to Rosenbaum, *Olmstead* does not require states to redesign their Medicaid programs and "integrate financing, social, housing, and other services to make community living a realistic and attainable option" for people with disabilities (Rosenbaum 2016, p. 592). However, given the dramatic shifts in the political climate since the 2016 election, questions about how to protect existing gains in integration have partially eclipsed—at least in the short term—hopes of further progress of the sort Rosenbaum describes. It was the all too real possibility of re-segregation that motivated protesters across the country in the spring, summer, and early autumn of 2017.

Rosenbaum's emphasis in 2016 was on the transformative moral force of *Olmstead*'s declaration that unnecessary institutionalization constitutes discrimination against persons with disabilities, and how the Court's decision propelled states toward an embrace of community integration. The moral outrage unleashed in 2017 by the proposed repeal of the ACA and draconian cuts to Medicaid, by contrast, was literally embodied in the actions of people with disabilities themselves. In response to Republican proposals, people with disabilities protested and engaged in acts of civil disobedience in the halls of Congress and nationwide. Many protesters were arrested; some arrests involved people being pulled from their wheelchairs and dragged away by police. People with disabilities decried proposals they believed would cause them to lose access to services permitting them to live in the community rather than in institutions, proposals they believed denied their full humanity (Black 2017).

America watched. During the prolonged "repeal and replace" efforts, media coverage regularly featured footage of people with disabilities putting their bodies on the line and suffering arrests. The protesters' courage and conviction elicited admiration from viewers not otherwise versed in disability rights and heaped shame on legislators seeking to roll back progress toward community integration. It is not the first time that people with disabilities have effectively harnessed the power of protest. In 1978, persons in wheelchairs blockaded a city bus in Denver to protest the lack of accessible transportation (Black 2017; Basas 2010). The protest lasted two days, until officials agreed to install lifts on buses. These early disability activists garnered national attention in 1978, but the ubiquity in 2017 of both traditional and social media images of people with disabilities repeatedly protesting over a period of months placed their concerns front and center in the nation's consciousness.

In the months and years to come, political scientists will offer varying explanations for why the Republican health care proposals ultimately failed in 2017. I am convinced, though, that the continuing vocal and corporeal protests from the disability community played a role in "dodging the bullet", at least for now. However, efforts to cut Medicaid spending and dismantle its entitlement structure are

likely to continue, and so questions about how to preserve progress toward community integration remain at the forefront of disability concerns.

The survivor's phrase "what doesn't kill you makes you stronger" is said to come from Frederich Nietzche. Time will tell whether the process of defending Medicaid against fundamental restructuring and decimating cuts may actually have left the disability rights movement in a stronger position, in terms of its political, social, and moral capital, regardless of the potency of *Olmstead's* legal protection. The television images, repeated night after night, of peaceful disabled protesters suffering arrest and bodily indignities were powerful. They called to my mind images of fire hoses and police dogs being turned on peaceful protesters in Birmingham in 1963. They left me wondering whether we have reached a point where the idea that people with disabilities could be forced to live in institutions in order to receive the services and supports they need has become intolerable to most people in America.

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References

Bagenstos, Samuel R. 2009. Law & the Contradictions of the Disability Rights Movement. New Haven: Yale University Press. Basas, Carrie Griffin. 2010. Olmstead's Promise and Cohousing's Potential. Georgia State University Law Review 26: 663. [CrossRef]

Black, Emily Rapp. 2017. Why is Our Existence as Humans Still Being Denied? New York Times, July 26.

Bliss, Charles R., and C. Talley Wells. 2010. Applying Lessons from the Evolution of Brown v. Board of Education to Olmstead: Moving from Gradualism to Immediate, Effective, and Comprehensive Integration. *Georgia State University Law Review* 26: 705.

Cook, Timothy. 1991. The Americans with Disabilities Act: The Move to Integration. Temple Law Review 64: 393.

Felix, Holly C., Glen P. Mays, M. Kathryn Stewart, Naomi Cottoms, and Mary Olson. 2011. Medicaid Savings Resulted When Community Health Workers Matched Those with Needs to Home and Community Care. Health Affairs 30: 1366–74. [CrossRef] [PubMed]

Hermer, Laura D. 2014. Rationalizing Home and Community-Based Services under Medicaid. *St. Louis University Journal of Health Law and Policy* 8: 61.

Kapp, Marshall B. 2014. Home and Community-Based Long-Term Services and Supports: Health Reform's Most Enduring Legacy? *St. Louis University Journal of Health Law & Policy* 8: 9.

Kaye, H. Stephen. 2012. Gradual Rebalancing of Medicaid Long-Term Services and Supports Saves Money and Serves More People, Statistical Model Shows. *Health Affairs* 31: 1195–203. [CrossRef] [PubMed]

Musumeci, MaryBeth. 2017. Data Do Not Support Relationship Between States' Medicaid Expansion Status and Home and Community-Based Services Waiver Waiting Lists. Data Note; Menlo Park: Kaiser Family Foundation.

Musumeci, MaryBeth, and Henry Claypool. 2014. Olmstead's Role in Community Integration for People with Disabilities under Medicaid: 15 Years after the Supreme Court's Decision. Issue Brief; Menlo Park: Kaiser Family Foundation.

Musumeci, MaryBeth, and Julia Foutz. 2017. *Medicaid Restructuring under the American Health Care Act and Nonelderly Persons with Disabilities*; Issue Brief. Kaiser Family Foundation. Available online: http://www.kff.org/report-section/medicaid-restructuring-under-the-american-health-care-act-and-nonelderly-adults-with-disabilities-issue-brief/#endnote_link_211797-9 (accessed on 23 October 2017).

Ng, Terrence, Charlene Harrington, MaryBeth Musumeci, and Petry Ubri. 2016. *Medicaid Home and Community-Based Services Programs: 2013 Data Update*. Kaiser Family Foundation Report; Menlo Park: Kaiser Family Foundation.

Rosenbaum, Sara. 2016. Using the Courts to Shape Medicaid Policy: Olmstead v. L.C. by Zimring and Its Community Integration Legacy. *Journal of Health Politics, Policy and Law* 41: 585–97. [CrossRef] [PubMed]

Rosenbaum, Sarah, Joel Teitelbaum, and Alexander Stewart. 2002. Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services. *Health Matrix* 12: 93. [PubMed]

- Solomon, Judith, and Jessica Schubel. 2017. *Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community-Based Services*. Report of the Center on Budget and Policy Priorities. Available online: https://www.cbpp.org/research/health/medicaid-cuts-in-house-aca-repeal-bill-would-limit-availability-of-home-and (accessed on 23 October 2017).
- Sowers, Mary, Henry Claypool, and MaryBeth Musumeci. 2016. *Streamlining Medicaid Home and Community-Based Services: Key Policy Questions*; Issue brief. Kaiser Family Foundation. Available online: http://www.kff.org/report-section/streamlining-medicaid-home-and-community-based-services-key-policy-questions-issue-brief/ (accessed on 23 October 2017).
- Vallas, Rebecca, Katherine Gallagher Robbins, and Jackie Odum. 2017. 5 Ways President Trump's Agenda Is a Disaster for People with Disabilities; Center for American Progress. Available online: https://www.americanprogress.org/issues/poverty/news/2017/03/08/427629/5-ways-president-trumps-agenda-disaster-people-disabilities (accessed on 23 October 2017).
- Watson, Sidney D. 2010. From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History. *Georgia State University Law Review* 26: 937.
- Watts, Molly O'Malley, Elizabeth Cornachione, and MaryBeth Musumeci. 2016. *Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015;* Report. Kaiser Family Foundation. Available online: http://www.kff.org/medicaid/report/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015/ (accessed on 23 October 2017).
- Weber, Mark C. 2004. Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion. *Wake Forest Law Review* 39: 269.
- Weber, Mark C. Forthcoming. Meaningful Access and Disability Discrimination: The Role of Social Science and Other Empirical Evidence. Cardoza Law Review. Available online: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3012118 (accessed on 23 October 2017).
- Wiener, Joshua M., Melissa Romaire, Nga (Trini) Thach, Aubrey Collins, Konny Kim, Huiling Pan, Giuseppina Chiri, Anna Sommers, Susan Habe, MaryBeth Musumeci, and et al. 2017. *Strategies to Reduce Medicaid Spending: Findings from a Literature Review*. Menlo Park: Henry J. Kaiser Family Foundation, Available online: http://files.kff.org/attachment/Issue-Brief-Strategies-to-Reduce-Medicaid-Spending-Findings-from-a-Literature-Review (accessed on 23 October 2017).



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