

## ADA at 25: Aging Advocates Celebrate Partnership And Progress

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### INTRODUCTION

On July 26, disability and aging advocates will celebrate the 25th anniversary of President George H.W. Bush signing the Americans with Disabilities Act (ADA) into law. ADA initiatives have done much to improve the quality of life for millions of people with disabilities, including older adults with disabilities, by expanding participation in community life, improving infrastructure, and reducing communication barriers. As one in three older adults lives with some type of disability,<sup>1</sup> and an aging population means this ratio will increase, the law's protections will continue to shape and improve the lives of older Americans.

This celebratory time offers an opportunity to reflect on the ADA's history and its future potential. The disability community's unwavering commitment to the passage and implementation of the ADA continues to inspire aging advocates. As the health care delivery system becomes increasingly complex and the struggle for full community integration persists, partnership between the disability and aging advocacy community is more important than ever.

Unfortunately, the aging community does not always recognize the important impact the ADA has had on older adults. This paper will provide aging advocates with some background on the ADA and outline four key areas where the ADA continues to shape the environment, care, and services for older adults. As aging and disability advocates continue to partner to advance policy, it's important to remember how much the ADA accomplished in just twenty-five years.

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1 ADMINISTRATION FOR COMMUNITY LIVING, *Profile of Older Americans: 2014*, [www.aoa.acl.gov/Aging\\_Statistics/Profile/2014/docs/2014-Profile.pdf](http://www.aoa.acl.gov/Aging_Statistics/Profile/2014/docs/2014-Profile.pdf).

# About the ADA and Olmstead

The ADA, Title II includes a mandate that individuals with disabilities should have the opportunity to live their lives like individuals without disabilities.<sup>7</sup> Nearly ten years into ADA implementation, in a landmark case, *Olmstead v. L.C.*,<sup>8</sup> the Supreme Court held that this mandate prohibits the segregation of individuals with disabilities. *Olmstead* and the ADA are embodied in the long-term services and supports advocacy movement. Here is some background on both:

The Americans with Disabilities Act's five titles encompass protections in the area of: employment, public entities and public transportation, public accommodations, and telecommunications.<sup>9</sup> Title I, Employment, establishes an equal opportunity for individuals with disabilities to benefit from employment opportunities by prohibiting discrimination in recruitment, hiring, promotions, and other employment opportunities.<sup>10</sup> Title II requires state and local governments to offer people with disabilities an equal opportunity to benefit from all programs and services. It also covers public transportation, and requires all public transit services to comply with accessibility requirements. Title III, the Public Accommodations section, prohibits businesses and nonprofit providers from discriminating against people with disabilities. This section also establishes specific architectural standards for new and altered buildings, and requires the removal of barriers in existing buildings. Title IV encompasses Telecommunications Relay services for individuals with hearing and speech disabilities. Finally, Title V covers miscellaneous provisions, such as the Act's relationship with other laws.

Nearly ten years after the ADA became law, the Supreme Court issued a decision protecting individuals against unnecessary institutionalization. In the *Olmstead* case two women who were confined in a Georgia state psychiatric hospital claimed the state's failure to provide them with a community-based alternative to institutionalization violated the ADA and its implementing regulations mandating community integration.<sup>11</sup> The Court agreed, finding that unnecessary institutionalization of a person with a disability is a form of discrimination under Title II of the ADA. The decision created a significant legal protection for all people in need of long-term care and provided renewed energy for advocates advancing policies designed to shift the provision of long-term care from institutions to home and community-based settings.

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2 DEPARTMENT OF JUSTICE, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (June 22, 2011), [www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm).

3 527 U.S. 581 (1999).

4 Americans with Disabilities Act of 1990, 42 U.S.C. 126.

5 ADA.Gov, *A Guide to Disability Rights Laws* (2009), [www.ada.gov/cguide.htm](http://www.ada.gov/cguide.htm).

6 Eric Carlson and Gene Coffey, *10-Plus Years after the Olmstead Ruling*, hereinafter OLMSTEAD REPORT (2010), [www.thescanfoundation.org/sites/default/files/nsclc\\_olmstead.pdf](http://www.thescanfoundation.org/sites/default/files/nsclc_olmstead.pdf).

## “Unwavering Perseverance:” The Disability Rights Community Secures Passage of the ADA

In her essay, *The History of the Americans with Disabilities Act: A Movement Perspective*,<sup>7</sup> Disability Rights Education and Defense Fund attorney Arlene Mayerson beautifully describes the disability rights community’s journey toward the ADA. Years before introducing legislation, thousands of committed advocates worked tirelessly “organizing and attending protests, licking envelopes, sending out alerts, drafting legislation, speaking, testifying, negotiating, lobbying, filing lawsuits, being arrested,” with the goal of publicizing the injustices people with disabilities faced daily.

This persistent advocacy developed into a legislative movement. On a Tuesday morning in September, 1988, over 700 people with disabilities, parents, and advocates packed a room to witness a joint Senate and House hearing on S. 2345, the initial draft of the ADA. Throughout that year—an election year—the disability rights community kept the momentum going.<sup>8</sup> Both presidential candidates, Republican George H.W. Bush and Democrat Michael Dukakis, endorsed civil rights protections for people with disabilities.

The disability community’s unwavering advocacy secured a 76-8 vote in the Senate for the Americans with Disabilities Act in 1989. Ten of the original “yea” votes, six Republican and three Democrat, remain in the Senate today.<sup>9</sup> In his remarks before the vote, ADA champion, Senator Tom Harkin, called on his colleagues to “celebrate the 25th anniversary of the Civil Rights Act of 1964” by “finally recognizing the civil rights of Americans with Disabilities.”<sup>10</sup> A year later, on May 22, 1990, the House of Representatives approved the legislation by a unanimous voice vote. Finally, after years of united grassroots advocacy and lobbying, Congress sent the legislation to the President. On July 26, 1990, as he signed the bill into law, President George H.W. Bush reflected on the “strong and inspiring coalition” of bipartisan lawmakers that worked for many years to make “this new historic civil right a reality.”<sup>11</sup>

## Long-Term Services and Supports Balanced Toward Home and Community-Based Care

The “aging in place” concept would not be making progress towards reality without the ADA. Disability rights law propelled the widespread availability of home and community-based services from a lofty goal, accessible only to those who could afford it, to an actionable policy expectation. Most people strongly prefer to receive care and services in their homes and communities, as opposed to institutional settings.<sup>12</sup> The ADA and *Olmstead* gave that preference the legal legs it needed to advance policy.

Twenty-five years ago, the overwhelming majority of long-term care was delivered in nursing homes and other institutional settings. In 1997, two years before *Olmstead*, 75% of Medicaid long-term care dollars paid for

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7 Arlene Mayerson, *The History of the Americans with Disabilities Act: A Movement Perspective* (1992), <http://dredf.org/news/publications/the-history-of-the-ada>.

8 Id.

9 Senator Coats (R-IN), Senator Cochran (R-MS), Senator Grassley (R-IA), Senator Hatch (R-UT), Senator Leahy (D-VT), Senator McCain (R-AZ), Senator McConnell (R-KY), Senator Reid (D-NV), Senator Shelby (R-AL) and Vice President Biden.

10 The ADA Legacy Project, *S. 933-Americans with Disabilities Act-101st Congress* (1990), [www.mn.gov/mnddc/ada-legacy/ada-legacy-moment21.html](http://www.mn.gov/mnddc/ada-legacy/ada-legacy-moment21.html).

11 EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, *Remarks of President George Bush at the Signing of the Americans with Disabilities Act* (July 26, 1990).

12 AARP, Research and Strategic Analysis, *Home and Community Preferences of the 45+ Population* (November, 2010), <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf>.

institutional care, while merely 25% paid for care where most people want it: at home and in the community.<sup>13</sup> *Olmstead*'s legal precedence, coupled with determined advocacy since then, advanced efforts to “rebalance” Medicaid long-term care spending and services away from institutions and towards home and community-based services (HCBS).

Now, fifteen years post-*Olmstead*, nearly half of all Medicaid long-term care spending goes to care at home and in the community.<sup>14</sup> Recent legislative and administrative policy changes have helped ensure progress on this front. During the health care reform debate, disability and aging advocates<sup>15</sup> coalesced to support rebalancing initiatives, such as the Balancing Incentive Payment Program,<sup>16</sup> Money Follows the Person extension, and the Community First Choice Option.<sup>17</sup> Thanks to the Affordable Care Act, these programs are now up and running and helping create new opportunities for older adults to receive care at home and in the community.

Progress has also been helped by the current administration's commitment to expand HCBS options. In 2009, President Obama commemorated the 10th anniversary of *Olmstead* and announced the “Year of Community Living.”<sup>18</sup> Department of Justice attorneys, in collaboration with disability rights attorneys across the country, are vigorously enforcing Title II integration mandate under *Olmstead* enforcement.<sup>19</sup> Three years ago, based on the principle that “people with disabilities and older adults should be able to live where they choose, with the people they choose and fully participate in their community,”<sup>20</sup> the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities merged to form the Administration on Community Living.<sup>21</sup>

As a result of the ADA and *Olmstead* and the work of advocates and policymakers since then, today's older adults have far more options than ever before. Twenty-five years ago, an older adult living with cognitive or physical limitations, and needing assistance with daily living activities, would likely find a nursing home was her only option. Today, she has greater access to care and services to live in her home, or in a less restrictive environment. More work, however, is needed as the rates of usage of HCBS by older adults still lags behind other populations and our systems continue to overly rely on institutions to meet long-term care needs.

## Improved Infrastructure and Physical Access

Today's older adults will age into communities that are better equipped to meet their mobility needs than any previous generation. ADA Title II implementation forever changed our nation's landscape by removing barriers and modernizing built environments to open up access for people with disabilities.

As older adults age, their physical mobility usually gradually declines. One in three older adults falls each year.<sup>22</sup>

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13 The Hilltop Institute, *Rebalancing Long-Term Services and Supports: Progress to Date and a Research Agenda for the Future* (June 14, 2011), [www.hilltopinstitute.org/publications/RebalancingLTSS-ProgressToDateAndResearchAgendaForFuture-June2011.pdf](http://www.hilltopinstitute.org/publications/RebalancingLTSS-ProgressToDateAndResearchAgendaForFuture-June2011.pdf).

14 CENTERS FOR MEDICARE AND MEDICAID SERVICES, *Medicaid Expenditures for Long-Term Services and Supports in 2012* (April 28, 2014), [www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-2012.pdf](http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-2012.pdf).

15 The Disability and Aging Collaborative, formerly known as the Friday Morning Collaborative, is a collaborative of national organizations led by the National Council on Aging, [www.ncoa.org/public-policy-action/long-term-services--supports/disability-aging-collaborative.html](http://www.ncoa.org/public-policy-action/long-term-services--supports/disability-aging-collaborative.html).

16 OLMSTEAD REPORT at 13.

17 OLMSTEAD REPORT at 2.

18 CENTERS FOR MEDICAID AND CHIP SERVICES, *Community Living Initiative*, [www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/community-living/community-living-initiative.html](http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/community-living/community-living-initiative.html).

19 DEPARTMENT OF JUSTICE, Civil Rights Division, *Olmstead: Community Integration for Everyone*, [www.ada.gov/olmstead/index.htm](http://www.ada.gov/olmstead/index.htm).

20 ADMINISTRATION FOR COMMUNITY LIVING, *Organization*, [www.acl.gov/About\\_ACL/Organization/Index.aspx](http://www.acl.gov/About_ACL/Organization/Index.aspx).

21 Id.

22 CENTERS FOR DISEASE CONTROL AND PREVENTION, *Falls Among Older Adults: An Overview* (2013), [www.naccho.org/advocacy/positions/upload/14-01-Prevention-of-Older-Adult-Falls.pdf](http://www.naccho.org/advocacy/positions/upload/14-01-Prevention-of-Older-Adult-Falls.pdf).

Multiple chronic conditions and the development of a later-in-life disability may limit mobility.<sup>23</sup> In addition to physical challenges, older adults face transportation limitations. Vision or cognitive loss, as well as physical changes, such as reduced strength and arthritis, may compromise older adults' ability to drive.<sup>24</sup> Without access to transit options, this driving loss causes isolation. On any given day, more than 50% of non-drivers 65 and older stay home.<sup>25</sup> Older adults with disabilities need access to transit services and environments where they can move safely.

The ADA Title II clearly defines the individual's right to transit programs and requires public transit providers to operate paratransit services for riders who cannot reach or use buses or rail.<sup>26</sup> Though these services have limitations, such as distance, cost, and trip time, they allow for greater access than traditional bus and rail systems.<sup>27</sup>

In addition to transit systems, older adults with disabilities need streetscapes that allow walking and wheelchair access through safe sidewalks, timed street crossings and safe traffic speeds.<sup>28</sup> In the last twenty-five years, to comply with the ADA, municipalities have implemented curb cuts and accessible and timed pedestrian crosswalks. These changes, while often thought of as primarily assisting younger individuals with disabilities, offer tremendous benefits to the many older adults with mobility limitations, including those walking more slowly with shorter steps, using a walker or other assistive walking device, or operating a wheelchair.

Moving forward, the ADA and changing demographic needs are forcing communities to rethink their design and infrastructure to foster greater accessibility. Cities will continue to evolve as the aging and disability communities continue to advocate for livable communities that support residents at all stages of mobility.<sup>29</sup>

## Advancements in Communications Access

Beyond breaking down physical barriers, the ADA's communication access protections connect people with disabilities to their communities and the world. The ADA's communications protections, coupled with rapidly-improving technological advancements, ensure today's older adults with disabilities are more connected than ever before.

Older adults are likely to face physical changes that may limit communication abilities. Between their 65th and 74th birthdays, 25 percent of older adults will face some hearing loss.<sup>30</sup> By 75, one in two older adults will live with a disabling hearing loss.<sup>31</sup> Vision loss is also a common part of aging. As a result of age-related macular degeneration, glaucoma, cataract, and diabetic retinopathy, one in three older adults lives with a vision-reducing eye disease.<sup>32</sup> For African American and Hispanic older adults, the chance of developing moderate or extreme vision loss as part of the

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23 CENTERS FOR DISEASE CONTROL AND PREVENTION, *The State of Aging and Health in America* (2013), [www.cdc.gov/features/agingandhealth/state\\_of\\_aging\\_and\\_health\\_in\\_america\\_2013.pdf](http://www.cdc.gov/features/agingandhealth/state_of_aging_and_health_in_america_2013.pdf).

24 Id.

25 AARP, *Enhancing Mobility Options for Older Americans* (2004), [www.aarp.org/content/dam/aarp/livable-communities/plan/transportation/enhancing-mobility-options-for-older-americans.pdf](http://www.aarp.org/content/dam/aarp/livable-communities/plan/transportation/enhancing-mobility-options-for-older-americans.pdf).

26 Mary Kihl et al., *Livable Communities: An Evaluation Guide*, AARP (2005), [http://assets.aarp.org/rgcenter/il/d18311\\_communities.pdf](http://assets.aarp.org/rgcenter/il/d18311_communities.pdf).

27 Rodney Harrell et al., *Preserving Affordability and Access in Livable Communities: Subsidized Housing Opportunities Near Transit and the 50+ Population*, AARP PUBLIC POLICY INSTITUTE (2009), [www.hud.gov/offices/cpd/about/conplan/pdf/preservingaffordablehousingNeartransit.pdf](http://www.hud.gov/offices/cpd/about/conplan/pdf/preservingaffordablehousingNeartransit.pdf).

28 *Transportation: A Challenge to Independence for Seniors: Hearing Before the Sen. Special Committee on Aging*, 113th Cong. (2013) (statement of Grant Baldwin, Director, Division of Unintentional Injury Prevention, Centers for Disease Control and Prevention).

29 See also *Livable Communities*, AARP, [www.aarp.org/livable-communities](http://www.aarp.org/livable-communities) (last visited June 15, 2015).

30 NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD) citing a review of the 1999-2010 Nation Health and Nutrition Examination Survey (2015), [www.nidcd.nih.gov/health/statistics/pages/quick.aspx](http://www.nidcd.nih.gov/health/statistics/pages/quick.aspx).

31 Id.

32 David A. Quillen, *Common Causes of Vision Loss in Elderly Patients*, AMERICAN FAMILY PHYSICIAN July, 1999.

aging process is particularly acute.<sup>33</sup>

The ADA requires state and local governments (Title II) and businesses and nonprofit organizations (Title III) to communicate effectively with people who have communication disabilities. This means that any person with a vision, hearing, or speech disability, has a right to receive information from the entity and a right to communicate with the entity.<sup>34</sup> As a result, these entities must provide auxiliary aids and services to allow for effective communication.<sup>35</sup> A host of aids that are now commonplace and easily accessible today were not a required prior to the ADA. These services include telephone handset amplifiers, assistive listening systems, hearing aid compatible telephones, open or closed captioning, videotext displays, audio recordings, large print materials, and materials in electronic formats.<sup>36</sup>

While the ADA continues to break down communication barriers, changing technology and infrastructure systems mean advocacy for accessible communication remains important. For example, as the public health care delivery system shifts to private and integrated models, communicating the changes to beneficiaries becomes increasingly important. These changes are increasingly complex, making thorough review and testing of beneficiary materials for accessibility even more important.

## Strengthened Legal Protections

After the ADA passed, disability rights attorney Arlene Mayerson noted the disability community is a “force to be contended with in Congress, in the voting booth and in the media.”<sup>37</sup> Twenty-five years and many, many important legal decisions later, the courtroom is another forum of power. The ADA continues to be a resource the aging and disability community use to protect access to critical programs and services.

A history of the ADA’s litigation prowess is beyond the scope of this paper. Briefly, beyond *Olmstead*, the Supreme Court interpreted the ADA in several seminal decisions over the last few decades. In *Bragdon v. Abbott*,<sup>38</sup> the Court found that HIV constitutes a disability under the ADA, and a dentist’s refusal to treat an HIV infected patient unless the treatment occurred in a hospital constituted discrimination based on the individual’s disability. Three years later, the ADA garnered major media attention as a powerful legal hook in *Casey Martin v. PGA*.<sup>39</sup> The Court interpreted Title III’s public accommodation provision as a protection against discrimination. Under the decision, the PGA’s refusal to allow Mr. Martin to use a golf cart, despite his disability, constituted an ADA violation.

In recent years, the disability and aging communities’ combined legal expertise proved to be a powerful force in the courts. In 2009, the Disability Rights Education and Defense Fund (DREDF), Disability Rights Oregon, and Justice in Aging (at the time, the National Senior Citizens Law Center), successfully partnered to represent a class of 3 million individuals with blindness and vision loss in *American Council of the Blind v. Astrue*. The class action case relied on the ADA to argue the Social Security Administration must produce its communications in alternate formats for beneficiaries with sight impairments. In *Oster v. Lightbourne*, Justice in Aging, Disability Rights California, the National Health Law Program, home care unions and others, partnered to prevent cuts in California’s In-Home Supportive Services (IHSS) program. Working together, the legal advocates and their clients

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33 CENTERS FOR DISEASE CONTROL, *The State of Vision, Aging and Public Health in America* (2011), [www.cdc.gov/visionhealth/pdf/vision\\_brief.pdf](http://www.cdc.gov/visionhealth/pdf/vision_brief.pdf).

34 DEPARTMENT OF JUSTICE, Civil Rights Division Disability Rights Section, *ADA Requirements: Effective Communication* (2014), available at [www.ada.gov/effective-comm.pdf](http://www.ada.gov/effective-comm.pdf).

35 *ADA Best Practices Tool Kit for State and Local Governments*, [www.ada.gov/pcatoolkit/chap3toolkit.htm](http://www.ada.gov/pcatoolkit/chap3toolkit.htm) (last visited June 15, 2015).

36 *Id.*

37 Mayerson, ADA Essay.

38 524 U.S. 624 (1998).

39 532 U.S. 661 (2001).

used the ADA to preserve Medicaid funding for California’s pioneering in-home services and supports program that allows low-income older adults and persons with disabilities to stay safely in their own homes. When Disability Rights California, the National Health Law Program, AARP Foundation Litigation, Justice in Aging, and Morrison and Foerster LLP (as pro bono counsel) combined forces in *Darling v. Douglas*, the organizations again used the power of the ADA to successfully preserve California’s Adult Day Health Care program as a Medicaid benefit for 35,000 low income people with disabilities, including older adults, who would have otherwise been threatened with institutionalization.

## CONCLUSION

As aging advocates mark this anniversary, we not only celebrate the law and its policy advancements, but the disability rights movement’s model for change. The policy improvements, outlined above, forever changed what it means to grow old in America. Three decades ago, the aging process meant a more confined world, limited options, and isolation. Today, thanks to the thousands of people with disabilities who spoke up and demanded equal rights, the “shameful wall of seclusion”<sup>40</sup> is coming down. However, discrimination and barriers for older adults with disabilities remain.

As aging advocates push to eliminate aging barriers, we look to the disability community for inspiration and partnership. In the years-long journey to develop the ADA, the disability community never faltered, always reminding the world that disability rights matter. When the legislation stalled in Congress, the advocacy community united in force, protesting at the Capitol, crawling up the steps,<sup>41</sup> and demanding Congress listen to their voice.

Though it took many years, Congress did listen, and decades later, the nation is far better for it. As aging and disability advocates continue to push for our shared goals—access to livable communities, communications in alternate formats, and long-term services and supports at home and in the community—we are far stronger when we advocate together.

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40 Remarks of President George H.W. Bush at the Signing of the Americans with Disabilities Act (1990) [www.eeoc.gov/eeoc/history/35th/videos/ada\\_signing\\_text.html](http://www.eeoc.gov/eeoc/history/35th/videos/ada_signing_text.html).

41 William J. Eaton, *Disabled Persons Rally, Crawl Up Capital Steps*, LOS ANGELES TIMES (Mar. 13, 1990), [http://articles.latimes.com/1990-03-13/news/mn-211\\_1\\_capitol-steps](http://articles.latimes.com/1990-03-13/news/mn-211_1_capitol-steps).

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