



Where Are We Five Years After *Olmstead*?

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This article follows up my “Community Integration of Individuals with Disabilities: An Update on *Olmstead* Implementation” in the November–December 2001 CLEARINGHOUSE REVIEW.¹ In that article I discussed case law development following the U.S. Supreme Court’s landmark disability rights decision, *Olmstead v. L.C.*, and states’ progress in implementing that decision.² *Olmstead* held that unnecessary institutionalization of individuals with disabilities was a form of discrimination prohibited by Title II of the Americans with Disabilities Act (ADA).³ The decision affirmed that states had an obligation to move individuals with disabilities from institutional settings into more integrated settings in the community if moving them would not fundamentally alter the states’ service systems.⁴ In this article I examine how the law has developed during the five years since the Supreme Court issued the decision and what progress states have made in effectuating the ADA’s integration mandate.

Five years after the *Olmstead* decision and fourteen years after the passage of the ADA, progress in implementing the ADA’s integration mandate remains disappointingly slow, and huge numbers of individuals with disabilities remain unnecessarily institutionalized in nursing homes, institutions for individuals with developmental disabilities, psychiatric hospitals, and board and care homes.⁵ State efforts to develop plans to facilitate integra-

¹Jennifer Mathis, *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 CLEARINGHOUSE REVIEW 395 (Nov.–Dec. 2001). For additional analysis of the *Olmstead v. L.C.* decision, see Ira Burnim & Jennifer Mathis, *After Olmstead v. L.C.: Enforcing the Integration Mandate of the Americans with Disabilities Act*, 33 CLEARINGHOUSE REVIEW 633 (March–April 2000).

²*Olmstead v. L.C.*, 527 U.S. 581 (1999) (Clearinghouse No. 52,203).

³*Id.* at 597; Title II, Americans with Disabilities Act (ADA), 42 U.S.C. § 12132.

⁴*Olmstead*, 527 U.S. at 606. The decision specifies that plaintiffs in integration-mandate cases must be able and willing to live in the community. *Id.* Few individuals, when given the opportunity to make an informed choice, are unwilling to live in community settings.

⁵A report by the National Council on Disability noted that nearly all of the approximately 106,000 people with developmental disabilities living in intermediate care facilities for individuals with mental retardation and the approximately 35,000 people with developmental disabilities living in nursing homes could live in community-based settings. National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives (Abridged Version)* 11–12 (2003), available at www.ncd.gov/newsroom/publications/2003/reclaimabridged.htm. The report suggests that most of the individuals living in nursing homes could live in more integrated settings and notes that community-based models of service for people with complex health issues have shown that even these individuals can live in the community. *Id.* at 15–16, 18. In 1999 a total of 1,302,315 people lived in nursing facilities nationwide. *Id.* at 13. While people with serious mental illnesses may need short-term hospitalization at times, state hospital closures and successful community-based programs such as intensive case management and consumer-directed services show that most people who might otherwise be confined in state psychiatric hospitals “clearly can be supported in their own homes or the community.” *Id.* at 17. Approximately 58,000 people remain institutionalized in state hospitals. *Id.* at 16. Most of the 827,584 or more individuals living in licensed board and care facilities—individuals who require a lower level of care than nursing facility residents—could live in the community. *Id.* at 17–18.

tion of individuals with disabilities into the community have continued, and more states have created plans to address unnecessary institutionalization.⁶ However, funding for most of these initiatives has been scant due to ongoing budget woes. States typically have been resistant to tie development of new community services with the closure of institutional beds. Many states accordingly have viewed the expansion of community services as a cost drain rather than a potentially cost-saving endeavor. Thus the implementation of *Olmstead* plans has remained modest.

In addition to these state-planning efforts, significant federal efforts have been undertaken to facilitate the development of community-based services for individuals with disabilities. Like the state-based *Olmstead* planning efforts, these federal efforts have resulted in few individuals moving into more integrated settings. However, federal *Olmstead* implementation efforts have identified many barriers to integration and recommended steps that may affect the long-term ability to serve people with disabilities effectively in the community. Also, the federal government has funded states' planning efforts and development of new programs to promote integration. The federal government did not design these measures to create large-scale development of community services and movement of institutional residents into more integrated settings but rather to help states get their planning efforts off the ground.

Because of the limitations of state and federal *Olmstead* implementation efforts, for many people with disabilities litigation has proved to be the most effective means of achieving meaningful reform promptly. Although *Olmstead* litigation is almost always a complex and costly endeavor with many uncertainties, it has enabled large numbers of individuals with disabilities to obtain the home- and

community-based services that state-planning efforts failed to deliver. I examine, in Section I, significant case law developments resulting from litigation under the ADA's integration mandate. I highlight, in Section II, some of the successes that litigation efforts under the ADA have brought for individuals who remained institutionalized despite *Olmstead* planning efforts. And I briefly discuss, in Sections III and IV, progress on federal and state fronts in facilitating compliance with *Olmstead* and the ADA's integration mandate.

I. Case Law Developments

Early case law interpreting *Olmstead* focused primarily on elements of the plaintiff's prima facie case, such as when an individual is "qualified" for community placement, when an individual is understood as not opposing community placement, whether an individual is covered by *Olmstead* if that individual is at risk of institutionalization, and whether an individual may assert a right under *Olmstead* to remain in an institution and prevent that individual's discharge. However, the more recent case law that I describe here focuses primarily on the states' "fundamental alteration" defense and fleshes out to some degree when providing community services will or will not fundamentally alter a state's service system.

A. Does the ADA's Integration Mandate Protect Individuals "at Risk" of Unnecessary Institutionalization?

Before I explore the case law on the "fundamental alteration" defense, some new developments on the issue of whether *Olmstead*'s requirements apply to individuals who are at risk of institutionalization but who are not currently institutionalized are worth noting. The federal government has interpreted *Olmstead* to

⁶*Olmstead* held that states would have a defense to the integration mandate if they could demonstrate that they had a comprehensive, effectively working plan that moved individuals from institutional to community settings at a reasonable pace and was not driven by a desire to keep institutional beds full. *Olmstead*, 527 U.S. at 605–6. States developed plans primarily as a response to this holding. For further discussion, see *infra* "IV. State *Olmstead* Compliance Efforts."

cover these individuals.⁷ Courts have followed suit, although they sometimes have required plaintiffs to demonstrate that they are truly at risk of institutionalization. In *Makin v. Hawaii* the district court permitted plaintiffs on a waiting list for institutional services for developmental disabilities to proceed with an *Olmstead* claim seeking community-based services.⁸ Even though they were not then institutionalized, the only alternative available to them, if they sought Medicaid services, was institutional services.⁹ In *Sanchez v. Johnson* another district court agreed that demonstrating a “threat of institutionalization” was sufficient to support an *Olmstead* lawsuit.¹⁰ However, it went on to conclude that plaintiffs who lived in the community did not show that they were at risk of institutionalization.¹¹ In *Sanchez* a plaintiff class challenged the disparities in wages for institutional workers and community service workers; the wage disparity resulted in unnecessary institutionalization of clients because institutions pay more than community providers and thus community providers have a hard time keeping staff and serving as many people.¹² With respect to the five named plaintiffs living in the community, the court observed that “[w]hile the future of those living with their parents may be uncertain, Plaintiffs have failed to show that there is more than a hypothetical risk that these individuals may be institutionalized.”¹³

One district court concluded that plaintiffs who were not living in an institution were not allowed to bring a claim under *Olmstead*.¹⁴ The Tenth Circuit reversed this decision and concluded that nothing in the plain language of the ADA regulations or in the *Olmstead* decision suggested that institutionalization was a prerequisite to an integration-mandate challenge.¹⁵ The protection provisions of the integration mandate “would be meaningless if plaintiffs were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation.”¹⁶

While “at risk” plaintiffs likely will be permitted to proceed with *Olmstead* litigation, cases on behalf of such individuals may present difficulties in overcoming the state’s fundamental alteration defense. If the individuals are currently on waiting lists for services and the state is not paying for their residential (and perhaps other) services, the state may be able to demonstrate that providing community-based services would be very expensive compared with the little or no cost that it is presently incurring to serve these individuals. However, if the plaintiffs can show that their institutionalization is imminent, the appropriate cost for the court to consider should be the cost that it will soon be paying to serve the individuals in

⁷See Letter from Timothy M. Westmoreland, Director, Center for Medicaid and State Operations, Health Care Financing Administration (now Centers for Medicare and Medicaid Services), U.S. Department of Health and Human Services, and Thomas Perez, Director, Office for Civil Rights, U.S. Department of Health and Human Services, to State Medicaid Director (Jan. 14, 2000), available at www.cms.hhs.gov/states/letters/smd1140a.asp (Comprehensive Effectively Working Plans ¶ 2) (on file with Jennifer Mathis).

⁸*Makin v. Hawaii*, 114 F. Supp. 2d 1017, 1033 (D. Haw. 1999).

⁹*Id.*

¹⁰*Sanchez v. Johnson*, No. C-00-01593 CW (JCS), slip op. at 37 (N.D. Cal. Aug. 6, 2002) (Clearinghouse No. 53,167).

¹¹*Id.* at 38–39.

¹²*Id.* at 2, 37.

¹³*Id.* at 39. The court found that the other two named plaintiffs were not unjustifiably institutionalized because the state was making ongoing, active efforts to place them in the community within a year. *Id.*

¹⁴*Fisher v. Oklahoma Health Care Authority*, No. 02CV-762P(C), slip op. at 6 (N.D. Okla. Oct. 31, 2002), rev’d, 335 F.3d 1175 (10th Cir. 2003).

¹⁵*Fisher*, 335 F.3d at 1181–82.

¹⁶*Id.* at 1181.

an institutional setting. For example, in *Fisher* the Tenth Circuit noted the “inescapable irony” that if plaintiffs were forced to enter a nursing home due to the state’s failure to provide full prescription coverage in the community, the costs of the institutional care would be approximately twice as high as the cost of their care in the community.¹⁷

B. What Constitutes a Fundamental Alteration?

Much of the recent case law interpreting *Olmstead* has grappled with how to determine whether providing community-based services for plaintiffs would amount to a “fundamental alteration” of a state or local government defendant’s service system. *Olmstead* advised that courts must consider—in light of the resources available to the state—the cost of the community placement and the state’s need to serve other individuals with disabilities in an evenhanded manner.¹⁸ The Court also noted that a state could meet the fundamental alteration defense by demonstrating “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.”¹⁹ More recent cases have shed some light on how courts are likely to analyze the fundamental alteration defense, although how the case law will develop in this area remains to be seen.

1. Are the Short-Term Costs of Placing Individuals in the Community Sufficient to Establish a Fundamental Alteration Defense?

Most courts have agreed that the mere existence of costs that are not immediately offset does not create a fundamental alteration. Congress envisioned in passing the ADA that reasonable accommodations may cost money and that some cost would not automatically render an accommodation unreasonable.²⁰ In the most recent case to analyze the fundamental alteration defense, *Frederick L. v. Department of Public Welfare*, the Third Circuit held that the short-term costs of community placement were not, without more, sufficient to establish a fundamental alteration.²¹

In *Frederick L.* a class of 300 residents of a Pennsylvania state hospital claimed that the Department of Public Welfare failed to administer its services in the most integrated setting appropriate and failed to do appropriate assessments to determine whether plaintiffs could be served in a more integrated setting.²² Plaintiffs sought to have defendants move sixty class members into community-based services each year.²³ After a trial the district court, ruling for the defendants, concluded that plaintiffs’ requested relief would be a fundamental alteration in light of the immediate extra cost of moving them into the community and concomitant lack of immediate aggregate cost savings, even if cost savings eventu-

¹⁷*Id.* at 1183 n.8.

¹⁸*Olmstead*, 527 U.S. at 597.

¹⁹*Id.* at 605–6.

²⁰See, e.g., 42 U.S.C. §§ 12112(b)(5)(A), 12182(b)(2)(A) (2003) (requiring reasonable accommodations under Titles I and III as long as they do not pose an undue hardship or fundamental alteration), 12131(2) (requiring reasonable modifications under Title II), 12134(b) (incorporating into Title II regulatory standards—under Section 504 of the Rehabilitation Act—that provide an undue burden and fundamental alteration defense); see also 134 CONG. REC. S5106, S5114 (April 28, 1988) (remarks of Sen. Tom Harkin) (stating that the costs of ending discrimination “provide no basis for exemption from the basic principles in the act, including the concept of reasonable accommodation”). The *Olmstead* decision contemplates that the cost of serving plaintiffs in the community is a factor in the fundamental alteration analysis, not an automatic bar to relief. See *Olmstead*, 527 U.S. at 603–4.

²¹*Frederick L. v. Department of Public Welfare*, 364 F.3d 487, 494–96 (3d Cir. 2004) (Clearinghouse No. 54,458).

²²*Id.* at 489–90.

²³*Id.* at 500.

ally would be achieved as hospital beds were closed.²⁴

The Third Circuit, vacating the decision and remanding, agreed with plaintiffs “that states cannot sustain a fundamental-alteration defense based solely upon the conclusory invocation of vaguely-defined fiscal constraints.”²⁵ The court observed that *Olmstead* listed several factors aside from the cost of community placement as relevant to the fundamental alteration defense, including the state’s ability to meet the needs of other institutionalized individuals with mental illness for whom community placement is not appropriate, whether the state has a waiting list for community services, and whether the state has a comprehensive plan to move individuals into community settings.²⁶

However, the Third Circuit did not read the district court’s opinion to rely solely on the short-term costs of placing the plaintiffs in community settings. Instead it understood the district court to have undertaken a more comprehensive analysis that also considered the Department of Public Welfare’s unsuccessful attempts to obtain additional funds through the governor’s budget, the department’s responsible spending of its budgetary allocation, the department’s reallocation of overtime savings to increase funding for community services, the department’s favorable closure rate compared to other areas, the difficulties that community opposition creates for developing community services, and the argument that increasing community placements would eventually lead to a

diminution of services for institutionalized individuals.²⁷

Other courts share the view that the short-term costs of community placement or the short-term fiscal constraints on a state are not sufficient by themselves to establish that community placement would be a fundamental alteration. In *Fisher* the Tenth Circuit held that “the fact that Oklahoma has a fiscal problem, by itself, does not lead to an automatic conclusion” that providing the community services that plaintiffs sought would be a fundamental alteration.²⁸ The Tenth Circuit went on to note:

In passing the ADA, Congress was clearly aware that “[w]hile the integration of people with disabilities will sometimes involve substantial short-term burdens, both financial and administrative, the long-range effects of integration will benefit society as a whole.” ... If every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the ADA’s integration mandate would be hollow indeed.²⁹

In *Fisher* the plaintiffs challenged the state’s decision to stop providing unlimited prescription drug coverage in a community-based Medicaid nursing home waiver program while continuing to provide unlimited prescription coverage to nursing home residents.³⁰ This policy put the program participants at risk of place-

²⁴*Frederick L.*, 217 F. Supp. 2d 581, 593 (E.D. Pa. 2002).

²⁵*Frederick L.*, 364 F.3d at 496.

²⁶*Id.* at 495.

²⁷*Id.* The court’s concern about community opposition was based on passing remarks by a witness. *Frederick L.*, 217 F. Supp. 2d at 589. In my view, prejudice against people with disabilities is not a permissible basis for claiming that complying with the ADA’s integration mandate is impossible. Cf. *Palmore v. Sidoti*, 466 U.S. 429, 434 (1984) (holding that the potential harms that racial prejudice might cause may not be considerations in determining whether divesting mother of custody of her child based on her remarriage to an African American violates the equal protection clause).

²⁸*Fisher*, 335 F.3d at 1182–83.

²⁹*Id.* at 1183 (quoting H.R. REP. NO. 101-485, pt. 3, at 50, reprinted in 1990 U.S.C.C.A.N. 445, 473).

³⁰*Id.* at 1177–78.

ment in a nursing home.³¹ The Tenth Circuit rejected the state's argument that changing its policy would have required a fundamental alteration simply because it was in the midst of a fiscal crisis.³²

In *Townsend v. Quasim* the Ninth Circuit also rejected the argument that additional costs of community placement necessarily would result in a fundamental alteration.³³ In *Townsend* plaintiffs challenged the State of Washington's refusal to extend its community-based Medicaid waiver services to cover Medicaid recipients who were "medically needy," that is, recipients with slightly higher incomes who were eligible for Medicaid by spending down their incomes on medical services.³⁴ The state argued that extending community-based services to medically needy individuals might require it to apply for additional Medicaid waivers, burdening the state's fisc and compelling significant cuts in Medicaid services for other individuals.³⁵ The court refused to accept these generalized concerns as sufficient evidence to establish a fundamental alteration and held that "even if extension of community-based long term care services to the medically needy were to generate greater expenses for the state's Medicaid program, it is unclear whether these extra costs would, in fact, compel cutbacks in services to other Medicaid recipients."³⁶ The court remanded for consideration of whether the costs of providing community services to the plaintiffs would in fact result in cutbacks for others.³⁷

Similarly in *Makin* the court refused to accept the state's generalized concerns about additional costs of services. Plaintiffs—individuals with mental retardation who were on the state's waiting list for mental retardation waiver services—challenged the state's failure to expand its waiver to provide community-based services for more individuals.³⁸ The state argued that the relief plaintiffs sought would require it to create an unlimited community-based program for individuals with retardation and that the relief would cause it to exceed the waiver cap and force it to forgo federal funds for the additional waiver services.³⁹ The court rejected this defense and stated that "[t]hese arguments fail to show how the modification would fundamentally alter the program, since it merely argues that the State would potentially have a problem funding it."⁴⁰

In one early case, *Williams v. Wasserman*, decided before the law in this area began to develop, the district court accepted the state's fundamental alteration defense based in part on the immediate costs of providing the plaintiffs with community services and the lack of concomitant cost savings to offset those costs immediately.⁴¹ Assuming incorrectly that plaintiffs were demanding "immediate" services, the court noted that it would take three to five years to realize the savings from moving individuals from institutional to community settings and in the meantime the state would be required to "double-fund" institutional and community beds.⁴² However,

³¹*Id.*

³²*Id.* at 1182–83.

³³*Townsend v. Quasim*, 328 F.3d 511, 519–20 (9th Cir. 2003).

³⁴*Id.* at 514–15.

³⁵*Id.* at 519.

³⁶*Id.* at 520.

³⁷*Id.*

³⁸*Makin*, 114 F. Supp. 2d at 1020.

³⁹*Id.* at 1034. The court correctly noted that the state could simply apply for an expanded waiver and presumably would not have to use 100 percent state funding for the additional waiver services provided. *Id.*

⁴⁰*Id.*

⁴¹*Williams v. Wasserman*, 164 F. Supp. 2d 591, 633–38 (D. Md. 2001).

⁴²*Id.* at 637, 638.

even in this case the court did not consider the immediate cost of placement sufficient by itself to constitute a fundamental alteration. The conclusion that providing community services for the plaintiffs would be a fundamental alteration was based on the three- to five-year period that would pass before the state would recoup the costs of community placement, on the progress Maryland had made in developing community services for others, and on the state's need to maintain a minimum number of hospital beds.⁴³ Moreover, the court did not explain why spending money on community services that would not be immediately offset by cost savings would be unreasonable for the state.

All of these cases suggest that the possibility that community placement might require an outlay of funds is not sufficient to establish that it would constitute a fundamental alteration. However, the case law has not addressed in detail the question of how much community placement may cost before becoming a fundamental alteration. In *Frederick L.* plaintiffs' requested relief would have cost the Department of Public Welfare only \$1 million—an extremely small amount in relation to the entire mental health budget. Yet, for reasons I discuss next, the court did not require the department to provide this relief. In short, the cases to date have offered little guidance on how much is too much.

2. What Is the Relevant Budget to Be Considered for the Fundamental Alteration Defense?

In determining whether shifting funds from other sources to develop more community-based services would be too costly for a state, what “available resources” are to

be taken into account must be established. *Olmstead* does not place any limitation on “available resources.” Accordingly all resources that the state could use, including federal Medicaid funds for a variety of services, federal housing funds such as Section 8 money, federal Ticket to Work funds, and other federal and state resources, may be considered.

However, in *Frederick L.* the Third Circuit held that, when determining whether other funds might be used for community services for individuals with mental illness, the relevant funds to consider were those with a nexus to mental health services.⁴⁴ The court rejected the plaintiffs' argument that the appropriate budget was the entire budget of the Department of Public Welfare rather than merely the mental health portion of that budget and concluded that “[the department's] myriad non-mental health responsibilities, which include cash welfare distribution, medical assistance, food stamps provision, youth centers, forestry camps, and chaplaincies, have no nexus to the ‘care and treatment’ of the mentally ill described in *Olmstead*.”⁴⁵ This reading of *Olmstead* seems more limiting than what the Supreme Court intended. Nonetheless, some other courts have ruled similarly.⁴⁶

In many states the mental health, developmental disabilities, or other health service agency may not have the broad range of responsibilities of Pennsylvania's Department of Public Welfare. However, even under the Third Circuit's narrow reading of the fundamental alteration analysis, resources beyond the agency budget must be considered in the fundamental alteration analysis as long as they have a nexus to the provision of community services. For example, resources

⁴³*Id.* at 633–38.

⁴⁴*Frederick L.*, 364 F.3d at 496 n.6.

⁴⁵*Id.* (citing *Olmstead*, 527 U.S. at 587).

⁴⁶See, e.g., *Pennsylvania Protection and Advocacy v. Department of Public Welfare*, 243 F. Supp. 2d 184, 195 (M.D. Pa. 2003) (noting that *Olmstead* spoke of “available resources” only in the context of services for individuals with mental disabilities), appeal pending, No. 03-1461 (3d Cir. argued Oct. 26, 2004); *Sanchez*, No. C-00-01593 CW (JCS), slip op. at 44 n.17 (noting that only the state's already existing budget for individuals with developmental disabilities should be considered).

allocated for housing, general health services, and meal programs may all be said to have a nexus to the provision of community-based services for individuals with disabilities. Accordingly, even under the Third Circuit's narrow reading of "available resources," funding for these services should be considered as an "available resource" for purposes of the fundamental alteration defense, even if it is outside the scope of the disability service agency budget at issue.

3. How Is Cost-Shifting from Institutional to Community Settings Considered in the Fundamental Alteration Analysis?

To demonstrate that state or local governments may serve people with disabilities in more integrated settings without fundamentally altering their service systems, *Olmstead* plaintiffs typically show that institutional beds may be closed and funds used for those beds may be shifted to develop services in the community. Funds for developing community-based services may come from other sources as well, but plaintiffs are in a stronger position when they can demonstrate that defendants simply can shift funds currently used in an institutional setting to serve the same individuals in the community; serving the same individuals in the community is typically less expensive. This type of analysis does not require the court to decide whether requiring government agencies to remove funds from other projects to develop community services is appropriate. Defendants typically cannot demonstrate how shifting funds to serve the same individuals in community settings instead of institutions would harm others.

Both *Fisher* and *Townsend* make clear that states may not resist shifting funds to the development of community-based services to achieve compliance with *Olmstead* unless they demonstrate that shifting resources would compel cutbacks in services to other individuals. As I

described above, the Tenth and Ninth Circuits did not accept generalized statements about state budget woes or about the negative impact that developing community services for the plaintiffs would have on other individuals without specific proof that other individuals would lose services. If community services can be provided at the same or lower cost than institutional services, plaintiffs in integration-mandate cases should be readily able to show that funds can be shifted from institutional to community services without a fundamental alteration of the service system.

Nonetheless, this argument sometimes has proved more difficult for plaintiffs than anticipated. The *Frederick L.* plaintiffs argued that the Department of Public Welfare could have shifted money from institutional settings and other programs to fund community-based services.⁴⁷ The Third Circuit held that, to the extent that doing so would have required shifting money appropriated for institutional care, it would run afoul of *Olmstead* because it would have favored those bringing ADA integration suits at the expense of institutionalized individuals who did not sue.⁴⁸ The court stated that "[a]ny effort to institute fund-shifting that would disadvantage other segments of the mentally disabled population would thus fail under *Olmstead*."⁴⁹ The blanket acceptance of generalized assumptions that shifting funds would disadvantage other institutionalized individuals contradicts the approach in *Fisher* and *Townsend* of requiring the state to establish affirmatively how the relief plaintiffs seek would result in harm to others.

To the extent that the Third Circuit in *Frederick L.* was concerned that providing community services to the plaintiffs would result in their placement before individuals in other hospitals who did not sue, that other individuals remain unnecessarily institutionalized else-

⁴⁷*Frederick L.*, 364 F.3d at 497–98.

⁴⁸*Id.* at 497.

⁴⁹*Id.*

where in the state should not be the basis for determining that placing plaintiffs would be a fundamental alteration. Otherwise, winning an *Olmstead* case would be impossible for any plaintiff group. *Olmstead*'s concern about line jumping was merely that if a state had a comprehensive plan to move institutionalized individuals into community settings and if that plan was moving at a reasonable pace—something that the *Frederick L.* court found Pennsylvania had failed to do—then allowing those at the end of the waiting list to jump ahead of those in front of them by suing first would not be appropriate.⁵⁰

Perhaps the most troubling part of the *Frederick L.* decision is the Third Circuit's rejection of the plaintiffs' basic cost analysis—that the cost of community placements for the plaintiffs (\$6 million) would be offset by the cost savings to the state of closing hospital beds for those plaintiffs who were moved into the community (\$5 million, including the consideration of the fixed costs of the closed beds, according to the state's own expert), with a resulting net cost of \$1 million.⁵¹ The court held that "Appellants' cost comparisons ... are precisely the sort of reductive cost comparisons proscribed by the *Olmstead* plurality...."⁵² That statement is simply incorrect. *Olmstead* did not preclude this type of cost-shifting analysis. What *Olmstead* did preclude, as the Third Circuit noted earlier in its decision, was a comparison of the cost of providing community services for the plaintiffs against the entire budget or a simple comparison of the cost of institutional care with the cost of community services since the latter would not account for the fixed overhead costs of operating partially full institutions.⁵³ However, the *Frederick L.* plain-

tiffs' analysis did not do either. Instead, it considered the larger picture of the entire hospital and the fixed costs associated with closed beds, as required by *Olmstead*.

The only logical way to read this portion of the *Frederick L.* decision is to assume that the court did not realize (particularly in light of the scant factual evidence recited in the opinion) that the cost-shifting analysis already took into account the fixed costs of operating a partially full institution. The decision cannot mean that plaintiffs are not permitted to demonstrate that the state could shift costs from institutional to community settings and take into account the cost savings achieved from closing institutional beds. Such an interpretation would flatly contradict the *Olmstead* decision and would make it impossible for plaintiffs to prevail in integration-mandate cases.

The *Frederick L.* court also constrained the plaintiffs' ability to overcome the fundamental alteration defense in that case by considering the state's ability to use funds from sources other than institutional care. Plaintiffs had argued that the Department of Public Welfare could have requested more money for community-based services during budget negotiation.⁵⁴ However, the Third Circuit held that decisions made in the prebudgetary process were beyond judicial scrutiny because of "a recognition of the realities of the budgetary process."⁵⁵ This holding appeared to be based specifically on governor's guidelines that limited the percentage increase that the department might request for community services.⁵⁶ However, there is no reason why the prebudgetary process ordinarily should be beyond judicial scrutiny, and federal courts routinely have scrutinized state executive actions in civil rights cases.

⁵⁰*Olmstead*, 527 U.S. at 605–6; *Frederick L.*, 364 F.3d at 499–500.

⁵¹See *Frederick L.*, 364 F.3d at 497.

⁵²*Id.*

⁵³*Olmstead*, 527 U.S. at 603, 604 n.15; *Frederick L.*, 364 F.3d at 493.

⁵⁴See *Frederick L.*, 364 F.3d at 497.

⁵⁵*Id.*

⁵⁶*Id.*

The *Frederick L.* court rejected the argument that the Department of Public Welfare could have shifted funds from budget items not associated with community or institutional care—such as \$9.5 million spent on general salary increases for state psychiatric services personnel, \$2.5 million for contracted repairs, and \$372,000 for travel.⁵⁷ The court observed that “the judiciary is not well-suited to superintend the internal budgetary decisions of [the department] or evaluate its physical plant needs” and therefore declined to decide which costs were essential and which were not.⁵⁸ However, such decisions are not unlike decisions that courts are asked to make every day concerning the allocation of public funds. Courts also may use expert testimony to guide decision making. Thus other courts adopting this approach and refusing to review states’ decisions not to reallocate funds being used for purposes other than the direct provision of services to individuals with disabilities would be surprising.

4. Are States Required to Have a Plan?

The Court in *Olmstead* held that a state could establish a fundamental alteration defense if “the State were to 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.”⁵⁹ *Olmstead* explained the plan requirement in the context of a defense to integration claims.⁶⁰ But imagining how a state could establish a fundamental alteration defense without having a detailed plan to

identify individuals with disabilities who are unnecessarily institutionalized and determine what their needs are and how much it would cost to serve them in more integrated settings is difficult. To demonstrate that providing community services for plaintiffs would be so costly as to prevent the state from serving other people with disabilities evenhandedly, the state would need to know how many individuals are unnecessarily institutionalized, what services are needed for those individuals to live in the community, how much those services would cost, and how much money could be saved by closing institutional beds as community services are developed. As *Fisher* and *Townsend* demonstrate, a state may not rely on generalized statements that it would be too costly to develop community services or would interfere with the state’s ability to serve others but must specify justifications for those conclusions.

The *Frederick L.* decision affirmatively required the state to submit a detailed plan to the court to establish a fundamental alteration defense.⁶¹ Like the district court in *Williams v. Wasserman*, the court acknowledged Pennsylvania’s past progress in deinstitutionalizing individuals with disabilities.⁶² However, *Frederick L.* declined to assume that such past progress was probative of future plans to continue deinstitutionalizing.⁶³ The court rejected the state’s argument that its policies and procedures at Norristown State Hospital requiring ongoing review of patients and individualized discharge planning constituted a comprehensive plan as contemplated by *Olmstead*.⁶⁴ The court stated that Pennsylvania’s articulation of its plan “falls far short of the type of plan that we believe

⁵⁷*Id.* at 497–98.

⁵⁸*Id.* at 498.

⁵⁹*Olmstead*, 527 U.S. at 605–6.

⁶⁰*Id.*

⁶¹*Frederick L.*, 364 F.3d at 499–500.

⁶²*Williams*, 164 F. Supp. 2d at 633; *Frederick L.*, 364 F.3d at 499–500.

⁶³*Frederick L.*, 364 F.3d at 500.

⁶⁴*Id.*

the Court referred to in *Olmstead*.⁶⁵ It noted that what *Olmstead* requires “at the very least is a plan that is communicated in some manner ... requiring a commitment ... to take all reasonable steps to continue that progress.”⁶⁶ The court went on to observe:

It is a gross injustice to keep these disabled persons in an institution notwithstanding the agreement of all relevant parties that they no longer require institutionalization. We must reflect on that for more than a passing moment. It is not enough for [the Department of Public Welfare] to give passing acknowledgment of that fact. It must be prepared to make a commitment to action in a manner for which it can be held accountable by the courts.⁶⁷

5. How Must States Change Their Medicaid Programs to Comply with *Olmstead*?

Because Medicaid is such an important funding source for community-based services for individuals with disabilities and states receive federal reimbursement for a substantial share of the cost of Medicaid services, expansion of community-based Medicaid programs is often a key element in *Olmstead* cases. The Medicaid program affords states substantial flexibility in determining the amount, duration, and scope of services covered under their Medicaid plans, but the ADA’s integration mandate requires states to expand services in ways that the Medicaid statute itself does not require.

The plaintiffs in *Olmstead* sought community-based waiver services to which they were not entitled under the Medicaid statute as long as the state was providing the number of waiver slots that it had agreed to provide.⁶⁸ Nothing in *Olmstead* suggests that the ADA’s integration mandate must be read to exempt states from doing anything that the Medicaid statute does not already require them to do. Yet states have argued that altering the flexibility given to states under Medicaid would be a fundamental alteration.⁶⁹

However, courts have required states to make various changes in their Medicaid programs to comply with *Olmstead*. For example, in *Townsend* the Ninth Circuit rejected the argument that the ADA may not compel states to alter their Medicaid programs in ways not required by Medicaid and held that Washington was required to expand its community-based nursing home waiver program to include another population (“medically needy” Medicaid recipients) unless it could demonstrate that doing so would compel cutbacks to other Medicaid recipients.⁷⁰ In *Fisher* the Tenth Circuit held that Oklahoma was required to provide additional services in its community-based nursing home waiver program (prescription coverage above five prescriptions per month) unless it could demonstrate that providing such coverage would compel service cutbacks to others or otherwise be inequitable.⁷¹ In *Makin* the district court required Hawaii to expand its community-based waiver for individuals with developmental disabilities to serve

⁶⁵*Id.*

⁶⁶*Id.*

⁶⁷*Id.* On remand the district court reviewed the defendants’ plan submissions, which gave detailed accounts of the regional and statewide needs-planning processes, and concluded that they were sufficient to meet the requirements of *Olmstead*. *Frederick L.*, No. Civ. A. 00-4510, 2004 WL 1945565 (E.D. Pa. Sept. 1, 2004).

⁶⁸See 42 U.S.C. §§ 1396a(a)(8), 1396a(a)(10), 1396n(c) (2003). For cases holding that there is an entitlement to Medicaid waiver services as long as there are unfilled waiver slots, see, e.g., *Bryson v. Shumway*, 308 F.3d 79, 88–89 (1st Cir. 2002) (Clearinghouse No. 54,939); *Boulet v. Cellucci*, 107 F. Supp. 2d 61, 76–77 (D. Mass. 2000); *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1351 (S.D. Fla. 1999).

⁶⁹See, e.g., *Townsend*, 328 F.3d at 523–27 (Beezer, J., dissenting) (accepting state’s arguments that ADA does not trump Medicaid requirements or, alternatively, expanding Medicaid program would not be a reasonable modification under ADA).

⁷⁰*Id.* at 520.

⁷¹*Fisher*, 335 F.3d at 1182–83.

more people unless it could demonstrate that doing so would be a fundamental alteration.⁷²

One limitation that some courts have imposed is to read *Olmstead* not to require states to provide “new” services. This limitation was first articulated in *Rodriguez v. City of New York* in which the Second Circuit held that the ADA did not require a state to offer a new type of Medicaid service to comply with the integration mandate.⁷³ Thus the plaintiffs could not prevail on their *Olmstead* claim challenging the elimination of New York City’s “safety monitoring” services under Medicaid; plaintiffs claimed that eliminating those services would force them into nursing homes.⁷⁴ *Rodriguez* based its conclusion about new services on a footnote in *Olmstead* noting that states “must adhere to the nondiscrimination requirement with regard to the services they *in fact provide*.”⁷⁵ However, this footnote merely reflected the Court’s clarification that the ADA did not create an entitlement to a specific “standard of care” but instead required that, once a state chose to provide services, it must not discriminate by providing those services in an unnecessarily segregated setting.⁷⁶

A state may not characterize services as “new” if it already provided them to others, even if it provided them only in an institutional setting, the Ninth Circuit clarified.⁷⁷ The court observed:

Characterizing community-based provision of services as a new program of services not currently provided by the state fails to account for the fact that the state is already providing those very same services. If services were determined to constitute distinct programs based solely on the location in which they were provided, *Olmstead* and the integration regulation would be effectively gutted. States could avoid compliance with the ADA simply by characterizing services offered in one isolated location as a program distinct from the provision of the same services in an integrated location.⁷⁸

Under the Ninth Circuit’s reading, the only services that *Olmstead* never would require would be those, such as the safety monitoring services, not provided even in the institutional setting. Any service—such as meals, housing, mental health services, and personal assistance services—provided in an institution would not be a “new” service. The Tenth Circuit took a similar position in *Fisher*: “Given that Oklahoma has, until recently, provided unlimited prescriptions to participants in the Advantage program, and continues to do so for those living in nursing homes, receiving medically necessary prescriptions is clearly in the nature of Oklahoma’s [home- and community-based services Medicaid waiver] program.”⁷⁹

⁷²*Makin*, 114 F. Supp. 2d at 1034.

⁷³*Rodriguez v. City of New York*, 197 F.3d 611, 619 (2d Cir. 1999) (Clearinghouse No. 52,696); see also *Davis v. California Health and Human Services Agency*, No. C00-2352 SBA, slip op. at 2 (N.D. Cal. Aug. 21, 2001) (Clearinghouse No. 53,146) (granting motion to dismiss *Olmstead* claims to the extent that they “are intended or may be interpreted as requiring San Francisco to create new programs or services”).

⁷⁴*Rodriguez*, 197 F.3d at 619.

⁷⁵*Id.* (citing *Olmstead*, 527 U.S. at 603 n.14 (emphasis added)).

⁷⁶See *Olmstead*, 527 U.S. at 603 n.14.

⁷⁷*Townsend*, 328 F.3d at 517.

⁷⁸*Id.*

⁷⁹*Fisher*, 335 F.3d at 1183. Interestingly, the Tenth Circuit expressed doubt that a service that had been provided and was only recently eliminated, sparking litigation under *Olmstead*, could be considered a “new” service or one that would fundamentally alter a state’s service program. This contrasts with the Second Circuit’s view in *Rodriguez*. See *Rodriguez*, 197 F.3d at 619.

II. Litigation Successes

Olmstead litigation has achieved some significant successes.⁸⁰ Despite much talk about state and federal efforts to promote community integration after *Olmstead*, many individuals with disabilities find that the only means of securing an opportunity to move to more integrated settings in the foreseeable future is through litigation. Although *Olmstead* litigation is complex and difficult to undertake, it has brought some significant movement toward integration.⁸¹

Rolland v. Cellucci. In this class action litigation, filed in 1998 on behalf of more than 1,600 individuals with mental retardation and other developmental disabilities, plaintiffs challenged their unnecessary confinement in Massachusetts nursing homes and challenged the state's failure to provide specialized services, such as independent living skills and day habilitation, to individuals who were determined to need them.⁸² Plaintiffs survived a motion to dismiss; the district court's decision came less than three weeks before the Supreme Court's *Olmstead* decision.⁸³

In October 1999 the parties entered into a settlement agreement, which required the state to develop community-based services for up to 1,175 people over seven years, provide specialized services to all

class members who needed them (inside and outside nursing facilities), and establish a diversion plan to prevent unnecessary admissions to nursing homes and redirect at least 225 individuals through new residential programs and supports.⁸⁴ The court approved the settlement on January 10, 2000, after a fairness hearing.⁸⁵ As of November 2004 approximately 500 class members had moved to community settings.⁸⁶

Townsend v. Quasim. This class action lawsuit, discussed above, was filed in 2000 on behalf of "medically needy" Medicaid recipients (i.e., those who met Medicaid income eligibility requirements after spending down their income on medical services) who would be forced into nursing homes in Washington unless the state provided community-based services to them, as it provided to "categorically needy" Medicaid recipients (i.e., those who met Medicaid income eligibility requirements without having to spend down income).⁸⁷ The state had created a home- and community-based waiver for categorically needy recipients who would otherwise be served in nursing homes but offered only nursing home services for medically needy recipients with similar needs.⁸⁸ The district court granted summary judgment for defendants on the ground that the plaintiffs

⁸⁰I do not present a list of all *Olmstead* litigation that has resulted in movement into community settings or a list of all litigation seeking community-based services that has proceeded primarily under the Medicaid statute. See, e.g., *Sabree v. Richman*, 367 F.3d 180, 193–94 (3d Cir. 2004) (Clearinghouse No. 55,662) (holding that plaintiffs seeking services in small community-based intermediate care facilities for individuals with mental retardation could privately enforce right to receive services with reasonable promptness under Pennsylvania's Medicaid program). For a more nearly complete list of *Olmstead* and Medicaid litigation seeking community-based services, see Human Services Research Institute, Status Report: Litigation Concerning Home and Community Services for People with Disabilities (updated Oct. 2004), <http://hsri.org/index.asp?id=news> (a revised report is issued every four to six weeks).

⁸¹Three of the cases I discuss—*Rolland v. Cellucci*, *Makin v. Hawaii*, and *Travis D. v. Eastmont Human Services Center*—were filed before the Supreme Court decided *Olmstead*, but the *Olmstead* decision was critical to the settlements negotiated in each case.

⁸²*Rolland v. Cellucci*, 52 F. Supp. 2d 231, 234, 235, 236–37 (D. Mass. 1999) (Clearinghouse No. 52,838).

⁸³*Id.* at 233–43.

⁸⁴*Rolland*, 191 F.R.D. 3, 7 (D. Mass. 2000) (see Clearinghouse No. 52,838G).

⁸⁵*Id.* at 4–16.

⁸⁶E-mail from Steven Schwartz, Executive Director, Center for Public Representation, to Jennifer Mathis, Senior Staff Attorney, Bazelon Center for Mental Health Law (Nov. 5, 2004) (on file with Jennifer Mathis).

⁸⁷*Townsend*, 328 F.3d at 514–15.

⁸⁸*Id.* at 514.

were requesting new services that the state did not currently provide.⁸⁹ The Ninth Circuit, reversing the district court, concluded that the services that plaintiffs sought were not a new benefit and required the state to demonstrate how providing these services would compel cutbacks in services to other Medicaid recipients.⁹⁰

On January 16, 2004, the parties stipulated to an agreement whereby the proceedings would be stayed until June 2006 and the defendants would serve 600 individuals at any given time in a community-based nursing home waiver for medically needy Medicaid recipients, apply to reactivate their in-home services nursing home waiver for medically needy recipients (which was reactivated in May 2004), and serve 200 individuals at any given time in the in-home waiver.⁹¹

Fisher v. Oklahoma Health Care Authority. In this case, also discussed above, three individuals who had disabilities and were in Oklahoma's Advantage Program, a community-based waiver program for Medicaid recipients who would otherwise be served in nursing homes, challenged the state's decision to limit coverage of prescription medications for individuals in the Advantage Program to five per month while continuing its unlimited prescription medication coverage for Medicaid recipients in nursing homes.⁹² As a result of the state's decision to stop

unlimited prescription coverage in the waiver program, plaintiffs would be forced to move into nursing homes.⁹³

The district court dismissed plaintiffs' *Olmstead* claim on the ground that *Olmstead* did not apply to individuals who were not currently institutionalized.⁹⁴ The Tenth Circuit, reversing the district court and remanding, allowed plaintiffs to proceed with their *Olmstead* claim and held that the state was required to restore unlimited prescription coverage in the waiver program unless it could demonstrate that doing so would be a fundamental alteration.⁹⁵ The case was settled following the Tenth Circuit's decision, and the state agreed to provide unlimited prescription coverage in the waiver program, with prior authorization required for prescriptions beyond the first five.⁹⁶

Miranda B. v. Kitzhaber. This class action litigation was filed in 2000 on behalf of more than 100 individuals who had mental illness and challenged their unnecessary confinement in the state psychiatric hospital and defendants' failure to provide adequate placements in the community.⁹⁷ Each of the plaintiffs had been found to be ready for discharge but was still at the hospital because of insufficient community facilities.⁹⁸ Plaintiffs prevailed on a motion to dismiss, which defendants appealed to the Ninth Circuit.⁹⁹ The circuit court upheld the plaintiffs' claims and remanded for trial.¹⁰⁰

⁸⁹*Townsend*, 163 F. Supp. 2d 1281, 1286–87 (W.D. Wash. 2001).

⁹⁰*Townsend*, 328 F.3d at 517, 519.

⁹¹Stipulated Agreement for Stay of Proceedings ¶¶ 2, 3, 4, 9, *Townsend*, No. 00-0944Z (Jan. 16, 2004); WASH. ADM. CODE § 388-515-1550 (2004).

⁹²*Fisher*, 335 F.3d at 1177–78.

⁹³*Id.*

⁹⁴*Id.* at 1180.

⁹⁵*Id.* at 1183, 1184.

⁹⁶E-mail from Stephen Gold, Plaintiffs' Counsel in *Fisher*, to Jennifer Mathis, Senior Staff Attorney, Bazelon Center for Mental Health Law (Nov. 5, 2004) (on file with Jennifer Mathis).

⁹⁷*Miranda B. v. Kitzhaber*, 328 F.3d 1181, 1183 (9th Cir. 2003) (Clearinghouse No. 54,481).

⁹⁸*Id.*

⁹⁹*Id.* at 1183–84.

¹⁰⁰*Id.*

The parties entered into a settlement agreement in December 2003, and the court approved the agreement on March 8, 2004.¹⁰¹ The defendants agreed to create seventy-five new community placements in 2003–2005 and create a fund of \$1.5 million to assist in placing those who had “exceptional barriers to placement,” including those with significant medical conditions, traumatic brain injury, or a history of significant substance abuse, assaultive behavior, or sexual offense.¹⁰² The defendants also agreed to implement a special review process for anyone who had been ready to be placed for more than 180 days yet remained in the hospital and to discharge at least thirty-one class members (of a total of sixty-nine) during the 2003–2005 biennium.¹⁰³

Staley v. Kulongoski. Filed in January 2000 on behalf of five individuals with developmental disabilities and the Arc of Oregon and later expanded to a class action, this lawsuit challenged Oregon’s failure to provide home- and community-based services to eligible individuals with developmental disabilities.¹⁰⁴ The parties entered into a settlement agreement, which the court approved on December 14, 2000, after a fairness hearing.¹⁰⁵ The settlement, which initially was to terminate in 2007, provided that the defendants would furnish non-

crisis “comprehensive services,” including twenty-four-hour residential services, to 50 people per year, for a total of 300 during the life of the agreement.¹⁰⁶ It also provided that all eligible people on the state’s waiting list would receive support services, defined as “in-home and personal supports costing up to \$20,000 per year.”¹⁰⁷ These support services were to be phased in over approximately four years.¹⁰⁸

Due to the state’s severe budget crisis, the parties obtained court approval in January 2004 to modify the agreement.¹⁰⁹ The same number of people would be served, but the services would be phased in over a longer time period. The state is required to implement the modified agreement fully by 2009. As of November 2004, approximately 3,500 people had received support services under the agreement and fewer than 20 had received comprehensive services, which have a longer phase-in period.¹¹⁰

Makin v. Hawaii. This class action litigation, discussed above, was filed in 1998 on behalf of approximately 700 individuals with developmental disabilities on waiting lists for community-based waiver services in Hawaii.¹¹¹ After the district court denied summary judgment for the state on plaintiffs’ *Olmstead* claims, the case was settled in April 2000.¹¹² The

¹⁰¹Settlement Agreement, *Miranda B. v. Kulongoski*, No. CV00-1753-HU (D. Or. Dec. 2003).

¹⁰²*Id.* at 5–7.

¹⁰³*Id.* at 6.

¹⁰⁴*Staley v. Kulongoski*, No. CV-00-0078-ST (D. Or. filed Jan. 2000) (Clearinghouse No. 53,008).

¹⁰⁵Order Granting Final Approval of Class Settlement and Dismissing Class Claims, *Staley v. Kulongoski*, No. CV00-0078-ST (D. Or. Dec. 14, 2000).

¹⁰⁶Settlement Agreement at 3, 4, 9, 13, *Staley v. Kitzhaber*, No. CV00-0078-ST (D. Or. Sept. 11, 2000) (see Clearinghouse No. 53008B).

¹⁰⁷*Id.* at 3, 6.

¹⁰⁸*Id.* at 7.

¹⁰⁹Order Granting Final Approval of Settlement Modification Agreement, *Staley v. Kulongoski*, No. CV-00-0078-ST (D. Or. Jan. 14, 2004).

¹¹⁰*Id.* at 2, 3; E-mail from Kathleen Wilde, Litigation Director, Oregon Advocacy Center, to Jennifer Mathis, Senior Staff Attorney, Bazelon Center for Mental Health Law (Nov. 9, 2004) (on file with Jennifer Mathis).

¹¹¹*Makin*, No. CV 98-00997 DAE (D. Haw. filed Dec. 21, 1998); Hawaii Disability Rights Center, General Information: HRDC News (Aug. 1, 2003), www.hawaiidisabilityrights.org/General_NewsDetail.aspx?nid=1009.

¹¹²Settlement, Release, and Defense and Indemnity Agreement, *Makin*, No. CV 98-00997 DAE (D. Haw. Apr. 25, 2000).

defendants agreed, among other points, to provide waiver services to 700 people by the end of June 2003, use best efforts to obtain appropriations from the legislature and approval from the federal government to expand the waiver, and develop a comprehensive plan to provide community-based services to individuals on the waiting list at a reasonable pace after June 2003.¹¹³

In September 2003 the plaintiffs' counsel reported that the defendants had failed to comply with the *Makin* settlement agreement by, among other ways, failing to use Medicaid funds that had been appropriated for waiver services, failing to provide services to all of the initial 700 class members, improperly persuading individuals to "defer" their waiver services, and failing to provide services at a reasonable pace.¹¹⁴ A new class action lawsuit was filed on behalf of more than 300 individuals challenging those practices and seeking to have the state eliminate the practice of deferral and reinstate deferred individuals to the waiting list, stop returning or misusing funds allocated for waiver services, and ensure that individuals are not kept on a waiting list for more than six months.¹¹⁵ As of November 2004, the parties were attempting to negotiate a settlement.

Davis v. California Health and Human Services Agency. In this class action litigation filed in 2000 plaintiffs with mental illness, developmental disabilities, and phys-

ical disabilities sued the City of San Francisco and the State of California for violating the integration mandate by unnecessarily institutionalizing them in Laguna Honda Hospital and Rehabilitation Center, a nursing home that houses more than 1,000 individuals.¹¹⁶ Plaintiffs survived a motion to dismiss their claims under the ADA and Section 504 of the Rehabilitation Act, although the court struck the complaint's allegations suggesting that the defendants were required to create new services in the community.¹¹⁷

On March 30, 2004, the court approved settlements between the plaintiffs and the city and state defendants.¹¹⁸ The state defendants agreed to modify the preadmission screening process for nursing home residents with mental disabilities to ensure that it identified community resources for which the individuals were qualified and specific reasons why nursing facility services were needed and why those services could not be provided in the community.¹¹⁹ The city defendants agreed to set up a targeted case management unit to screen and assess the needs of Laguna Honda residents, individuals on waiting lists for admission to Laguna Honda, and individuals in San Francisco hospitals eligible for discharge to Laguna Honda and assist with service and discharge planning and link them with community-based services.¹²⁰ Assessments and discharge plans for approximately 500 residents should be completed by early 2005.¹²¹

¹¹³*Id.* at 7, 9.

¹¹⁴Hawaii Disability Rights Center, A Report on Compliance with the *Makin v. State of Hawaii* Class Action Settlement Agreement, External Draft 1 (Sept. 2003), available at www.hawaiidisabilityrights.org/Forms/MakinReportOfFindings9.18.03.doc.

¹¹⁵First Amended Complaint, *Hawaii Disability Rights Center v. Hawaii*, Civ. No. 03-00524 HG-KSC (D. Haw. filed Oct. 21, 2003), available at [www.hawaiidisabilityrights.org/Forms/SMComplaint10.01.03\(web\).doc](http://www.hawaiidisabilityrights.org/Forms/SMComplaint10.01.03(web).doc).

¹¹⁶Third Amended Complaint for Declaratory and Injunctive Relief ¶¶ 1-4, *Davis*, No. C00-2532 SBA (N.D. Cal. filed Dec. 18, 2003).

¹¹⁷*Davis*, No. C00-2352 SBA, slip op. at 6; 29 U.S.C. § 794.

¹¹⁸Order Granting Final Approval of the Settlement Agreements, *Davis*, No. C00-2532 SBA (N.D. Cal. March 30, 2004).

¹¹⁹Settlement Agreement Between Plaintiffs and State Defendants ¶¶ 2-5, *Davis*, No. C00-2532 SBA (N.D. Cal. Dec. 2003).

¹²⁰Settlement Agreement Between Plaintiffs and Defendant City and County of San Francisco ¶¶ 3.0-6.7, *Davis*, No. C00-2532 SBA (N.D. Cal. Dec. 12, 2003).

¹²¹Based on my conversations with *Davis* cocounsel.

The court dismissed without prejudice the plaintiffs' claims that the city and state failed to develop sufficient community capacity to serve class members in more integrated settings, but plaintiffs expect to refile them in 2005, when the assessments of Laguna Honda residents should be completed.¹²² The U.S. Department of Justice conducted its own investigation of the city and state for violations of the integration mandate and concluded that both the city and the state violated *Olmstead* by unnecessarily institutionalizing a large number of Laguna Honda residents who were willing and able to live in the community.¹²³

Travis D. v. Eastmont Human Services Center. This class action lawsuit was filed on behalf of individuals with mental retardation and other developmental disabilities in 1996, long before the Supreme Court's *Olmstead* decision.¹²⁴ The plaintiffs challenged their unnecessary confinement in Montana's developmental centers.¹²⁵ In 2003 the state closed one of its developmental centers and transferred some individuals to the community and others to the remaining developmental center, Montana Developmental Center. In 2004 the case was finally settled.¹²⁶ At settlement, the class that the court approved included 200 individuals who had been institutionalized

between August 1996 and February 2004.¹²⁷

The settlement provided, among other points, for the development of community services for forty-five residents of the Montana Developmental Center (approximately one-half of the class members who remained institutionalized), the closure of two of the center's units, a legislative proposal by the defendants to eliminate a statutory provision that allowed individuals to be committed to the center too easily, community services for class members who moved out of the center but had not been receiving them, crisis prevention funding to prevent unnecessary institutionalization, and various measures to facilitate the discharge of additional center residents.¹²⁸

III. Federal Efforts to Facilitate *Olmstead* Compliance

In addition to interpreting the ADA's integration mandate, the federal government has provided various sources of funding designed to facilitate states' efforts to comply with *Olmstead*.¹²⁹ The primary federal grant program that has allowed states to act on community integration initiatives for people with disabilities is the Centers for Medicare and Medicaid

¹²²Order Granting Final Approval of the Settlement Agreements at 2, *Davis*, No. C00-2532 SBA.

¹²³See Letter from R. Alexander Acosta, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, to Arnold Schwarzenegger, Governor of California, 2-3, 7, 8, 23, 24, www.usdoj.gov/crt/split/documents/laguna_honda_findlet_aug3.pdf (Aug. 3, 2004) (on file with Jennifer Mathis) (findings letter concerning state); Letter from Ralph F. Boyd, Jr., Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, to Dennis J. Herrera, City Attorney, City and County of San Francisco, 3, 7-8, 9, 22, www.usdoj.gov/crt/split/documents/launa_honda_hosp.pdf (April 1, 2003) (on file with Jennifer Mathis) (findings letter concerning city).

¹²⁴Class Action Settlement Agreement at 2, *Travis D. v. Eastmont Human Services Center*, No. CV-96-63-H-CSO (D. Mont. Feb. 5, 2004).

¹²⁵*Id.*

¹²⁶*Id.*

¹²⁷E-mail from Andree Larose, Staff Attorney, Montana Advocacy Program, to Jennifer Mathis, Senior Staff Attorney, Bazelon Center for Mental Health Law (Nov. 10, 2004) (on file with Jennifer Mathis).

¹²⁸Class Action Settlement Agreement, Exhibit B, at 1, 4-11, 13-14, 15-17, 18, *Travis D.*, No. CV-96-63-H-CSO.

¹²⁹See, e.g., Brief for the United States as Amicus Curiae Supporting Respondents in *Olmstead v. L.C.*, 1999 WL 149653, at *8-9 (Mar. 15, 1999) (arguing that ADA's integration regulation prohibited states from unnecessarily institutionalizing people with disabilities where state treatment professionals' reasonable professional judgments were that community placement was available and where such placement would not require a fundamental alteration of the state's treatment program); series of guidance letters from U.S. Centers for Medicare and Medicaid Services and Office for Civil Rights of the Department of Health and Human Services to State Medicaid Director, www.cms.hhs.gov/states/letters/smd1140a.asp, www.cms.hhs.gov/states/letters/smd72500.asp, www.cms.hhs.gov/states/letters/smd725a0.asp, www.cms.hhs.gov/states/letters/smd11001.pdf, www.cms.hhs.gov/states/letters/smd110a1.pdf (dates vary).

Services' systems change grant program.¹³⁰ These grants are designed to help states develop infrastructure to enable the transition of individuals from institutional to community settings. They are not intended to support the movement of large numbers of individuals from institutional to community settings.

That the federal government has offered financial support to assist states in accomplishing the critical task of planning and developing necessary infrastructure to support change is encouraging. However, much of this money has gone to support planning meetings and small pilot projects. Notably the National Council on Disability has recommended refocusing the real choice systems grant program (the largest part of the systems change program) "as a true systems-change project by shifting from funding demonstration projects to funding change that affects entire service systems."¹³¹

Other federal measures to promote *Olmstead* compliance include a comprehensive effort by federal agencies, pursuant to President Bush's Executive Order 13217, to identify federal laws, regulations, policies, and practices that impede community participation by peo-

ple with disabilities.¹³² *Delivering on the Promise* compiles the reports of the various agencies.¹³³ The reports identified such systemic problems as Medicaid's "institutional bias," a huge unmet need for affordable and accessible housing, and the lack of trained staff to provide services to individuals with disabilities.¹³⁴

While *Delivering on the Promise* holds much potential for long-range planning to promote community integration, it does not offer many immediate solutions that would result in significant movement of individuals with disabilities into more integrated settings. The National Council on Disability offered this criticism: "[M]ost of the proposed agency actions consisted of technical assistance, training, research, demonstration, policy review, public awareness campaigns, outreach, enforcement of existing regulations, information dissemination, convening of advisory committees, and interagency coordination and collaboration. Systemic solutions, measurable goals, timelines, deliverables, and outcomes were lacking."¹³⁵

In 2003 the President's New Freedom Commission on Mental Health published a set of goals and recommendations to

¹³⁰Wendy Fox-Grage et al., National Conference of State Legislatures, The States' Response to the *Olmstead* Decision: A 2003 Update 3 (2004), available at www.ncsl.org/programs/health/forum/olmstead/2003/03olmstd.pdf. Systems change grants include nursing facility transitions grants (supporting state initiatives to transition nursing home residents to community settings), community-integrated personal assistance services and supports grants (supporting the provision of consumer-directed personal assistance services), real choice systems grants (supporting the design and implementation of community-based long-term care services), and national technical assistance exchange for community living grants (giving technical assistance and training to states, consumers, families, and others). Press Release, U.S. Department of Health and Human Services, Administration Announces Steps to Promote Community Living for People with Disabilities (March 25, 2002), www.hhs.gov/news/press/2002pres/20020325a.html (on file with Jennifer Mathis) (listing the different types of grants).

¹³¹National Council on Disability, *supra* note 5, at 8 (Section VI: Conclusions and Recommendations—Recommendation No. 7).

¹³²Exec. Order 13217, 66 Fed. Reg. 33,155 (June 18, 2001), reprinted in 42 U.S.C. § 12131 notes (2003). This executive order was part of President Bush's New Freedom Initiative to eliminate barriers that prevent individuals with disabilities from participating fully in community life. See U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, DELIVERING ON THE PROMISE, PRELIMINARY REPORT OF FEDERAL AGENCIES' ACTIONS TO ELIMINATE BARRIERS AND PROMOTE COMMUNITY INTEGRATION (2001), www.hhs.gov/newfreedom/presidentrpt.html; see also George W. Bush, The White House, New Freedom Initiative (2001), www.whitehouse.gov/news/freedominitiative/freedominitiative.html.

¹³³DELIVERING ON THE PROMISE: COMPILATION OF INDIVIDUAL FEDERAL AGENCY REPORTS OF ACTIONS TO ELIMINATE BARRIERS AND PROMOTE COMMUNITY INTEGRATION (2002), available at www.hhs.gov/newfreedom/final/.

¹³⁴U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, DELIVERING ON THE PROMISE: SELF-EVALUATION TO PROMOTE COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES ch. 3 at 21–22 (last revised April 15, 2002), in DELIVERING ON THE PROMISE, *id.*; U.S. DEPARTMENT OF JUSTICE, DELIVERING ON THE PROMISE: SELF-EVALUATION TO PROMOTE COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES ch. 1 at 5 (last revised April 21, 2002), in DELIVERING ON THE PROMISE, *id.*

¹³⁵National Council on Disability, *supra* note 5, at 4 (Executive Summary, Delivering on the Promise ¶ 2).

improve the broken mental health systems across the country. Among the many integration-focused recommendations in this report, entitled *Achieving the Promise*, were demonstration programs that would provide community-based services to children now served in residential treatment centers, allow funding to follow an individual from an institutional setting to the community, and enhance supported employment opportunities for individuals with disabilities.¹³⁶ The report states:

The Commission calls for swiftly eliminating unnecessary and inappropriate institutionalization that severely limits integrating adults with serious mental illnesses and children with serious emotional disturbances into their communities. Federal, State, and local entities must continue to implement *Olmstead* and ensure full community integration for all individuals with psychiatric disabilities. The Commission urges the HHS [U.S. Department of Health and Human Services] Office for Civil Rights (OCR) to follow through on the current *Olmstead* voluntary compliance initiatives, including widely disseminating information about *Olmstead* compliance and promoting community care, technical assistance for States, and clarifying Medicaid policies that affect individuals with serious mental illnesses.¹³⁷

While federal agencies and federally convened bodies widely recognize that much work remains to be done to ensure that individuals with disabilities are served in the most integrated settings appropriate to their needs, federal efforts have been

focused primarily on identifying barriers and creating infrastructure necessary to achieve and sustain change in the long term. In the meantime, more immediate efforts are needed to ensure that, for many people with disabilities, the “promise” of community living comes within their lifetimes.

IV. State *Olmstead* Compliance Efforts

Most striking about efforts to implement *Olmstead* is how much time state-based coalitions have spent developing plans designed to facilitate community integration of individuals with disabilities and how little actual movement has been accomplished through most states’ planning efforts. These planning efforts were undertaken primarily as a response to *Olmstead*’s holding that states would have a defense to the integration mandate if they could demonstrate that they had a comprehensive, effectively working plan that moved individuals from institutional to community settings at a reasonable pace and was not driven by a desire to keep institutional beds full.¹³⁸

As I detailed in my 2001 CLEARINGHOUSE REVIEW article, states’ *Olmstead* planning efforts typically yield few meaningful results because they do not specify time frames for identifying individuals who are unnecessarily institutionalized, assessing their needs, and moving them into more integrated settings; do not require appropriate assessment of individuals’ needs; and do not commit to fund plan recommendations.¹³⁹ Also, no doubt because part of the purpose of these plans is to create a defense that states have done enough to avoid liability, many of the plans contain more recitations of past efforts than specific steps to be taken.

¹³⁶PRESIDENT’S NEW FREEDOM COMMISSION ON MENTAL HEALTH, DHHS PUB. NO. SMA-03-3832, *ACHIEVING THE PROMISE: TRANSFORMING MENTAL HEALTH CARE IN AMERICA*, FINAL REPORT (2003), available at www.mentalhealthcommission.gov/reports/FinalReport/toc.html.

¹³⁷*Id.* at 45–46.

¹³⁸*Olmstead*, 527 U.S. at 605–6.

¹³⁹Mathis, *supra* note 1, at 407–9.

As states have continued to develop their plans for implementing *Olmstead*, more has been accomplished. The latest report of the National Conference of State Legislatures on this topic indicates that twenty-nine states have now issued *Olmstead*-related plans or reports.¹⁴⁰ However, the report goes on to state that budget shortfalls and declining revenues have continued to delay *Olmstead* implementation, and states implemented primarily low-cost or cost-neutral solutions.¹⁴¹ Those included (1) efforts in ten states to promote consumer-directed care by allowing consumers to use government funds to manage care workers of their choosing (using existing community-based waiver funds and “Independence Plus” waivers), (2) efforts in twenty-five states to move more residents of nursing homes and institutions for individuals with developmental disabilities into the community or divert people from unnecessary institutional placements during hospital discharge planning (through pilot nursing home waiver or transition projects and “money follows the person” programs allowing funds to follow institutional residents into the community), and (3) consumer information and outreach efforts in twelve states.¹⁴² Little information is given about the numbers of individuals who moved from institutional to community settings in each state.

States apparently have viewed plans to expand community-based services as a drain on resources rather than a cost-saving measure either because they have been unwilling to close institutional beds or they have considered the savings from closing institutional beds to be too remote to offset immediately the costs of increasing community services. The National Conference of State Legislatures notes that states cited the “dismal fiscal situation” as the most significant barrier to *Olmstead* implementation and that new state appropriations would be needed to accomplish plan recommendations to increase the number of waiver slots or residential settings available in the community.¹⁴³ However, adopting a slightly less short-term financial view and a willingness to close more institutional beds would make it possible for states to view compliance with *Olmstead* as a cost-saving measure.¹⁴⁴ As long as states view it instead as a depletion of needed resources, they are unlikely ever to make *Olmstead* compliance a significant priority.

The National Conference of State Legislatures acknowledges that, during the past several years, “new initiatives to better serve people with mental illness have been minimal,” although in the conference’s most recent survey eighteen states described efforts to improve the quality of mental health services.¹⁴⁵

¹⁴⁰As of November 2004 when I wrote this article, the most recent report was Grage et al., *supra* note 130. Previous reports can be found on the National Conference of State Legislatures’ www.ncsl.org/programs/health/forum/olmsreport.htm.

¹⁴¹Grage et al., *supra* note 130, at 4–5.

¹⁴²*Id.* at 5–6.

¹⁴³*Id.* at 5.

¹⁴⁴See, e.g., James W. Conroy, *Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?* 151 (2002) (“All studies published thus far are consistent.... Community service models are less costly than institutional models.”). While states sometimes cite Medicaid obligations to keep institutional beds open, nothing in the Medicaid statute precludes states from limiting the number of institutional beds financed, with the exception of nursing home beds, which must be provided to the extent that they are needed by Medicaid recipients who want them. 42 U.S.C. § 1396a(a)(10) (2002). Of course, Medicaid recipients who are eligible for nursing facility services may choose instead home- or community-based services through a Medicaid nursing home waiver if they can live appropriately in the community. *Id.* § 1396n(c). However, most nursing home residents in most states never are given that choice because waiver services are made available only to a limited extent. The number of nursing home beds could be greatly reduced if states actually took steps to identify which institutional residents could be served appropriately in the community, assessed what services they would need to live in the community, and presented them with a meaningful choice of community versus institutional services. See, e.g., Acosta, *supra* note 123, at 2–3 (findings concerning state); Boyd, *supra* note 123, at 2 (findings concerning city) (concluding that city and state failed to ensure that nursing home residents’ needs and appropriateness for community living were properly assessed and to inform residents of community options, that a large number of residents could appropriately live in the community, and that there did not appear to be any documented need to rebuild the facility with 1,200 beds as planned).

¹⁴⁵Grage et al., *supra* note 130, at 7.

However, most of these initiatives do not contain discrete action plans and funding to move individuals from institutional to community-based settings. Moreover, some of the efforts demonstrate something less than a strong commitment to *Olmstead* compliance. The conference report cites New York's attempts to address the problem of substandard care for individuals with mental illness in adult homes.¹⁴⁶ After decades of abuse, neglect, and squalid conditions chronicled repeatedly in government investigation reports, and most recently in a series of front-page *New York Times* articles, the state considered measures to expand community services and to improve conditions in the adult homes.¹⁴⁷ However, these measures were inadequate.¹⁴⁸ Thus an *Olmstead* lawsuit challenged the state's use of these large, institutional facilities to serve people with mental illness. The suit, filed in July 2003, seeks to have the state develop community services for New York City adult home residents who can and want to live in more integrated settings.¹⁴⁹

The National Conference of State Legislatures highlights Washington's closure of 178 psychiatric state hospital beds.¹⁵⁰ At least in Pierce County, where litigation is proceeding against the state concerning the closure of state hospital beds without concomitant development of community services, beds appear to have been closed without the state having adequately considered community-serv-

ice needs.¹⁵¹ Thus the closures appear to have been more cost-saving measures than genuine integration efforts. An expert report in the *Pierce County* case stated that, as a result of the closures, many residents of Western State Hospital have been discharged without appropriate services, only to be readmitted to the hospital within a short time.

Most states' *Olmstead* implementation plans do not address the placement of large number of individuals with disabilities in privately operated institutions that are funded, licensed, regulated, and used by states as part of their mental health or other disability service systems. The failure to consider privately operated facilities in *Olmstead* implementation planning has permitted the transinstitutionalization of people from psychiatric hospitals, developmental centers, and other facilities to privately operated institutions, such as nursing homes and board and care homes. In some states, such as New York, Connecticut, Ohio, and Illinois, some privately operated nursing homes even have created locked units for individuals with mental illness or "privilege" systems that restrict mentally ill residents' freedom to leave the facility.

As I noted above, the National Council on Disability, in its report on *Olmstead* implementation, observed that huge numbers of individuals with disabilities remain unnecessarily institutionalized in nursing homes, institutions for individ-

¹⁴⁶*Id.* at 7.

¹⁴⁷See, e.g., these three articles by Clifford J. Levy: *For Mentally Ill, Death and Misery*, *NEW YORK TIMES*, April 28, 2002, § 1, at 1; *Here, Life Is Squalor and Chaos*, *id.*, April 29, 2002, at A1; *Voiceless, Defenseless, and a Source of Cash*, *id.*, April 30, 2002, at A1. See also Complaint ¶¶ 26–32, 77–117, *Disability Advocates v. Pataki*, No. 03cv3209(NGG) (E.D.N.Y. filed July 1, 2003) (Clearinghouse No. 55,370), available at www.bazelon.org/issues/disabilityrights/nycomplaint/finalcomplaint.pdf.

¹⁴⁸Funding appropriated for developing community services was not targeted specifically for adult home residents, initial funds would not become available for more than two years after they were proposed, much of the funding was uncertain after the first year, and, even if funding were certain and allocated exclusively for community services for adult home residents, it would serve only a small portion of adult home residents in the community. Funds initially proposed for assessing the needs of adult home residents and improving conditions in the homes were redirected to a bonus program for adult home operators. See Complaint ¶¶ 112 n.3, 114–17, *Disability Advocates v. Pataki*, No. 03cv3209(NGG).

¹⁴⁹*Id.* ¶ 165. The Bazelon Center, along with Disability Advocates, New York Lawyers for the Public Interest, MFY Legal Services, the Urban Justice Center, and the law firm of Paul, Weiss, Rifkind, Wharton & Garrison, are counsel for the plaintiff.

¹⁵⁰Grage et al., *supra* note 130, at 8.

¹⁵¹See *Pierce County v. Department of Social and Health Services*, No. 03-2-00918-8 (Thurston County Super. Ct. filed Nov. 20, 2002). The Bazelon Center and the Washington Protection and Advocacy Service represent the latter in this litigation.

uals with developmental disabilities, psychiatric hospitals, and board and care homes.¹⁵² The council has little confidence in the *Olmstead* implementation planning by states and observes:¹⁵³

- Plans do not consistently provide for opportunities for life in the most integrated setting as people with disabilities define “the most integrated setting.”
- A majority of states have not planned to identify or provide community placement to all institutionalized persons who do not oppose community placement.
- Few plans identify systemic barriers to community placement or state action steps to remove them, and few plans contain timelines and targets for community placement.
- State budgets often do not reflect *Olmstead* planning goals.

■ ■ ■

That the overuse of institutional settings to serve people with disabilities and the inadequacy of community-based service systems across the nation have been rec-

ognized at both federal and state levels is encouraging. However, startlingly little movement has occurred. As documented by the National Council on Disability, the number of individuals with disabilities who remain unnecessarily institutionalized is staggering. The federal government’s efforts are a helpful start in planning for long-term integration efforts, but they have been geared toward identifying barriers and helping states take initial steps to create the infrastructure needed for change. They have not promoted large-scale movement of individuals into community settings. State *Olmstead* planning efforts have been stalled repeatedly by budget crises, and, as long as states view *Olmstead* compliance as a drain on resources, such efforts are unlikely to promote the development of sufficient community services to serve widespread unmet needs. While litigation in this area has proved complex and difficult, it has yielded fruitful results in many cases and has been the most viable avenue for many people with disabilities to obtain desperately desired liberation from institutional environments and receive needed community services.

¹⁵²National Council on Disability, *supra* note 5, at 11–18 (Section I: Barriers to Community Integration in the United States—The Extent of Unnecessary Institutionalization in the United States); see numbers listed in *supra* note 5.

¹⁵³*Id.* at 5 (Executive Summary: The States’ Response).