HOME SWEET HOME: THE PROBLEM WITH COST-NEUTRALITY FOR OLDER AMERICANS SEEKING HOME- AND COMMUNITY-BASED SERVICES

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INTRODUCTION

Most people with an aging loved one may eventually be faced with the daunting decision of whether to place their loved one in a nursing facility. This decision can be heartbreaking, as some nursing home residents live in deplorable conditions and receive insufficient care.1 Residents feel lonely

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and forgotten and, in the most extreme cases, may be subject to abuse by facility staff. Nursing facilities can conjure images of a cold, hospital-like institution where residents are forced to age in an undignified manner. For these reasons, many seniors opt to age in their homes as opposed to a nursing facility.

Medicaid’s 1915(c) waiver offers a solution for older Americans who require nursing facility levels of care but wish to remain in their homes. Under 1915(c) waivers, states can provide home- and community-based long-term care services not otherwise provided in state Medicaid plans. These programs are available for people who, but-for the services provided under the

draft


5. See PENN SCHOEN BERLAND, THE UNITED STATES OF AGING SURVEY 4 (2012) (finding that 90% of seniors prefer to age in their home).


7. See U.S. DEPT. OF HEALTH & HUMAN SERVS., COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED LONG-TERM CARE SERVICES 3 (2000) [hereinafter COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED SERVICES BACKGROUND] (stating that coverage of other home- and community-based waiver and personal care services is at the discretion of the state).
1915(c) waiver, would be reduced to entering a nursing facility. However, 1915(c) waivers are subject to a burdensome cost-neutrality requirement, wherein states cannot spend more on home- and community-based services than the amount spent on nursing facility care. Consequently, states are severely restricted in their ability to provide the necessary long-term care services in the seniors’ preferred location.

Part I of this Comment discusses the projected population of seniors and explains the level of care they require. Part II of this Comment introduces the 1915(c) Medicaid waiver and the accompanying cost-neutrality limitations. Part III explains the integration mandate under the Americans with Disabilities Act (ADA). Part IV argues that the cost-neutrality requirement is inconsistent with the general purpose of the integration mandate because it severely limits the states’ ability to expand home- and community-based long-term care services, exemplifies an artificial calculation, and is arbitrary and capricious under the Administrative Procedure Act (APA). Finally, Part V suggests two solutions to resolve this inconsistency. First, the Centers for Medicare and Medicaid Services (CMS) should revise the cost-neutrality formula to more accurately represent the costs associated with home- and community-based services. Alternatively, Congress could eliminate the cost-neutrality requirement by repealing the statute or by incorporating home- and community-based services into mandatory Medicaid plans. States could explore less expensive types of services to offer. Ultimately, this Comment concludes by recommending that CMS revise the cost-neutrality calculation and that Congress consider eliminating the cost-neutrality requirement altogether.

I. THE GROWING NUMBER AND NEEDS OF OLDER AMERICANS

By the year 2040, one in five Americans will be over the age of sixty-five. Some call this phenomenon the Gray or Silver “Tsunami,” referring to the projected growth of the number of older Americans based on the rapidly increasing number of seniors. By the year 2040, one in five Americans will be over the age of sixty-five. Some call this phenomenon the Gray or Silver “Tsunami,” referring to the projected growth of the number of older Americans based on the rapidly increasing number of seniors.

8. 42 U.S.C. § 1396n(c)(1). Some seniors will never choose to move into a nursing facility, meaning their lives are likely to be shortened because they cannot perform essential tasks independently. See Judith Solomon, Medicaid Cuts Are Real Threat to Home- and Community-Based Services, CTR. ON BUDGET & POL’Y PRIORITIES (Feb. 23, 2017, 2:00 PM), https://www.cbpp.org/blog/medicaid-cuts-are-real-threat-to-home-and-community-based-services.

9. See 42 U.S.C. § 1396n(c)(2)(D); 42 C.F.R. § 441.303(b)(1) (“The annual average per capita expenditure estimate of the cost of home and community-based . . . services under the waiver must not exceed the estimated annual average per capita expenditures of the cost of the services in the absence of a waiver.”).

10. See U.S. DEP’T OF HEALTH & HUMAN SERVS., 2017 PROFILE OF OLDER AMERICANS 3 (2018) [hereinafter PROFILE OF OLDER AMERICANS] (finding that seniors aged sixty-five and over are expected to be 21.7% of the population by 2040).
increasing population over the last few decades. As a result of the advances in modern medicine, Americans—including individuals with disabilities—are expected to live longer than ever before. The growing number of older Americans and their increased life expectancies are paralleled with a growing need for long-term care services.

Long-term care includes a variety of services designed to meet an aging person’s health and personal needs, which typically involves assistance with regular and instrumental activities of daily life. While aging is universally accompanied by health and personal care concerns, seniors may also face financial challenges related to their healthcare costs. In addition to medical services, some seniors also require substantial assistance with basic tasks like eating, using the bathroom, taking medication, and budgeting money.

11. See id. at 2; Fed. Interagency Forum on Aging-Related Statistics, 2016 Older Americans: Key Indicators of Well-Being 2 (2016) [hereinafter Key Indicators of Well-Being] (noting that this population growth is projected to stabilize after the year 2030).

12. See Key Indicators of Well-Being, supra note 11, at 26 (reporting that life expectancies have increased for both individuals aged sixty-five and eighty-five); Profile of Older Americans, supra note 10, at 2 (finding that in 2016, sixty-five-year-olds had an average life expectancy of an additional nineteen years); Sally Sara, For People With Down Syndrome, Longer Life Has Complications, N.Y. TIMES (June 1, 2008), https://www.nytimes.com/2008/06/01/nyregion/01down.html (noting that healthcare advances doubled the life expectancy of people with Down syndrome).

13. See Profile of Older Americans, supra note 10, at 15 (revealing that nearly a quarter of seniors age eighty-five and over need assistance with personal care).

14. See What Is Long-Term Care?, Nat’l Inst. on Aging, https://www.nia.nih.gov/health/what-long-term-care (last visited Jan. 15, 2019). Long-term care describes the comprehensive set of services an elderly or disabled person may want or need, such as part-time medical services ordered through home healthcare, personal care services offered by a homemaker, transportation, and more. See id.

15. See Robin Osborn et al., Older Americans Were Sicker and Faced More Financial Barriers to Health Care Than Counterparts in Other Countries: 2017 Commonwealth Fund International Health Policy Survey of Older Adults, COMMONWEALTH FUND (Nov. 15, 2017), https://www.commonwealthfund.org/publications/journal-article/2017/nov/older-americans-were-sicker-and-faced-more-financial-barriers (finding that a quarter of U.S. seniors reported avoiding necessary medical treatment due to cost); Profile of Older Americans, supra note 10, at 12 (indicating that seniors have higher out-of-pocket healthcare expenses than the rest of the population).

16. See What Is Long-Term Care?, U.S. Dep’t of Health & Human Servs., https://longtermcare.acl.gov/the-basics/what-is-long-term-care.html (last visited Jan. 15, 2019) (describing these tasks as “activities of daily living” and “instrumental activities of daily living”); Key Indicators of Well-Being, supra note 11, at 123 (reporting in 2013 that 44% of Medicare beneficiaries in long-term care facilities had limited ability to perform daily activities).
Thus, access to Medicaid financial assistance is critical for many older Americans to cover long-term care costs in their preferred locations.\textsuperscript{17} Unsurprisingly, most seniors prefer to “age in place” by residing in their homes rather than transitioning to an institution.\textsuperscript{18} Home- and community-based programs offered through Medicaid allow seniors to age in place at little to no cost to the elderly beneficiary.\textsuperscript{19} However, home- and community-based programs are subject to a budget-controlling mechanism, known as cost-neutrality.\textsuperscript{20} Cost-neutrality severely limits the states’ ability to provide in-home services for the growing number of seniors and the high level of care they require.\textsuperscript{21} As a result, low-income seniors who are otherwise eligible to receive home- and community-based services may be denied from the Medicaid program and required to move into a nursing facility against their wishes.\textsuperscript{22}

II. MEDICAID HOME- AND COMMUNITY-BASED WAIVER PROGRAMS EXPLAINED

The Centers for Medicaid and Medicare Services (CMS) administers the Medicaid program pursuant to Title XIX of the Social Security Act.\textsuperscript{23} Medicaid is a federal and state-funded program that provides medical assistance to low-income families and individuals.\textsuperscript{24} Though states that accept Medicaid funding must provide certain mandatory services in their state Medicaid plans,\textsuperscript{25} states are not required to provide long-term care services in home- or community-based settings.\textsuperscript{26} CMS requires states to offer some level of

\textsuperscript{17} See \textit{PROFILE OF OLDER AMERICANS}, supra note 10, at 5 (finding that 28% of noninstitutionalized seniors lived alone in 2017 and the percent of seniors living alone increased with age).

\textsuperscript{18} See BERLAND, supra note 5, at 4. Institutional settings include hospitals, nursing facilities, and intermediate care facilities for people with intellectual disabilities. See 42 C.F.R. § 441.301(a)(3)(i)–(iii) (2017).

\textsuperscript{19} Out-of-pocket costs for Medicaid services vary by state and by the beneficiary’s income level; however, costs are often limited to minimal amounts. See Cost Sharing Out of Pocket Costs, MEDICAID, https://www.medicaid.gov/medicaid/cost-sharing/out-of-pocket-costs/index.html (last visited Jan. 15, 2019) (explaining that the costs are often limited to nominal or minimal amounts while the maximum amount is what the state pays for the service).


\textsuperscript{21} See infra Part IV.

\textsuperscript{22} See, e.g., Haddad v. Dudek, 784 F. Supp. 2d 1308, 1313 (M.D. Fla. 2011) (noting plaintiff’s argument that the state’s failure to provide her with home- and community-based services would force her into an institutionalized nursing care facility).

\textsuperscript{23} See 42 C.F.R. § 430.0 (granting funds to the states through authority in Title XIX of the Social Security Act).

\textsuperscript{24} See generally 42 U.S.C. § 1396.

\textsuperscript{25} See 42 U.S.C. § 1396a(10)(A); § 1396d(1)–(5), (17), (21), (28).

\textsuperscript{26} See 42 C.F.R. § 440.70.
home health services; however, these services are insufficient for seniors that require long-term care. While states are not required to provide comprehensive long-term care services, they may include elements of long-term care in their state Medicaid plans—such as personal care aides, private duty nursing services, or case management.

All state Medicaid plans must comply with certain requirements: (1) state-wideness; (2) comparability; and (3) agencies must use the same income eligibility groups for all applicants. However, CMS may waive these requirements under one of the Medicaid waiver programs—such as the 1915(c) waiver—to provide services to people who would otherwise be ineligible to receive them. If granted a 1915(c) waiver, a state can provide home- and community-based services specifically for individuals requiring a nursing facility level of care.

By implementing a 1915(c) waiver, states can target particular groups that need publicly funded long-term care because the requirements for state-wideness, comparability, and income eligibility no longer apply. For example, states can target populations by age, diagnosis, or geographic area.

27. While long-term care can be provided at the home, it is different from home health services. See What Is Long-Term Care?, supra note 16. Long-term care includes a broad array of services that meet a senior’s personal care needs, whereas home health services describe a much narrower subset of medical services ordered by a physician to treat a specific condition, such as occupational therapy. Id.


29. See 42 U.S.C. § 1396a(a)(1) (requiring the State Medicaid Plan be available throughout the entire state).

30. See id. § 1396a(a)(10)(B) (requiring all Medicaid beneficiaries to have access to comparable services in amount, duration, and scope).

31. See id. § 1396a(a)(10)(C)(iii).


34. See 42 U.S.C. § 1396n(c)(1); 42 C.F.R. §§ 435.217(b), 441.302(c)(1)(ii) (2017). Nursing facility level of care means that the individual must demonstrate she would meet the state’s eligibility requirements for services in a nursing facility. See Home & Community-Based Services 1915(c), supra note 6.

35. 42 U.S.C. § 1396n(c)(3).

36. See Home & Community-Based Services 1915(c), supra note 6.
Waiver programs allow states to design innovative programs to serve the long-term needs of particular populations—such as the elderly—and to avoid the institutionalization of those persons.\textsuperscript{37} The services available under 1915(c) waivers range from medical to non-medical, and states may design creative programs to meet seniors’ unique needs.\textsuperscript{38}

For CMS to grant a 1915(c) waiver, states must offer proof of certain cost controls, or “cost-neutrality.”\textsuperscript{39} To meet this requirement, states must assure CMS that the average, annual cost of home- and community-based services for an individual does not exceed the average, annual cost of providing long-term care services for that individual in a nursing facility.\textsuperscript{40} This applies to both the estimated cost when applying for the waiver and actual costs once the waiver is in effect.\textsuperscript{41} In summary, cost-neutrality requires that the state spend an equal amount or less on home- and community-based services for a particular individual than what it would spend if that same individual received services in an institutional setting.

Under the current cost-neutrality limitations, a beneficiary can be denied home- and community-based services if the state’s estimated cost of

\begin{itemize}
\item \textsuperscript{37} See 42 C.F.R. §§ 441.300, 430.25(b). Institutionalization refers to placing someone in a residential facility, such as a nursing home. See Institutional Long Term Care, Medicaid, https://www.medicaid.gov/medicaid/lts/ institutional/index.html (last visited Jan. 15, 2019).
\item \textsuperscript{39} See 42 U.S.C. § 1396n(c)(2)(D).
\item \textsuperscript{40} See id.; 42 C.F.R. § 441.302(c) (“[A]verage per capita fiscal year expenditures under the waiver will not exceed 100 percent of the average per capita expenditures that would have been made in the fiscal year for the level of care provided in [an institution] had the waiver not been granted.”) (emphasis added). The Centers for Medicare and Medicaid Services (CMS) calculates cost-neutrality assurances using the following equation: $D+D' \leq G + G'$. Id. § 441.303(f)(1). The left side of the equation represents the cost estimate of providing home- and community-based services, and the right side represents the cost estimates in the absence of the waiver. Id. State Medicaid agencies must make assurances in their 1915(c) waiver applications and the accompanying Quality Improvement Strategy. CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE, AND REVIEW CRITERIA 45 (2015).
\item \textsuperscript{41} See 42 C.F.R. § 441.302(f).
providing these services for that beneficiary is higher than the state’s estimated cost of nursing facility care for that beneficiary, regardless of whether the state can actually accommodate the person in its home- and community-based program.\textsuperscript{42} States are required to provide services in the most integrated setting possible, which for long-term care services is in a home- or community-based setting.\textsuperscript{43} However, they can evade this obligation under the guise of the stringent cost-neutrality requirement.\textsuperscript{44} As a result, low-income seniors who are denied home- and community-based services must move into a nursing facility.\textsuperscript{45}

III. INTEGRATION UNDER THE AMERICANS WITH DISABILITIES ACT AND OLMSTEAD

A. The Integration Mandate

The ADA establishes a broad scope of protection and national standards for addressing disability-based discrimination.\textsuperscript{46} The ADA applies to older Americans who have functional limitations due to a disability resulting from old age or other illness or injury.\textsuperscript{47} Title II of the ADA prohibits public entities, such as state agencies, from excluding disabled individuals from programs like Medicaid.\textsuperscript{48} Public entities are required to make reasonable accommodations to provide individuals with disabilities the opportunity to fully

\textsuperscript{42} See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,013 (Mar. 13, 1985) (permitting a state to exclude individuals from a home- and community-based services program if it reasonably believes that the provision of these services would be more expensive than the institutional Medicaid services the person would otherwise receive).

\textsuperscript{43} 28 C.F.R. § 35.130(d) (2018).

\textsuperscript{44} See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,013 (Mar. 13, 1985).

\textsuperscript{45} See, e.g., Hadland v. Dudek, 784 F. Supp. 2d 1308, 1313 (M.D. Fla. 2011) (noting plaintiff’s argument that the state’s failure to provide her with home- and community-based services would force her into an institutionalized nursing care facility).


\textsuperscript{47} The ADA applies to individuals with a disability that substantially limits a life activity. See 42 U.S.C § 12102(1)(A). Major life activities include walking, bending, and performing manual tasks. Id. § 12102(2)(A). The ADA Amendments Act of 2008 defines “substantially limits” to be read in conjunction with the findings and purpose of the Act: namely preventing discrimination and segregation of people with disabilities. See id. §§ 12102(4)(B), 12101(a)–(b).

\textsuperscript{48} See id. § 12132 (“[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in, or be denied the benefits of, the services, programs, or activities of a public entity . . . .”; § 12131(1)(A)–(B); see, e.g., Alexander v. Chooate, 469 U.S. 287, 309 (1985) (finding that Title II of the ADA applies to Medicaid programs).
participate in publicly-funded programs.\footnote{49} Courts have interpreted this requirement to compel public entities to provide individuals with disabilities meaningful access to the benefits that a specific program offers.\footnote{50} Public entities, however, do not have to make modifications that would fundamentally change the existing program.\footnote{51}

The integration mandate, a provision under Title II of the ADA, provides that “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."\footnote{52} For individuals with disabilities, including seniors, the most integrated setting is one that allows them to interact with the general population to the fullest extent possible.\footnote{53} In the context of long-term care services, the most integrated setting is almost always the home.\footnote{54} When applying the integration mandate to Medicaid programs, courts have required medical assistance to be provided in the most integrated setting possible and have repeatedly used the integration mandate to expand Medicaid-funded home- and community-based services programs.\footnote{55} Further signifying the importance of the integration mandate, CMS sent advisory letters to every state Medicaid agency directing them to comply with the integration mandate.\footnote{56}


\footnote{50} See, e.g., Alexander, 469 U.S. at 301 (finding that meaningful access was met because both handicapped and nonhandicapped Medicaid beneficiaries had access to the same hospital services and both groups were subject to the same duration limitation).

\footnote{51} See 28 C.F.R. § 35.130(b)(7)(i); see, e.g., Rodriguez v. City of New York, 197 F.3d 611, 618 (2d Cir. 1999) (holding that New York did not have to provide personal care aide services for mentally disabled persons because it would fundamentally change the program by essentially creating a completely new Medicaid program).

\footnote{52} 28 C.F.R. § 35.130(d).


\footnote{54} See U.S. DEP’T OF JUSTICE, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND OLMESTAD v. L.C. 4, 5 (2011) [hereinafter STATEMENT OF DOJ ON INTEGRATION MANDATE] (stating that integrated settings are located in mainstream society, allowing people to exercise choice in their daily life and providing an opportunity to interact with non-disabled people, whereas segregated settings have characteristics of institutions).

\footnote{55} See, e.g., Olmstead v. L.C., 527 U.S. 581, 597 (1999) (holding community placement is required when it can be reasonably accommodated); Helen L. v. DiDario, 46 F.3d 325, 333 (3d Cir. 1995) (holding that unnecessary segregation constitutes illegal discrimination against disabled individuals).

\footnote{56} See Letter from Sally K. Richardson, Director of the Health Care Finance Administration, to State Medicaid Directors (July 29, 1998).
B. Integration Obligation Under Olmstead

Courts determine the reasonableness of a modification by assessing whether the proposed modification changes the essential nature of the service or poses an undue burden on the program as a whole. In the context of requests for medical services, reasonableness depends on the nature of the program and the population that the program is intended to serve. However, Congress has recognized that fiscal convenience is not a valid justification for providing long-term care services in a segregated manner under Title II of the ADA.

In *Olmstead v. L.C.*, the Supreme Court interpreted the integration mandate for the first time. Two women with intellectual disabilities and mental illnesses were voluntarily admitted to a Georgia hospital and confined to the psychiatric unit. Because the women’s conditions began to stabilize and improve, the physicians concluded that they could be adequately cared for with community-based services provided through Georgia’s Medicaid home- and community-based waiver program. However, they remained institutionalized because the state claimed it did not have the funds available to provide home- and community-based treatment for the women, as these funds were being used to help other disabled people. The women filed suit against the state seeking community-based services. Writing for the

57. See Easley v. Snider, 36 F.3d 297, 305 (3d Cir. 1994). A proposal to alter the eligibility criteria for a home-care program specifically designed for individuals with physical disabilities to include individuals with physical disabilities and cognitive impairments is a fundamental alteration because the proposed modification changes the nature of the program as envisioned by the Legislature. See id. (holding that such a program could create an undue or impossible burden for the State).

58. For example, in *Helen L.*, a paralyzed woman, who was otherwise eligible for home-based care, was ultimately denied because the State asserted lack of funding. See *Helen L.*, 46 F.3d at 328–29. The Third Circuit held that compliance with the integration mandate would not require a fundamental alteration of the existing program; in fact, the woman’s request “merely requires [the Agency] to fulfill its own obligations under state law.” Id. at 338.


61. Id. at 580.

62. See id. at 593.

63. Id. The physicians concluded that residential community placement was appropriate once both women’s aggressive behavior had been subdued. See also Brief for Petitioners at 8–11, *Olmstead* v. L.C., 527 U.S. 581 (1999) (No. 98-536), 1999 WL 54623. While the women no longer needed inpatient care in the psychiatric unit, they still required care in some form. Id. at 12.

64. See id. at 10–11; *Olmstead*, 527 U.S. at 594 (“The State reasserted that it was already using all available funds to provide services to other persons with disabilities.”).

65. *Olmstead*, 527 U.S. at 593–94. When the case reached the Eleventh Circuit, the women had been moved to residential community placements but were still seeking
majority, Justice Ginsburg explained the purpose of the integration mandate as preventing or remediying unjustified institutionalization, and the ability of states to raise a fundamental alterations defense. The Court deferred to the Department of Justice’s (DOJ’s) interpretation that unnecessary institutionalization constitutes discrimination by reason of disability, in violation of Title II of the ADA. It also noted the trend toward providing home- and community-based services through Medicaid waiver programs, as well as the policy of promoting the 1915(c) waiver program.

The Court developed a three-prong test to determine whether a state is required to provide services in a community-based setting. Such services are required when (1) the state’s treatment professionals have determined that community placement is appropriate, (2) the individual does not oppose the transfer from an institutional setting to a less restrictive setting, and (3) community placement can be reasonably accommodated considering the state’s resources. The four-Justice plurality recognized that the state’s responsibility is not limitless; rather, the state is only required to make modifications that are reasonable. Their analysis implied that states do not have to immediately provide home- and community-based services to otherwise eligible applicants if they raise a fundamental alterations defense and prove that reallocation of resources would result in inequity for all other beneficiaries of a declaratory relief that their confinement to the Georgia hospital violated the ADA’s integration mandate. See Brief for Petitioners at 11.

66. See Olmstead, 527 U.S. at 600–01 (stating that unjustified isolation on the basis of disability is a form of discrimination which perpetuates stereotypes about isolated persons and diminishes their independence and advancement).

67. Id. at 596–97 (“States could resist modifications that ‘would fundamentally alter the nature of the service, program, or activity.’”). The fundamental alterations defense asserts that substantial modifications to an existing program are not required to accommodate a person with disabilities. See 28 C.F.R. § 35.130(b)(7)(i) (2017).

68. Olmstead, 527 U.S. at 597–98.

69. Id. at 601.

70. See id. (“[The agency] ‘has a policy of encouraging States to take advantage of the waiver program, and often approves more waiver slots than a State ultimately uses.’”).

71. See id. at 607.

72. See id. at 587.

73. Id. at 603–04. Moreover, a state could meet the reasonable modifications requirement by demonstrating that it has 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 . . . .” See id. at 605–06. The DOJ noted that “Congress anticipated that the placement of persons in the community . . . would not impose undue costs,” but if a state could prove that it did, it would not be required to provide community-based services. See Brief for the United States as Amicus Curiae Supporting Respondents at 7, Olmstead v. L.C., 527 U.S. 581 (1999) (No. 98-536), 1999 WL 149653.
medical assistance program. In its ruling, the Court remanded the case to the Eleventh Circuit to consider Georgia’s fundamental alterations defense.

The DOJ guidelines for conforming with the integration mandate imply that its purpose was to expand community-based services and limit restrictions on integration. For example, the guidelines explicitly allow individuals who are not currently institutionalized to bring claims under the integration mandate if they are at risk of being unnecessarily institutionalized. Furthermore, the DOJ’s guidance indicates that the purpose of the integration mandate is not only to promote deinstitutionalization, but also to prevent future unnecessary institutionalization by providing home- and community-based services for the growing number of older individuals with functional limitations.

IV. COST-NEUTRALITY HINDERS THE GOAL OF INTEGRATION

A. Barriers to Integration

As public entities, state Medicaid agencies must comply with the ADA, including its integration mandate. Following the Olmstead decision, CMS


75. See Olmstead, 527 U.S. at 607. Circuit courts have since held that budgetary concerns alone are insufficient to sustain a state’s fundamental alterations defense. See, e.g., M.R. v. Dreyfus, 697 F.3d 706, 737 (9th Cir. 2012) (holding that the state’s fundamental alterations defense could not be sustained if it could not identify which programs would be cut if the plaintiff’s request for home- and community-based services were granted); Radaszewski v. Maram, 383 F.3d 599, 614 (7th Cir. 2004); Frederick L. v. Dep’t of Pub. Welfare of Pa., 364 F.3d 487, 495 (3d Cir. 2004); Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1182–83 (10th Cir. 2003).

76. DOJ’s guidelines are “entitled to substantial deference” because the ADA directs the Attorney General to promulgate such regulations. See Chevron, U.S.A., Inc. v. Nat. Res. Def. Council, Inc., 467 U.S. 837, 844 (1984) (“[C]onsiderable weight should be accorded to an executive department’s construction of a statutory scheme it is entrusted to administer . . . .”).

77. See Statement of DOJ on Integration Mandate, supra note 54, at 5 (stating that the ADA and the Olmstead decision also apply to people at serious risk of institutionalization); see also Fisher, 335 F.3d at 1184 (10th Cir. 2003) (holding that Medicaid beneficiaries who are at “high risk for premature entry into a nursing home” could bring a claim under the integration mandate). While the DOJ withdrew its Statement in 2017, it noted that the withdrawal did not undermine the principles it originally set forth. See Withdrawn Technical Assistance and Guidance Documents, ADA (Dec. 21, 2017), https://www.ada.gov/withdrawn_olmstead.html.

78. See Statement of DOJ on Integration Mandate, supra note 54, at 2.

sent a letter to state Medicaid agencies stating that Olmstead reflected the agency’s position: institutionalization is unjustified for an individual who can remain in the community with the appropriate services. Recent communication from CMS further clarifies that a state must fulfill its integration obligations under the ADA and Olmstead even after its 1915(c) application is approved. Despite the clear intent of Congress to actively achieve integration in Medicaid programs, cost-neutrality continues to hinder the statutorily mandated objective. Out of fear of penalties from CMS, states impose strict requirements that ultimately limit, rather than expand, the availability of home- and community-based services. Home- and community-based services should be viewed as a mechanism to ensure the equality and integration of older Americans as envisioned by the ADA, rather than as a cost-cutting mechanism. The goal of ending unnecessary institutionalization requires dramatic expansion of home- and community-based services. Unfortunately, the requirement of cost-

80. See Letter from Timothy M. Westmoreland, Director Center for Medicaid and State Operations Health Care Financing Administration, & Thomas Perez, Director Office for Civil Rights, to State Medicaid Directors 1, 2, 4 Jan. 14, 2000 (”Olmstead confirms what HHS already believes: that no one should have to live in an institution or a nursing home if they can live in the community with the right support.”). CMS expected State Medicaid agencies to prevent and correct unnecessary institutionalization and to develop comprehensive plans for integrating people with disabilities. Id.

81. See CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A 1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 13 (2015); TRAINING & ADVOCACY SUPPORT CENTER, Q & A SERVICE LIMITS IN HOME & COMMUNITY-BASED SERVICES (HCBS) 1 (2017) (stating that approval of a waiver application does not excuse the state from its integration obligations).

82. See, e.g., HARRINGTON infra, note 86, at 15–16 (stating that with the restricted spending, some people with disabilities may enter institutions unnecessarily).

83. For example, the District of Columbia recently adopted stringent procedures for assessing seniors’ level of care needs, as a result many applications for 1915(c) services were denied and seniors who have been relying on the services are being terminated from the program. D.C. Mun. Regs. tit. § 29-989 (2019); see also Letter from Advocates to Melisa Byrd, State Medicaid Director (Dec. 6, 2018). The new procedures include a new assessment test, a measure that only evaluates a person’s functional ability for the previous three days, and a nineteen-hour cap for personal care aide services. D.C. Mun. Regs. tit. § 29-989 (2019); see also Letter from Advocates to Melisa Byrd, State Medicaid Director (Dec. 6, 2018).

84. See James C. Vertees et al., Cost Effectiveness of Home and Community-Based Care, 10 HEALTH CARE FIN. REV. 65, 78 (1989) (“[Cost] neutrality is a criterion that is not usually applied to health programs. No one requires that Medicaid hospital payments or expenditures for physician services be budget neutral.”); Mark C. Weber, Disability Rights, Welfare Law 32 CARDOZO L. REV. 2483, 2510 (2011) (stating HCBS should be viewed “as a vital support for equality for people with disabilities”).

85. See Loretta Williams, Long Term Care After Olmstead v. L.C.: Will the Potential of the
neutrality prevents states from expanding these services, especially in light of the growing number and needs of older adults. The stringent cost-neutrality restrictions are reflective of CMS’s impermissible preference for providing long-term care services in an institutional setting, as opposed to an integrated setting. The general preference for institutions is further displayed in Medicaid expenditures: between 1993 and 1999 expenditures on 1915(c) waivers only increased from $0.3 billion to $1 billion, whereas expenditures on nursing facilities increased from $25 billion to $34 billion. Moreover, 1915(c) expenditures for the elderly have seen the least growth, as compared to expenditures on other groups.

Cost controls can result in states designing waiver programs for arbitrarily-defined groups in an effort to make the waiver cost-neutral. In reality, this

ADA’s Integration Mandate be Achieved?, 17 J. Contemp. Health L. & Pol’y 205, 237 (2000) (arguing for a mandatory long-term care benefit that entitles seniors to service, rather than settings, and allows them to choose where they want to receive those services). In fact, thirty states and the District of Columbia include personal care services in their state plan and three states provide home-based services primarily through their state plans. See Cost-Effectiveness of Home and Community-Based Services Background, supra note 7, at 3–4. Ultimately, the 1915(c) waiver remains the better option because it provides more services and naturally limits runaway spending by limiting services to specified groups. Id. at 4–5.

Studies show that states strategically make their 1915(c) waiver plans restrictive in order to remain cost-neutral. See Charlene Harrington et al., U.C.S.F. Ctr. for Personal Assistance Servs., Home and Community-Based Services: Public Policies to Improve Access, Costs, and Quality 15–16 (2009) (finding that every state used a cost-containment mechanism for home-based services and at least 600,000 people with long-term care needs were not receiving services).

See Shirk, supra note 33, at 11 (noting the various ways in which Medicaid programs demonstrate a bias towards institutional settings). The limitation is particularly apparent for individuals with mental illnesses who do not have intellectual or developmental disabilities; since there is no comparable institutional program for such individuals available through state Medicaid plans, states can never meet cost-neutrality if they attempt to provide home- and community-based services for such individuals. See John V. Jacobi, Federal Power, Segregation, and Mental Disability, 39 Hous. L. Rev. 1231, 1288 (2003).

See Shirk, supra note 33, at 8.

See Steven Lutzky et al., U.S. Dep’t of Health & Human Servs., Review of the Medicaid 1915(c) Home and Community Based Services Waiver Program 8–9 (2000) (reporting that expenditures for aging and disability 1915(c) waivers increased from $0.6 billion to $1.7 billion between 1992 and 1997, while expenditures for mental retardation and developmental disability waivers increased from $1.5 billion to $5.9 billion in that period).

Applicants must have some type of functional limitation to be eligible to receive home- and community-based services; however, states vary enormously in what they consider to be a functional limitation. Id. at 14. For example, some states use the same functional eligibility criterion used for entrance into a nursing facility, while others look for functional limitations in specific activities. Id. Some states even require applicants to have
practice excludes a whole subset of the group that should be benefiting from the waiver’s services.\textsuperscript{91} For certain individuals with severe disabilities or extremely high level-of-care needs, the cost of in-home services may never be less expensive than institutional services.\textsuperscript{92} Due to the cost-neutrality restriction, these groups may be intentionally excluded from a state’s 1915(c) waiver program because including them as beneficiaries would increase the average cost of home- and community-based services, thus making the whole program fail its requirement of cost-neutrality.\textsuperscript{93} As a result, severely disabled individuals—who have been historically isolated in society and face the highest risk of ongoing segregation—continue to be placed in institutions against their will.\textsuperscript{94}

States currently have the option of making their cost-neutrality assurances based on either an individual or aggregate basis.\textsuperscript{95} The majority of states

\begin{itemize}
\item a minimum number of impairments, and some use a subjective assessment administered by a person. \textit{Id.}
\item For example, D.C.’s Persons with Intellectual and Developmental Disabilities 1915(c) waiver program serves individuals with intellectual disabilities or both intellectual and developmental disabilities but excludes individuals who solely have a developmental disability. \textit{See District of Columbia Waiver Factsheet, MEDICAID, https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/Waiver-Descript-Factsheet/DC-Waiver-Factsheet.html} (last visited Feb. 26, 2019).
\item The average cost for a personal care aide (PCA) is $20.50 an hour, bringing the annual cost of in-home care for a person requiring sixteen hours of PCA services per day to over $116,000. \textit{See Nursing Home Costs, SENIOR LIVING,} https://www.seniorliving.org/life-styles/nursing-homes/costs/ (last visited Jan. 14, 2019). Whereas the average annual cost for a private room in a nursing home is approximately $92,000 per year. \textit{Id.}
\item \textit{Contra} Cost-Effectiveness of Home and Community-Based Services Background, \textit{supra} note 7, at 9 (noting that New York is the only state that routinely authorizes personal care services costing more than $1,500 per month for severely disabled people). Recall that states can target home- and community-based services to specific groups because the statewide and comparability requirements are waived. \textit{See Home & Community-Based Services 1915(c),} \textit{supra} note 6, at 1–2. CMS explicitly recognized this discretion in its 1985 final rule. \textit{See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,013 (Mar. 13, 1985)} (“Under the waiver, the State may exclude those individuals for whom there is a reasonable expectation that home and community-based services would be more expensive than the Medicaid services the individual would otherwise receive.”).
\item \textit{See generally} Williams, \textit{supra} note 85, at 235 (explaining that states focus their home- and community-based services to certain types of disabilities, rather than degree of disability). In addition to limiting services by diagnoses, states often use more restrictive financial eligibility criteria for home- and community-based waiver applicants as a way to cut costs. \textit{See generally} Harrington, \textit{supra} note 86, at 5.
\item \textit{See Assurance 5 – Financial Accountability, HCBS Waiver Assurances,} http://www.hcbsassurances.org/financial/finance1.html (last visited Feb. 26, 2019). An aggregate calculation is the total cost of services for all waiver participants divided by the number of
\end{itemize}
choose to make their assurances on an individual basis and can therefore more readily exclude an individual from the program if the cost of home- and community-based services for that specific individual exceeds the cost-neutral cap.\textsuperscript{96} Furthermore, as more individuals transition out of or are diverted from institutions, there will be fewer institutionalized costs to compare with the community-based costs.\textsuperscript{97} In effect, a state’s success in replacing institutional services with community-based services will be fatal to integration as the state’s 1915(c) waiver will no longer be cost-neutral.\textsuperscript{98} Consequently, states are discouraged from expanding the availability of home- and community-based services, meaning they are not zealously pursing their integration obligations.\textsuperscript{99}

Additionally, fear of penalties resulting from failure to comply with cost-neutrality wrongly encourages states to reduce, rather than expand, their home- and community-based services.\textsuperscript{100} Researchers have consistently found that states use more restrictive cost-controlling mechanisms in formulating their 1915(c) waiver programs that are beyond what is required under cost-neutrality.\textsuperscript{101} For example, by establishing coverage limits states ensure

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\item Conversely, states that make the determination on the aggregate basis can still provide services to an individual whose costs exceed the cap, so long as the average cost of home- and community-based services for this group are cost-neutral. \textit{See} Eric M. Carlson, \textit{Trends and Tips in Long-Term Care: Who Benefits—or Loses—from Expanded Choices?}, 18 Elder L.J. 191, 193–94 (2010). As of 2001, only fourteen states determine cost-neutrality on the aggregate level. \textit{See} Allen J. LeBlanc et al., \textit{State Medicaid Programs Offering Personal Care Services}, 22 Health Care Fin. Rev. 155, 165 (2001).
\item \textit{See} id. (“[A]s more people are diverted from institutions, there is a smaller institutional base against which costs can be compared.”).
\item \textit{See} Cost-Effectiveness of Home and Community-Based Services Background, \textit{supra} note 7, at 6 (suggesting that states may decide to limit their annual expenditure to levels that are lower than the cost-neutral cap to avoid penalties).
\item \textit{See} Cost-Effectiveness of Home and Community-Based Services Background, \textit{supra} note 7, at 6 (explaining that states believe CMS is entitled to take disallowances if the state exceeds cost-neutrality, meaning state officials believe they would be in a financially risky position if they exceeded the cost-neutral cap).
\end{itemize}
that they spend considerably less than the cost-neutrality cap. Another method states employ is appropriating a fixed annual budget for their share of the Medicaid waiver expenditures, which does not provide adequate funding to fill all approved waiver slots.\textsuperscript{102} Additionally, states may also be hesitant to authorize coverage amounts that would bring the average per capita spending of community-based services up to the maximum amount allowed under cost-neutrality because individuals who remain in the community will use other health services, thus adding to Medicaid expenditures.\textsuperscript{103} Again, these measures ultimately curb the expansion of home- and community-based services and prevent the integration of seniors into the general population.\textsuperscript{104}

\textbf{B. The Inaccuracy of the Cost-Neutrality Formula}

Cost-neutrality measurements are also inaccurate, making them an artificial limitation on an otherwise important objective.\textsuperscript{105} Researchers have had difficulties measuring the cost of providing long-term care services in an institutional setting as compared to the cost of providing long-term care in the community.\textsuperscript{106} As some beneficiaries of 1915(c) state waiver programs are unlikely to enter nursing facilities, comparing the cost of home-based services to the potential cost of a nursing facility placement is inaccurate.\textsuperscript{107} Receipt of long-term care services in the community compared to an institution is a personal choice, thus comparing the costs associated with each setting is futile because some individuals will never choose the institutional setting.\textsuperscript{108}

The cost of institutional care is central to the cost-neutrality calculation; however, this factor is not a valuable element against which to compare

\begin{footnotesize}
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\item \textsuperscript{102} \textit{Programs: Data Update 5–6} (2005); \textit{see also Terence Ng et al., Medicaid Home and Community-Based Services Programs: 2012 Update 1} (2015) (finding that half of the states used more stringent financial eligibility criterion for home- and community-based waivers than they did for nursing facilities).
\item \textsuperscript{103} \textit{Cost-Effectiveness of Home and Community-Based Services Background, supra note 7, at 6–7.}
\item \textsuperscript{104} \textit{See id. at 9.}
\item \textsuperscript{105} \textit{See id. at 6.}
\item \textsuperscript{106} \textit{See, e.g., Vertees, supra note 84, at 78; Berland, supra note 5, at 2.}
\item \textsuperscript{107} \textit{See Vertees, supra note 84, at 69 (recognizing the study was not able to use an optimal control group to gather data for analysis); Lutzky, supra note 89, at 6–7 (noting problems understanding the costs of home- and community-based services due to lack of publicly available data).}
\item \textsuperscript{108} \textit{See, e.g., Vertees, supra note 84, at 66, 75–76, 78 (enumerating multiple factors indicating that neither California’s nor Georgia’s 1915(c) waiver was likely to affect a persons’ likelihood of entering a nursing home).}
\item \textsuperscript{109} \textit{See Berland, supra note 5, at 4 (finding that 90% of seniors plan to “age in place”).}
\end{enumerate}
\end{footnotesize}
costs. The cost-neutrality calculation incorrectly assumes that there is room available to provide long-term care services to an individual in an institutional setting if the waiver application is denied.109 In reality, the supply of beds in institutions is declining as more nursing facilities close.110 Nursing facility and in-home services are also not comparable because home-based services promise one-on-one care that is tailored to an individual’s unique needs.111 In addition, many people who enter nursing facilities may do so for short, finite periods of time;112 if the cost associated with these individuals is included in the calculation, the resulting cost-neutral cap is incorrectly skewed.

The calculation becomes even more complex when states create new 1915(c) waiver programs because they do not have any experience upon which to base their estimates for the costs of the home- and community-based services.113 In reviewing the estimated costs, CMS will deny a state’s 1915(c) waiver application if it fails to demonstrate a reasonable cost estimate that is based on sound statistical data.114 Even if CMS approves the application, it may later terminate a state’s 1915(c) waiver if the cost estimates are unreasonably low in light of actual costs.115

Proponents of cost-neutrality deem it as a method to combat the “woodwork effect”: states fear that if they begin funding a gamut of services, a large number of people will suddenly start seeking long-term care services through

109. See 42 C.F.R. § 441.303(f)(1) (2018) (stating that one of the factors in the cost-neutrality calculation is the estimated cost for hospital or nursing facility care that would be incurred for people if they did not receive home- or community-based services).

110. See generally Paula Span, In the Nursing Home, Empty Beds and Quiet Halls, N.Y. TIMES (Sept. 28, 2018) (noting that 200 to 300 nursing facilities close each year). Moreover, since the abolishment of the “cold bed rule,” the supply of beds in institutions should not be considered during CMS’s review of a state’s 1915(c) waiver application. See COST-EFFECTIVENESS OF HOME AND COMMUNITY-BASED SERVICES BACKGROUND, supra note 7, at 8.

111. For example, an individual that receives sixteen hours of home health aide services per day will not receive that same treatment in a nursing facility; at best, the individual can hope for a couple of hours of one-on-one time with a licensed nurse. See, e.g., Nursing Home Profile: Sibley Memorial Hospital, NURSING HOME COMPARE, https://www.medicare.gov/nursinghomecompare/profile.html#profTab=3&ID=095030&Disn=0.9&lat=38.937408&lng=-77.0852258&loc=20016 (last visited Jan. 15, 2019) (reporting that the national average for licensed nurse staff hours per resident is one hour, thirty minutes per day).

112. See generally A Place For Mom Staff, Getting the Right Care After a Hospital Discharge, A PLACE FOR MOM (Apr. 23, 2015), https://www.aplaceformom.com/blog/4-23-15-what-to-do-after-a-hospital-discharge/ (noting that some people go to nursing facilities for short periods of time after hospital discharge for rehabilitation purposes).

113. See SHIRK, supra note 33, at 10.


115. 42 C.F.R. § 441.356(b)(1).
Medicaid. Though states’ budgetary concerns are legitimate, there are other cost-controlling mechanisms that better resolve these concerns. 117 1915(c) eligibility is designed with other requirements that seek to control runaway spending, including restricted conditions of eligibility that limit the number of individuals who qualify for each waiver program. 118 Unlike services provided through regular state Medicaid that must be equally available to all beneficiaries, 119 1915(c) waiver services can be limited to a subset of the population, such as the elderly. 120 This narrow tailoring can naturally limit runaway spending while still fulfilling the goal of integration for individuals at risk of institutionalization. 121 The states’ ability to impose population limits for 1915(c) waiver programs is another way they can control costs without imposing arbitrary standards. 122 Finally, integration itself has the potential to serve as a cost control. When seniors live in the community rather than in institutions, they contribute to the local and national economy, pay taxes, and are active members of society. 123 Despite the available cost control mechanisms, CMS continues to enforce the cost-neutrality provision as it stands; however, a reviewing court could find that CMS acted arbitrarily and capriciously.

C. An Arbitrary and Capricious Formula

The APA provides standards that govern judicial review of agency actions. 124 When reviewing an agency action, a court may set an action aside if it is arbitrary and capricious. 125 Under this standard, the agency must
“articulate a rational connection between the facts” it considered and the decision it made. The reviewing court must then determine whether the agency considered the factors relevant to its determination when making its decision and whether it demonstrated a clear error in judgment.

CMS has the authority to waive certain requirements when granting a state’s 1915(c) waiver program to provide home- and community-based services to individuals at risk of institutionalization. In return, states must assure that their estimated per capita expenditures on the waiver do not exceed the amount of their expenditures without the waiver. Though this requirement seems straightforward, CMS still maintains discretion in interpreting how cost-neutrality is determined. For example, CMS retains discretion in designing the formula used to evaluate cost-neutrality, determining which factors are considered, and deciding whether to compare costs in the aggregate or on a case-by-case basis. Should someone challenge CMS’s decisions in promulgating the cost-neutrality calculation, the reviewing court could find that CMS acted arbitrarily and capriciously because it excluded important cost factors from the formula and did not require states to compare the costs in the aggregate.

CMS’s predecessor, the Health Care Financing Administration (HCFA), exercised this discretion in determining cost-neutrality in its 1985 final rule when it designed the first cost-neutrality calculation. The pilot formula contained eleven different factors, including the estimated number of individuals who would likely receive institutional care without the waiver, those who would receive non-institutional services under the state plan, and those who would receive acute services under the regular state plan. Moreover, the Agency specified that states must include the estimated costs of services

126. Friends of Yosemite Valley v. Kempthorne, 520 F.3d 1024, 1032 (9th Cir. 2008).
127. See Motor Vehicle Mfr.’s Ass’n v. State Farm Mut. Auto. Ins., 463 U.S. 29, 43 (1983). An agency’s decision is arbitrary and capricious if the agency (1) relied on factors which the Legislature did not intend for the agency to consider, (2) entirely ignored an aspect of the problem, (3) offered an explanation that was contrary to the evidence before the agency, or (4) offered a conclusion that was so implausible that it could not be ascribed to the agency’s expertise or a difference in views. Motor Vehicle Mfr.’s Ass’n v. State Farm Mut. Auto. Ins., 463 U.S. 29, 43 (1983).
129. Id. § 1396n(c)(2)(D).
130. See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,015 (Mar. 13, 1985) (demonstrating that CMS exercised this leeway in interpreting the cost-neutrality requirement in its 1985 rulemaking).
131. See 42 C.F.R. § 441.303(f)(2)–(10).
132. See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. at 10,013–16.
133. The eleven-factor formula is reproduced below.
like physician visits, hospitalization, and prescription drugs when making their cost-neutral assurances.  

In 1994, CMS revised the cost-neutrality regulation by reducing the formula to only four factors. These factors only represent the estimated average cost of institutional care and the estimated average cost for home- and community-based services. In justifying this change, CMS stated it wanted to simplify the calculation and reduce the complexity of the procedure. CMS asserted that its experience with the program justified reducing the formula to consider only the cost of services.

Similar to the facts in State Farm, CMS did not articulate a sufficient reason for revising the equation to only consider these four factors. Specifically, CMS failed to explain why it did not consider other implicated costs. For example, including administrative and non-service costs would have a significant impact on cost-neutrality determinations because there are many fees associated with running an institution that are nonexistent in home- and community-based services. These costs to the government are eliminated in home- and community-based settings because the beneficiary is responsible for them. The current cost-neutrality formula fails to reflect the amount of money the government saves by providing home- and community-based services. CMS failed to articulate any reason for this decision.

134. Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. at 10,015.
135. See 42 C.F.R. § 441.303(f)(1).
136. Id.
137. See id. (using the following equation to compare factors: \( D + D' \leq G + G' \)).
138. See Medicaid Program; Home and Community-Based Services and Respiratory Care for Ventilator-Dependent Individuals, 59 Fed. Reg. 37,702, 37,708 (July 25, 1994).
139. See id.
140. In its previous rulemaking, CMS explicitly stated that administrative costs would not be considered because it assumed such costs were equal in institutional and community settings. See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,024–25 (Mar. 13, 1985). Building costs continue to be excluded from the calculation, and states must explain their method for subtracting room and board costs in their 1915(c) waiver applications. See Application for a 1915(c) Home and Community-Based Services Waivers, Appendix 1-5: Exclusion of Medicaid Payment for Room and Board, MEDICAID, https://www.medicaid.gov/medicaid-program-information/by-topics/waivers/downloads/hcbs-waivers-application.pdf (last visited May 2, 2019).
141. Institutional expenses can include rent, utilities, insurance, appliances, and furniture, as well as the cost of providing food, transportation, and activities. See H.R. Rep. No. 97-208, at 966 (1981) (Conf. Rep.).
Moreover, CMS does not explicitly require that cost-neutrality assurances be made on an aggregate level, which is more consistent with the pursuit of integration.\textsuperscript{144} Although CMS recognized the benefit of calculating cost-neutrality on an aggregate basis, it failed to require that states use this method.\textsuperscript{145} It went on to imply that in most cases an aggregate calculation is used.\textsuperscript{146} The data, however, does not support CMS’s contention. In fact, a study conducted only six years after the final rule found that only fourteen states were using the aggregate-based calculation.\textsuperscript{147} Therefore, CMS failed to provide a rational explanation for its decision and should be challenged under the APA’s arbitrary and capricious standard.

V. PRELIMINARY RECOMMENDATIONS

A. What can CMS Do to be Consistent with Integration Goals?

CMS can revisit the cost-neutrality provision by reopening the notice-and-comment rulemaking period and providing interested parties with an opportunity to share insights on how the cost-controlling mechanism can be improved to meet the needs of older Americans.\textsuperscript{148} By posting a notice for a request for information, CMS can solicit comments from relevant stakeholders regarding improvements to the cost-neutrality formula.\textsuperscript{149} CMS can engage in informal notice-and-comment rulemaking to consider the suggestions and expertise of relevant stakeholders and revise the cost-neutrality formula.\textsuperscript{150}

\textsuperscript{144} See Medicaid Program; Home and Community-Based Services and Respiratory Care for Ventilator-Dependent Individuals, 59 Fed. Reg. at 37,708 (stating that the state has the option to calculate cost-neutrality on the aggregate, and in virtually all cases it does). In passing the 1915(c) waiver legislation, Congress expected that states would use an aggregate calculation. See H.R. Rep. No. 97-208, at 965 (“The conferees expect the costs of medical assistance for the home and community-based care recipients will be divided by the number of individuals who are determined likely to be institutionalized without these services.”).

\textsuperscript{145} See Medicaid Program; Home and Community-Based Services and Respiratory Care for Ventilator-Dependent Individuals, 59 Fed. Reg. at 37,708.

\textsuperscript{146} See 42 C.F.R. §§ 354(b)(3), (c), (d), 464(c).

\textsuperscript{147} See LeBlanc, supra note 96, at 165 (emphasizing the lack of consistent implementation across the states).


\textsuperscript{149} Agencies use requests for information when seeking input on whether there is a need to change an existing rule. See HHS Regulations Toolkit, U.S. DEP’T OF HEALTH & HUMAN SERVS., https://www.hhs.gov/regulations/regulations-toolkit/index.html (last visited Jan. 16, 2019).

\textsuperscript{150} See generally 5 U.S.C. § 553. CMS can accomplish this by issuing a notice of proposed rulemaking in the \textit{Federal Register}, providing an opportunity for public comment, and then publishing a final rule with an accompanying statement of its basis and purpose after considering relevant comments.
There are several possible ways to improve the cost-neutrality calculation to be consistent with the overall objective of integration. First, CMS can require states to calculate average per capita costs based on aggregate data. By mandating cost-neutral assurances on an aggregate basis, states would be able to accept seniors whose long-term care costs are higher than the cost-neutral cap so long as the average long-term care costs of all seniors on the 1915(c) waiver are lower than the cap. CMS can also change the current formula to reflect factors that ultimately weigh in favor of individuals seeking community-based services. Currently, the regulation does not consider administrative or other non-service costs for either home- and community-based services or institutional-based settings. Considering those costs may prove to be favorable for individuals seeking community-based services because the cost-neutral cap would be higher. The formula could also be improved to account for other costs associated with institutional settings, such as litigation and liability insurance.

Another possibility is to reformulate the cost-neutral calculation to reflect decreased medical assistance expenses as institutions are replaced with community-based services. As more seniors choose to age in-home, a state Medicaid agency may be paying to maintain an institution that is not at full capacity while also providing community-based care during the first year of its 1915(c) program. As the state increases provisions of community-based

151. See Medicaid Program; Home and Community-Based Services and Respiratory Care for Ventilator-Dependent Individuals, 59 Fed. Reg. 37,702, 37,708 (July 25, 1994).

152. See Carlson, supra note 96, at 193–94. Previously, CMS assumed that states would automatically choose to use an aggregate calculation and refused to make this a requirement; in fact, research shows that most states do not use the aggregate calculation. See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. 10,013, 10,024 (Mar. 13, 1985) (rejecting commenters’ suggestions to allow states to use their own computations as long as they demonstrate a reduction in long-term care expenditures); LeBlanc, supra note 96.


154. Id. However, the administrative and non-service costs for institutional services can be higher than those for community-based services. See generally H.R. REP. No. 97-208, at 967 (1981) (Conf. Rep.).


156. Despite this cost-saving potential, CMS previously asserted that it would not fully consider this factor. See Medicaid Program; Home and Community-Based Services, 50 Fed. Reg. at 10,025.

157. See Paula Span, In the Nursing Home, Empty Beds and Quiet Halls, N.Y. TIMES (Sept. 28,
services, the institution may be closed.\textsuperscript{158} A state Medicaid agency could create an eight-year plan under the 1915(c) waiver, demonstrating its intent to phase out institutions; however, under the current cost-neutrality formula, the state’s 1915(c) application would be denied.\textsuperscript{159} A cost-neutrality calculation that allows a state to average the annual cost of home- and community-based services and institutional services would be more favorable because the higher expenses incurred during the beginning are offset by the savings during subsequent years of the program.\textsuperscript{160} The solutions discussed in this section will address some of the existing problems under the current, arguably arbitrary and capricious, regulation.

\section*{B. What Can Congress and State Agencies Do?}

Aside from challenging the cost-neutrality provision under the APA, there are many solutions available that the federal legislature and state agencies can address. The Legislative Branch can also address the problems caused by cost-neutrality by eliminating the provision altogether, or by incorporating home- and community-based services as part of the mandatory services provided by state Medicaid plans. The ADA was enacted twenty-eight years ago, and \textit{Olmstead} was decided nineteen years ago.\textsuperscript{161} The 1915(c) waiver was initially a method for states to experiment with providing home- and community-based services through innovative programs.\textsuperscript{162} Now, it may be time for Congress to recognize home- and community-based services as the standard, not the exception.\textsuperscript{163}

\begin{itemize}
 \item 158. See \textit{id.}
 \item 159. Waivers are initially approved for three years and can be extended by another five years; however, extensions are not granted if the state does not meet its cost-neutrality assurances during the initial three-year waiver period. See 42 C.F.R. § 441.304(a)-(b) (2017).
 \item 160. This calculation is consistent with one of the original justifications of the 1915(c) waiver: cost containment. See \textit{H.R. Rep. No. 97-208}, at 964 (1981) (Conf. Rep.). Congress even promoted closing under-utilized facilities when it enacted the 1915(c) legislation. \textit{Id.} at 952–53.
\end{itemize}
When Congress first considered home- and community-based services, it was cognizant of the costs that might be associated with providing these services but still realized that such services would benefit society.\textsuperscript{164} It also recognized that it is the Legislature’s duty to combat historic isolation and segregation of disabled individuals, including seniors.\textsuperscript{165} Congress can resolve the issues associated with cost-neutrality by addressing the root of the issue and repealing the cost-neutral mandate.\textsuperscript{166}

One solution is to eliminate the cost-neutrality requirement and rely on the cost controlling mechanisms inherent in the 1915(c) waiver to prevent runaway spending.\textsuperscript{167} Any concerns about run-away spending can be adequately dealt with by the existing eligibility requirements of the 1915(c) waiver, which limit the number of people who can receive services.\textsuperscript{168} The limited eligibility standards put any fear of the “woodwork” effect to rest because home- and community-based services are already reserved only for people who, but-for the provision of in-home services, would be institutionalized.\textsuperscript{169} States can impose further restrictions, such as limiting eligibility to people with certain diagnoses or residing in certain regions—these measures allow states to focus availability of services to the populations that have the greatest need while also preventing excess spending.\textsuperscript{170}

Another option is to create a single federal program exclusively for home- and community-based waivers.\textsuperscript{171} One issue with 1915(c) waivers is that they are designed to target specific groups and some scholars argue that this targeting causes fragmentation of services, meaning that groups of equally deserving individuals are competing for limited resources.\textsuperscript{172} Unfortunately, states continuously opt to limit services—to specific populations, to specific

\textsuperscript{164} See H.R. Rep. No. 101-485, at 490 (1990) (stating that short-term financial burdens are outweighed by the long-term benefit to society).

\textsuperscript{165} The congressional sponsors of the ADA’s predecessor, § 504, described the treatment of disabled individuals as “shameful oversights,” forcing them to live “shunted aside, hidden and ignored.” 117 Cong. Rec. 45,974 (1971) (statement of Hon. Charles A. Vanick).

\textsuperscript{166} See Williams, supra note 85, at 237 (arguing that publicly funded long-term care should be centered around services, not settings).

\textsuperscript{167} See Williams, supra note 85, at 238.

\textsuperscript{168} 42 U.S.C. § 1396a(a)(10)(B) (2012). But see Cost-Effectiveness of Home and Community-Based Services Background, supra note 7, at 20 (noting that states frequently create long waiting lists for home- and community-based services because the 1915(c) programs are so limited).

\textsuperscript{169} See 42 U.S.C. § 1396c(1).

\textsuperscript{170} See Home & Community-Based Services 1915(c), supra note 6.

\textsuperscript{171} See Nick Vento, There’s No Place Like Home: How PPACA Falls Short in Expanding Home Care Services to the Elderly, 28 J.L. & HEALTH 347, 370 (2015).

regions, and by specific monetary amounts—as long they are permitted to do so.  

A single, mandatory home- and community-based services program would not only eliminate any incentive for states to limit services, it would also simplify the application process for seniors because there would be a single point of entry for home- and community-based services.

Home- and community-based services should be incorporated into the mandatory services offered through state Medicaid plans. State Medicaid plans are not subject to cost-neutrality requirements, thus incorporating the 1915(c) services into the mandatory plans resolves the problems that cost-neutrality currently poses. This solution is socially important because it makes home- and community-based services the rule, rather than the exception.  

Beneficiaries of the 1915(c) waiver value the range and amount of services provided because many of these services are not included in the existing home health services for state Medicaid plans. When incorporating home- and community-based services into the mandatory services required for all state Medicaid plans, Congress should not eliminate any of the vital services currently offered through the 1915(c) waiver.

A final solution would put the burden on states to rethink the way they provide long-term care services in the home or community. The most commonly used service by beneficiaries is personal care aides, a relatively expensive service. However, there are a myriad of other types of services available that can meet a senior's long-term care needs at a lower expense. Some older individuals may have needs that can be fully addressed by a homemaker or with adult day care; alternatively, they may benefit from a combination of part-time personal care aide services and some less expensive services. Not all states offer these services, and those that do offer them

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173. See Hermer, supra note 172, at 79.
174. See Vento, supra note 171, at 371.
175. See Vertees, supra note 84, at 65 (noting that other health care programs are not subject to cost-neutrality).
176. See Cost-Effectiveness of Home and Community-Based Services Background, supra note 7.
178. For example, in the District of Columbia, personal care aide services are reimbursed at $20.04 per hour, while homemaker services are reimbursed at $18.75 per hour and adult day health services are reimbursed at $25.72. See D.C. Mun. Regs. tit. §§ 29-4211.4, 4214.1, 4218.1 (2017).
179. See generally MACPAC, supra note 177, at 7 (finding that high-cost beneficiaries were twice as likely to use day services than the average 1915(c) beneficiary).
180. See, e.g., Georgia Waiver Fact Sheet, Medicaid, https://www.medicaid.gov/
do not make good use of them. By exploring a combination of services, states can reduce overall spending on long-term care services while still providing services in the seniors’ preferred location.

CONCLUSION

Community integration is a critical component of elder and disability rights. Not only does integration combat the historic isolation and stereotyping of disabled individuals, it also provides substantial health benefits. Aging in-home is a healthier and safer alternative to residing in a nursing facility, not to mention that most seniors prefer to age in their homes. Medicaid’s home- and community-based waiver programs offer the right services and support that allow seniors to live and participate in their communities at little to no cost to them. However, the current approach to cost-neutrality severely impedes states’ ability to use the 1915(c) waiver to effectuate their goal of community integration. In light of the fast-growing elderly population in the United States, the cost-neutrality calculation must be reformed to meet the need for community integration. Alternatively, Congress or state Medicaid agencies can explore alternatives to cost-neutrality to limit expenses while still providing essential long-term care services to people who need them.

181. Some states, such as the District of Columbia, technically offer these less expensive services. See D.C. Mun. Regs. tit. § 29-4200.1 (2017). However, they are almost never used. See Mary Ann Parker & Tina Nelson, AARP Legal Counsel For the Elderly, Spech at the D.C. Bar Pro Bono Center Training: Untangling D.C. Medicaid: Representing D.C Residents to Protect Home and Community Based Services (Apr. 4, 2019).

182. See Marilyn J. Rantz et al., Evaluation of Aging in Place Model with Home Care Services and Registered Nurse Care Coordination in Senior Housing, 59 NURSING OUTLOOK 37, 37 (2011) (finding that seniors who aged in home exhibit better physical and mental health); see also Jaffe, supra note 3.

183. See Cost Sharing Out of Pocket Costs, supra note 19.