

Section 2. History of Disability Statutes

While we focus here on federal legislation addressing the rights of persons with disabilities to Accessible Healthcare – Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ACA) and Section 1557 of the Patient Protection and Affordable Care Act (PPACA) – over the decades there have been significant pieces of federal legislation addressing the needs of persons with disabilities, all of which served as the foundation for legislation mandating Accessible Healthcare. Among them, the Social Security Act of 1935,¹ which, in addition to creating the Social Security program, it also provided financial assistance for blind persons, dependent and “crippled” children, aged persons and others. The Civil Rights Act of 1964² promised to eliminate discrimination in any place of public accommodation based on race, color, religion, or national origin. Although persons with disabilities were omitted from the Civil Rights Act, the legislation is important as it served as a model for legislation protecting the rights of persons with disabilities, albeit 9 years later. In 1965, Title 19 of the Social Security Act³ created Medicaid, a federal and state funded program to pay medical costs for certain persons with disabilities and others with low income. The Architectural Barriers Act of 1968⁴ was the first measure by Congress to ensure access to the built environment for people with disabilities. It required the buildings and facilities that were designed, built or altered with federal dollars or leased by federal agencies be accessible. The law covered a wide range of facilities including Veterans Affairs’ medical facilities, federal office buildings, U.S. courthouses, among others. Also,

¹ Cohen, Wilbur J., "The Development of the Social Security Act of 1935: Reflections Some Fifty Years Later" (1984). *Minnesota Law Review*. 2500. <https://scholarship.law.umn.edu/mlr/2500>

² Pub. L. 88 – 352, 78 Stat. 241, July 2, 1964

³ 42 U.S.C. §§1396–1396v; subchapter XIX, chapter 7, Title 42. Regulations relating to Title XIX are contained in chapter IV, Title 42, and subtitle A, Title 45, Code of Federal Regulations.

⁴ Pub. L. 90–480 (42 U.S.C. §§4151 et seq.)

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in 1968, Congress passed the Fair Housing Act⁵ in an effort to impose a solution to the problem of unlawful discrimination in housing based on race, color, sex, national origin or religion. Again, persons with disabilities were not even contemplated in that legislation. In 1972, Title IX of the Education Amendment Act⁶ was passed to prohibit discrimination based on sex at educational institutions receiving federal funds. Section 1684 of the Educational Amendment Act⁷ prohibited discrimination against the blind and severely visually impaired in any education program or activity receiving federal funds. Educational institutions were not required to provide special services, but admission was not to be denied solely based upon blindness or severely impaired vision. The Fair Housing Act was amended in 1988 to prohibit discrimination on the basis of handicap in the sale or rental of housing, and also mandated barrier-free construction for designated new multi-unit housing construction.⁸

All of those laws were the foundational building blocks for the trio of federal legislation – discussed in this Section – that explicitly address the civil rights of persons with disabilities to accessible healthcare.

A. Section 504 of the Rehabilitation Act of 1973⁹

The most consequential piece of federal legislation affecting the lives of persons with disabilities – as it was the first and served as the predicate for legislation to come – was the Rehabilitation Act of 1973 (“Rehabilitation Act”). The Rehabilitation Act has three major sections.

⁵ 42 U.S.C. §§ 3601 – 3631

⁶ 20 U.S.C. §1681, et seq.

⁷ Pub. L. 92-318; 20 U.S.C. § 1684

⁸ 42 U.S.C.A. §§ 3601 et seq.

⁹ 29 U.S.C. § 794.

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The first, Section 501 mandates federal agencies to develop affirmative action programs for the hiring, placement and advancement of persons with disabilities.¹⁰ Section 502 established the Architectural and Transportation Barriers Compliance Board, which would ensure compliance with the Architectural Barriers Act of 1968, pursue ways to eliminate transportation barriers and seek ways to make housing accessible.¹¹ Section 503 required parties contracting with the United States to use affirmative action to employ qualified persons with disabilities.¹² However, the most important section of the Rehabilitation Act is Section 504 (Section 504).¹³ Modeled after Title VI of the Civil Rights Act of 1964 and Title IX of the Education Amendments Act of 1972, it states:

“No otherwise qualified handicapped individual in the United States... shall solely on the basis of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.”¹⁴

In 1974, a major amendment to Section 504 expanded the definition of a person with disability from one who could benefit from rehabilitation services to any person who “has a physical or mental impairment which substantially limits one or more of such persons major life activities; has a record of such impairment; or is regarded as having such an impairment.”¹⁵ That expanded definition broadened the scope and reach of Section 504.

¹⁰ 29 U.S.C.A. § 791

¹¹ 29 U.S.C.A. § 792

¹² 29 U.S.C.A. § 793

¹³ 29 U.S.C.A. § 794

¹⁴ *Id.*

¹⁵ 29 U.S.C.A. § 706(8)(B).

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Interestingly, Section 504 was inserted into the legislation almost as an afterthought. As explained in the National Council on Disability's, *Equality of Opportunity: The Making of the Americans with Disabilities Act*,¹⁶ "... [u]nlike the Civil Rights Act of 1964, Section 504 did not emerge in response to protest. Rather, it was created silently by a group of congressional staff members. No suggestion for such a provision was made at the hearings, and the provision was not in the original draft of the bill. Staff added the section late in the deliberative process without any statement of congressional intent or appropriations to finance it. Not a single member of Congress mentioned the section during floor debate..."¹⁷ However, the surreptitious inclusion of the Section 504 language came with a price, that is, as there was no deliberation as to its language, there were also no appropriations or specific mandate that regulations be promulgated to give it effect.

The drafting of those regulations fell upon the Department of Health, Education and Welfare ("HEW," the predecessor to the Department of Health and Human Services), and its regulations would become the guidelines for all the other federal agencies. However, between 1973 and 1977, spanning over three consecutive administrations – Nixon's, Ford's and Carter's – Section 504 regulations were delayed, in large part over concerns about potential costs.¹⁸ During that period regulations were drafted by attorneys in the Department of HEW's Office for Civil Rights, which were sent to the Secretary of HEW with a recommendation to publish them in

¹⁶ National Council on Disability's, *Equality of Opportunity: The Making of the Americans with Disabilities Act*, pp. 1-17, originally published July 26, 1997, reissued, 2010. Available at: https://ncd.gov/publications/1997/Equality_of_Opportunity_The_Making_of_the_Americans_with_Disabilities_Act

¹⁷ *Id.* at 12.

¹⁸ *Id.* at 13.

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proposed form in the Federal Register for public comment, which he did, resulting in proposed regulations.¹⁹ However, opposition was developing on the part of covered entities — hospitals, universities, state and county governments - and the regulations were not published. In 1976, the disability community filed a lawsuit in federal court, *Cherry v. Mathews*, 419 F. Supp. 922 (D.D.C. 1976), to compel the HEW Secretary to promulgate regulations implementing Section 504. The government defended the case asserting that the statute imposed no explicit duty to issue regulations in contrast to other civil rights and similar statutes which directly confer rule-making authority.²⁰ However, in examining the legislative history of Section 504, the court ruled that Congress contemplated swift implementation of Section 504 through a comprehensive set of regulations, noting the discrimination prohibitions were not self-executing, and therefore, regulations must be issued, but he did not specify when.²¹ Once the Carter Administration was in office in 1977, instead of signing the regulations, HEW set up a task force to “study” the regulations, but with no representation from the disability community. It was learned by the disability community, through delays and leaks from inside HEW, that the regulations were being seriously weakened in coverage, enforcement, and the whole integration mandate.

¹⁹ See 41 Fed.Reg. 20296 (May 17, 1976); *id.* at 29548 (July 16, 1976).

²⁰ *Id.* at 924.

²¹ *Cherry v. Mathews*, 419 F. Supp. 922, 924 (D.D.C. 1976)(The statute's discrimination prohibitions were certainly not intended to be self-executing. Reports from the Senate and the House on the 1974 Amendments to the Act indicate that Congress contemplated swift implementation of 504 through a comprehensive set of regulations. S.Rep. No. 1139, 93d Cong., 2d Sess. 24-25 (1974); H.R.Rep. No. 1457, 93d Cong., 2d Sess. 27-28 (1974) (Conference report); S.Rep. No. 1297, 93d Cong., 2d Sess. 39-40 (1974); see *Red Lion Broadcasting Co. v. FCC*, 395 U.S. 367, 380-81, 89 S.Ct. 1794, 23 L.Ed.2d 371 (1969) (importance of subsequent congressional declaration of intent). In view of the foregoing, the Court concludes that the Secretary is required to promulgate regulations effectuating 504.

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Regulations were critically needed to clarify what Section 504's provisions meant as there was no definition, for example, of "handicapped" and no definition of what "otherwise qualified" meant. In addition, enforcement timelines had to be developed, as well as an administrative enforcement mechanism. The regulations would provide a consistent, coherent interpretation of Section 504's legal intent rather than leaving it up to any judge who heard a Section 504 case to interpret what the law meant, which was what was occurring. Throughout the country, contradictory rulings were being handed down by courts who were asked to interpret the meaning of Section 504's nondiscrimination mandate. In 1977, a series of transportation cases across the country made that point clear. In Alabama, a District Court held that although it was necessary for persons in wheelchairs to arrange for someone to help them board and alight from buses owned by a county transit authority, the fact that they were permitted to ride was sufficient for compliance with the Rehabilitation Act of 1973 and therefore there was no cause of action for the plaintiff or the class she purported to represent. *Snowden v. Birmingham-Jefferson Cty. Transit Auth.*, 407 F. Supp. 394, 397 (N.D. Ala. 1975), *aff'd*, 551 F.2d 862 (5th Cir. 1977). In Wisconsin, a District Court held that it was discriminatory for a county transit board to operate a public mass transit system which did not assure the availability of mass transportation to handicapped persons. *Bartels v. Biernat*, 427 F. Supp. 226, 232 (E.D. Wis. 1977). In Ohio, a District Court held that Section 504's provision that no otherwise qualified handicapped individual should be excluded from participation, solely by reason of handicap, from any program receiving federal financial assistance *did not* require a regional transit authority to make all its buses accessible to wheelchairs. *Vanko v. Finley*, 440 F. Supp. 656 (N.D. Ohio 1977).

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The frustration over the absence of regulations clarifying the meaning of Section 504's mandates was articulated in 1978 by one District Court judge in Colorado:

How plain is the language of ... [Section] 504? What must be done to provide handicapped persons with the same right to utilize mass transportation facilities as other persons? Does each bus have to have special capacity? Must each seat on each bus be removable? Must the bus routes be changed to provide stops at all hospitals, therapy centers and nursing homes? Is it required that buses be able to accommodate bedridden persons? Is it discriminatory to answer any of these questions in the negative? Will the operation of hydraulic lifts on buses involve stigmatizing effects on the persons who use them? If so, is that a discrimination solely by reason of handicap within the meaning of [Section] 504?

Atlantis Cmty., Inc. v. Adams, 453 F. Supp. 825, 831 (D. Colo. 1978).

Jurists were not the only ones frustrated by the absence of Section 504 regulations. The disability community took notice and mobilized. What followed was the first national mass organization of the disability community to engage in civil nonviolent disobedience mandating the passage of Section 504 regulations, culminating in the now infamous "Section 504 Sit-In."²² Sit-ins occurred by persons with disabilities and their supporters throughout the country, but it was the 28 consecutive day occupation of the San Francisco building of the Department of HEW by over 150 persons of varying disabilities, of all ages, races, social and economic backgrounds, that compelled the issuance of the Section 504 regulations. It remains today is the longest

²² We are fortunate in that there's been a number of books, documentaries and movies that recorded the history of the fight for Section 504 regulations. See Disability Rights Education & Defense Fund ("DREDF"), *The Power of 504*, an 18 minute documentary video capturing the drama emotions of this historic civil rights demonstration, available at <https://vimeo.com/channels/504sitin>; also, DREDF's *The 504 Sit-In for Disability Civil Rights*, a June 1997 audio documentary featuring contemporary media coverage of the five or citizens and interviews with some of this demonstrators, available at <https://dredf.org/we-shall-not-be-moved/>; and Short History of the 504 Sit In, Kitty Cohen, available at: <https://dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/>.

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nonviolent occupation of federal building in the United States.²³ As a direct result of the sit-in, the HEW Secretary signed the Section 504 regulations.

Congress amended the Rehabilitation Act in 1978 providing for private right of action by adding Section 505(a)(2), which provides that "... the remedies, procedures, and rights set forth in Title VI of the Civil Rights Act of 1964 shall be available to any person aggrieved by any act or failure to act by any recipient of Federal assistance or provider of such assistance under section 504."²⁴ In addition, Section 505(b) was added, authorizing a court "... in any action or proceeding to enforce or charge a violation of a provision of this subchapter, . . . to allow a prevailing party, other than the United States, a reasonable attorney's fee as part of its costs."²⁵ The availability of attorney's fees to a prevailing party was important as it facilitated private litigants' enforcement of the Section 504 mandates, who may otherwise be dissuaded from enforcing their rights under Section 504 for the fear of being burdened by extensive attorney's fees.

Section 504 is far-reaching in that it applies to education programs, public facilities, transportation, and health and welfare services. Until 1990, Section 504 of the Rehabilitation Act was the most significant federal protection for persons with disabilities.

²³ The 504 Sit-in now memorialized in Netflix's 2020 award-winning documentary, *Crip Camp*.

²⁴ Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, § 120, 29 U.S.C. § 794a(b) (Supp. V 1981).

²⁵ *Id.*

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B. The Americans with Disabilities Act²⁶

The Americans with Disabilities Act (“ADA”) is a landmark piece of legislation guaranteeing the civil rights of the then forty-three million Americans with disabilities. The ADA is the most significant comprehensive civil rights legislation since the Civil Rights Act of 1964. Its enactment profoundly changed the legal rights of persons with disabilities. Building upon Section 504 and all of the other laws previously discussed above and incorporating the judicial interpretations of Section 504, the ADA expanded the scope of protection for persons with disabilities by extending its application to employers, public entities and public services, public accommodations, transportation programs and telecommunications, regardless of whether they received federal financial assistance. The ADA promised a future in which civil rights would join existing programs of financial support to create meaningful equality of opportunity for persons with disabilities.

The ADA originated in a 1987 proposal from the then National Council on the Handicapped (now known as the “National Council on Disability,” (referred to here as the “Council”)) consisting of a complete draft of what was called the Americans with Disabilities Act of 1987.²⁷ The Council is an independent federal agency whose statutory functions include providing to the Congress recommendations affecting disabled individuals.²⁸ The Council’s

²⁶ Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C.A. §§ 12101-12213 (West Supp. 1991) and 47 U.S.C.A. §§ 225, 611 (West 1991) For a comprehensive overview of the story behind the passage of the ADA, see Lennard J. Davis, *Enabling Acts: The Hidden Story of How the Americans with Disabilities Act Gave the Largest US Minority Its Rights* (2015). See also Rothstein, *Would the ADA Pass Today? Disability Rights in an Age of Partisan Politics*, 12 St. Louis U. Health L.J. 271–330 (2019).

²⁷ National Council on Disability’s, *Equality of Opportunity: The Making of the Americans with Disabilities Act*, pp.50-51.

²⁸ 29 U.S.C. § 781 (1988).

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proposal followed its two prior reports - *Toward Independence (1986)* and *On The Threshold Of Independence (1988)*.²⁹ In *Toward Independence*, the Council issued a report on all federal laws and programs affecting persons with disabilities and made 45 specific legislative remedies to identified problems, all geared towards increasing the dignity and independence of Americans with disabilities, to the President, the Congress, the Secretary of the Department of Education, the Commissioner of the Rehabilitation Services Administration, and the Director of the National Institute of Handicapped Research. In *Toward Independence* the Council prioritized the advancement of “equal opportunity laws” for persons with disabilities as its primary recommendation and proposed that Congress “in act a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage in setting clear, consistent and enforceable standards prohibiting discrimination on the basis of handicap.”³⁰ While the recommendations in *Towards Independence* were well received by both sides of the aisle in Congress, there was a lack of attention to the number one recommendation in the report – the creation of an equal opportunity law. Thus, *On The Threshold Of Independence* documented the progress that occurred since *Towards Independence* was published and consistent with its recommendations in *Towards Independence*, it identified 21 statutory provisions that were enacted into law and eight bills that were introduced in Congress, but not yet enacted, that would

²⁹ See *Toward Independence An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations*, A Report to the President and to the Congress of the United States, February 1986. Available at <https://ncd.gov/publications/1986/February1986>; and *On the Threshold of Independence Progress on Legislative Recommendations from Toward Independence*, January 1988. Available At <https://ncd.gov/publications/1988/Jan1988>

³⁰ *Toward Independence*, p. 18.

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further proposals included in *Towards Independence*.

On April 20, 1988, the Americans with Disabilities Act (Act) was introduced on the floor of the United States Senate and on the following day an identical bill was introduced on the floor of the House of Representatives. It was shepherded through the Senate and House by legislators that had a personal connection to disability – personally, or siblings, parents, or others with disabilities. What followed was a concerted mobilization of disability community to publicize the Act, mobilize grassroots support, solicit the endorsement of presidential candidates, enlist congressional cosponsors and establish the Act as a top priority for the next Congress.³¹ As noted in the Council’s *Equality of Opportunity: The Making of the Americans with Disabilities Act*, the goal was not to have the Act enacted, but to get it on the legislative agenda as a congressional priority; indeed, its sponsors never intended it to come to a vote in 1988.³² And in fact, no further Congressional action was taken on the Act in 1988, but the introduction of the Act fulfilled its intended purpose as it became one of the first orders of business when Congress convened for the 101ST session in 1989.³³

In January through March 1989, the original version of the American with Disabilities Act, was redrafted and reintroduced as its major sponsors concluded the original bill introduced in 1988 was too ambitious and stood little chance for passage, noting that one of the major obstacles in passage of the Act was the cost and burden imposed upon covered entities.³⁴ Cost became an issue because unlike other civil rights legislations, the ADA requires businesses and

³¹ National Council on Disability’s, *Equality of Opportunity: The Making of the Americans with Disabilities Act*, p. 58

³² *Id.* at 75.

³³ *Id.*

³⁴ *Id.* at 81.

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employers to spend money on accommodations and modifications. Doors just did not need to be opened, they needed to be widened. The distinguishing feature of the ADA when compared to civil rights legislation for other persons in the country is that actual change (*i.e.*, dollars and cents) is needed above and beyond a change of heart. Hearings on the revised Act began in the Senate in May 1989. Religious organizations argued for an exemption from the public accommodation provisions for religious schools and religious organizations as it would be too costly. The small business community also argued for an exemption from the public accommodation provisions because of associated costs and as small business owners were exempt from other civil rights legislation. All the while, the disability community organized across the country taking to the streets demanding passage of the Act as they were growing impatient.³⁵

The bill finally made it out of the Senate on September 7, 1989 by a vote of 76 to 8, in what was described as a remarkable demonstration of bipartisanship.³⁶ As the House began deliberation on the bill in the spring of 1989, the business community vigorously and strategically lobbied the House by mobilizing pressure throughout the country. The US Chamber of Commerce focused attention to the public accommodations provisions that would apply to virtually every publicly and privately owned business that opens its doors to the public. The American Bus Association, the American Public Transit Authority and Greyhound focused on transportation issues. The National Restaurant Association, the US Chamber of Commerce and the National Association of Manufacturers focus their attentions on the provisions dealing with employment. Business groups believed the language in the ADA was vague and that terms, such as “undue

³⁵ *Id.* at 86-90.

³⁶ *Id.* at 99

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hardship,” “readily achievable,” and “readily accessible,” were inadequately defined and thereby invited frivolous lawsuits and provided little guidance to businesses to determine if they were compliance.³⁷

Continuing their advocacy for the passage of the ADA, the disability community engaged in grassroots lobbying appealing directly to their representatives in their home offices, calling into local radio shows and making local television appearances. As described in the Council’s *Equality of Opportunity: The Making of the Americans with Disabilities Act*, during the winter of 1989 – 1990, the largest single letter writing campaign took place directed at members of the House of Representatives.³⁸ Thousands of “New Year’s” postcards were mailed to congressional representatives, committee members and the Speaker of the House as well as the minority leader of the House of Representatives. Printed on the front of the postcard was “ADA” in giant letters for background and set over it was a statement “Our New Year’s Wish for Congress: Open the Doors to America. Pass the Americans with Disabilities Act.” Printed on the back of the postcard was “The President has endorsed it. The Senate has overwhelmingly passed it.” In large letters: “Now it’s up to you. Don’t weaken a law that will strengthen America.”³⁹ In addition, persons with disabilities were providing powerful testimony at congressional hearings while at the same time taking to the streets. Countless numbers of protests occurred throughout the country, occupying federal buildings and blockading main entrances to those buildings. Some attached chains and bicycle locks to their necks and locked them to door handles in federal buildings so

³⁷ Id. at 107-108.

³⁸ Id., at 110-111

³⁹ Council’s *Equality of Opportunity: The Making of the Americans with Disabilities Act*, pp. 110-111.

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security could not simply lift them from their wheelchairs.⁴⁰ Bus terminals were being effectively shut down as persons with wheelchairs had circled terminals and blocked buses.

Deliberation of the ADA in the House of Representatives was significantly more complex than in the Senate. As detailed in the Council's *Equality of Opportunity: The Making of the Americans with Disabilities Act*, in the Senate the bill went only to one committee and one subcommittee. However, in the House it went to four committees and six subcommittees in addition to a number of non-legislative hearings to generate information that could be used by other committees during floor deliberations, resulting in 164 representatives, compared with 16 senators and many more House staff than Senate staff, reviewing the bill in committee.⁴¹ Moreover, whereas chairmen of full committees in the Senate were chief sponsors of the bill, in the House, its sponsor was not even a member of any of the committees reviewing the bill.⁴²

The bill finally made its way to the House floor for a vote on May 17, 1990, at which time seven amendments were introduced, one allowing wheelchair use in wilderness areas, another opposing a 10% salary cap on the amount of funding for accommodations an employer had to provide to an employee.⁴³ Two of the proposed amendments concerned transportation: one rejected a requirement that all new rail vehicles had to be accessible; and the second proposed giving the Secretary of Transportation authority to waive a mandate requiring lifts in buses for urban areas of less than 200,000 or in non-urban areas.⁴⁴ Another amendment, the most

⁴⁰ *Id.* at 111-112.

⁴¹ *Id.* at 103-104.

⁴² *Id.* at 105.

⁴³ *Id.* at 128-132

⁴⁴ *Id.* at 132-133.

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controversial, would have enabled employers to remove persons with contagious diseases, such as AIDS, from food handling positions.⁴⁵ After debate and vote on those amendments, the House then passed the bill, approving it overwhelmingly with 95% of the vote.⁴⁶

As the House and the Senate passed two separate bills, the House and Senate conferred on May 24, 1990 to try to resolve the differences between the two bills.⁴⁷ 81 points of dispute were at issue between the two bills.⁴⁸ House and Senate staff were able to reach agreement on all but two disputed issues. The first, was a House amendment granting employers the right to remove persons with contagious diseases from food handling positions. The second, related to whether persons alleging discrimination by either a member of the House or Senate would have a private right of action (meaning, the right to sue) a senator or representative in District Court.⁴⁹ The first was ultimately rejected, and as for the second, it was decided persons with disabilities would have the same enforcement rights against members of the House and Senate as they otherwise would against other entities covered by the ADA.⁵⁰ With all hurdles cleared, on July 12, 1990, the House passed the ADA by more than 90% of affirmative votes, and the Senate passed it the following day with over 93% affirmative votes.⁵¹

At 10:00 a.m., on July 26, 1990, President George H. W. Bush signed into law the ADA on the south lawn of the White House in front of approximately 3,000 people, abled and disabled.⁵²

⁴⁵ *Id.*

⁴⁶ *Id.* at 134. Of the 423 members voting, 403 voted in favor of the ADA.

⁴⁷ *Id.* at 137.

⁴⁸ *Id.*

⁴⁹ *Id.* at 138.

⁵⁰ *Id.* at 143-144.

⁵¹ *Id.* at 144-145.

⁵² *Id.* at 145-147.

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Noting that a year earlier the Berlin Wall came tumbling down, the President as he signed the ADA said “Let shameful wall of exclusion finally come tumbling down.”⁵³ The promise of equality of opportunity, full participation, independent living and economic self-sufficiency for the then approximately 43 million persons with disabilities in the United States was cemented in writing. Its intent was to level the playing field for persons with disabilities who were ignored in all of the previous legislation securing the civil rights of Americans.

C. The Patient Protection and Affordable Care Act

On March 23, 2010, a Democratic-controlled Congress passed the Patient Protection and Affordable Care Act (Affordable Care Act or ACA)⁵⁴ landmark legislation, which increased eligibility for Medicaid for the poor in most states, and it provided subsidies for private and small-group insurance for the middle class through qualified health plans that are sold by health insurance exchanges. It enacted a series of market reforms that addressed long-standing complaints regarding health insurance coverage, including limiting the use of gender and age ratings, lifetime and annual maximums, and exclusions for preexisting conditions. The ACA also addressed other long-standing coverage complaints by requiring many health plans to cover “essential health benefits” such as maternity care, child health services, and mental health and substance use disorder services.⁵⁵

While overwhelmingly deemed healthcare reform and healthcare insurance reform

⁵³ *Id.* at 147.

⁵⁴ Public Law 111-148, 111th Congress, 2nd Session, 124 Stat. 119, An act entitled The Patient Protection and Affordable Care Act.

⁵⁵ The Bureau of National Affairs, Inc., Federal Health Care Discrimination Law, Chapter 1. Introduction, www.bloomberglaw.com.

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legislation, the ACA also contained several provisions affecting the rights of persons with disabilities and aimed at improving their access to healthcare services, specifically:

- Section 1557, Nondiscrimination, is the ACA's general nondiscrimination mandate. By specific incorporation of the Civil Rights Act of 1964, the Education Amendments of 1972 and the Age Discrimination Act, together with Section 504 of the Rehabilitation Act of 1973, Congress for the first time enacted a civil rights act that is expressly directed at health programs and activities.⁵⁶ By incorporating statutes granting civil rights protections to persons based upon race, color, national origin, gender age, and now disability, Congress made it clear that civil rights extend to health programs and activities. And critically important unlike Section 504, Section 1557 did not exclude religious organizations that own or operate healthcare facilities.
- Section 2705, Prohibiting Discrimination against Individual Participants and Beneficiaries Based on Health Status. Ensures that persons with disabilities and other persons with preexisting conditions will have access to private health insurance. As of 2014, health insurers were no longer able to discriminate against people due to the presence of disabilities or other pre-existing conditions. Health insurers were no longer allowed to deny coverage, charge higher premiums, exclude benefits relating to pre-existing conditions, rescind coverage or impose annual caps on benefits after someone is injured, becomes disabled or acquires a new condition.⁵⁷
- Section 4302. Understanding Health Disparities: Data Collection and Analysis. Amends the Public Health Service Act, 42 U.S.C. 201, et seq. by adding Sec. 3101, Data Collection, Analysis, and Quality, which identifies, for the first time, disability as a bona fide health disparity demographic for research and data collection. It also promotes research of the reasons for health and health care disparities among persons with disabilities and requires the Secretary of Health and Human Services to survey health care providers to assess: locations where persons with disabilities access primary, acute (including intensive), and long term care; the number of providers with

⁵⁶ 42 U.S.C § 18116(A), Except as otherwise provided for in this title (or an amendment made by this title), an individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments). The enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purposes of violations of this subsection.

⁵⁷ U.S. Code, 42 U.S.C. § 300gg-4. Prohibiting discrimination against individual participants and beneficiaries based on health status

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accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria set forth in the Section 510 of the Rehabilitation Act of 1973; and the number of employees of health care providers trained in disability awareness and patient care of individuals with disabilities.⁵⁸

- Section 4203, Removing Barriers and Improving Access to Wellness for Individuals with Disabilities. Amended the Rehabilitation Act of 1973 by adding Sec. 510, Establishment of Standards for Accessible Medical Diagnostic Equipment. It directed the U.S. Access Board (Access Board) in consultation with the Food and Drug Administration, to develop, by March 23, 2012, new access standards for medical diagnostic equipment used in (or in conjunction with) physician's offices, clinics, emergency rooms, hospitals, and other medical settings.⁵⁹ Medical diagnostic equipment includes equipment historically problematic for persons with disabilities, such as: examination tables, examination chairs (including chairs used for eye examinations or procedures, and dental examinations or procedures), weight scales, mammography equipment x-ray machines, and other radiological equipment commonly used for diagnostic purposes by health professionals. The standards are to address independent access to, and use of, equipment by people with disabilities to the maximum extent possible. The access standards are merely voluntary guidelines for hospitals, healthcare facilities and providers and do not become enforceable standards until adopted by the Department of Justice or the Department of Health and Human Services. Once the Department of Justice and/or the Department of health and Human services adopted the guidelines as standards, the Access Board was then required to develop ADA Accessibility Guidelines (ADAAG) to serve as the minimum baseline for the standards. The voluntary guidelines and standards are very similar, but only the standards have legal authority.
- Sec. 5307, Cultural Competency, Prevention, and Public Health and Individuals with Disabilities Training. Amended Section 741 of the Public Health Service Act, 42 U.S.C. 293e, to require hospitals and schools of medicine and dentistry to develop educational curricula on cultural (disability) competency.⁶⁰ Cultural competency is essential in closing the disparities gap in healthcare. It improves providers' knowledge and awareness of disabilities and of the diverse needs of patients not only with different types of disabilities, but also of patients with the same type of disability.

⁵⁸ 42 U.S.C. § 300kk

⁵⁹ 29 U.S.C. § 794f

⁶⁰ SEC. 5307. CULTURAL COMPETENCY, PREVENTION, AND PUBLIC HEALTH AND INDIVIDUALS WITH DISABILITIES TRAINING, Public Law 111-148, 111th Congress, 2nd Session, 124 Stat. 119, An act entitled The Patient Protection and Affordable Care Act.

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The Affordable Care Act has come under considerable attack and the scope of its application has been diminished considerably since its enactment in 2010. In 2012, the United States Supreme Court narrowly preserved the ACA's "individual mandate" in *National Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519 (2012), which required certain individuals to maintain minimum essential health insurance coverage and imposed a penalty on certain taxpayers who failed to meet those requirements. The majority of the Supreme Court found the individual mandate was a valid exercise of Congress's taxing power.⁶¹ In December 2017, flexing its taxing power, Congress enacted the Tax Cuts and Jobs Act (TCJA),⁶² which among other things, eliminated the individual mandate payment as of January 1, 2019 by reducing the amount of the required payment specified in the Affordable Care Act to zero.⁶³ As of the date of this paper, before the Supreme Court of the United States, is the Trump Administration's push for the court to invalidate, in totality, the Affordable Care Act. In *State of California, et al. v. State of Texas, et al.*, Docket No. 19 –840 (U.S. Jan 3, 2020) the Trump Administration is asking the justices, among other questions, as Congress has eliminated the individual mandate payment with the passage of TCJA, whether the remainder of the ACA's provisions are inseparable from it.⁶⁴

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⁶¹ *National Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 539 (2012).

⁶² Pub. L. No. 115-97, Tit. I, 131 Stat. 2054.

⁶³ § 11081, 131 Stat. 2092.

⁶⁴ See, Brief for Federal Respondents, In the *State of California, et al. v. State of Texas, et al.*, Docket No. 19 –840 (U.S. Jan 3, 2020). Three questions are presented in the Brief for the Federal Respondents: 1. Whether the plaintiffs have standing to challenge the application of certain provisions of the Patient Protection and Affordable Care Act (ACA), Pub. L. No. 111-148, 124 Stat. 119. 2. Whether, as a result of the elimination of the monetary penalty for noncompliance with the ACA's minimum-essential-coverage requirement, 26 U.S.C. 5000A(a), that requirement is no longer a valid exercise of Congress's legislative authority. 3. Whether, if the minimum-essential-coverage requirement is now invalid, the remainder of the ACA's provisions are inseparable from it.

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Section 4203 of the ACA,⁶⁵ amended Title V of the Rehabilitation Act of 1973⁶⁶ by adding a new section, Section 510. This new section required the Access Board, in consultation with the Food and Drug Administration, to issue accessibility standards for medical diagnostic equipment (“MDE Standards”). Shortly thereafter, on July 26, 2010, the Department of Justice issued its advanced notice of proposed rulemaking as it considered proposing rules to address accessible medical and diagnostic equipment.⁶⁷ As part of its rationale, the Department of Justice stated its experience in the 20 years since the ADA was enacted has given it a better understanding of the barriers posed by inaccessible equipment and furniture and the solutions provided by accessible equipment and furniture, noting that “... [a]ccessible equipment and furniture is often critical to an entity’s ability to provide a person with a disability equal access to its services. Changes in technology have resulted in the development and improved availability of accessible equipment and furniture that benefit individuals with disabilities...”⁶⁸ Also in July 2010, the Department of Justice, together with the Department of Health and Human Services, published a comprehensive guide for healthcare providers and persons with paralysis and mobility disabilities – *Americans with Disabilities Act: Access to Medical Care for Individuals with Mobility Disabilities*⁶⁹ – emphasizing that the accessibility of doctors’ offices, clinics, and other healthcare providers is essential in providing medical care to people with disabilities and that due to barriers, individuals

⁶⁵ 42 U.S.C. § 18001, *et seq.*, Pub. L. 111-148.

⁶⁶ 29 U.S.C. § 794f.

⁶⁷ 75 FR 43452 (July 26, 2010).

⁶⁸ *Id.*

⁶⁹ *Americans with Disabilities Act: Access to Medical Care for Individuals with Mobility Disabilities*. Originally issued July 22, 2010, last updated February 28, 2020. Available at: https://www.ada.gov/medcare_mobility_ta/medcare_ta.htm (last accessed: November 1, 2020).

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with disabilities are less likely to get routine preventive medical care than persons without disabilities.⁷⁰

The Access Board's MDE Standards Advisory Committee issued its final report in December 2013 (Final Report).⁷¹ The Final Report was incredibly comprehensive and identified "inaccessible medical equipment" among the reasons for the susceptibility of persons with disabilities to "experiencing substandard care."⁷² The Final Report cited the growing number of studies (19 in total) documenting physical access barriers involving medical diagnostic equipment, and health disparities experienced by the then approximately 57 million persons with disabilities, including reports concerning individual patients, findings from focus groups, in-depth individual interviews, surveys of relatively small numbers of patients or practitioners, and several larger studies as important contextual considerations that shaped the committee's view of the need for, and the potential nature of, the MDE Standards Report.⁷³

⁷⁰ *Id.*

⁷¹ U.S. Access Board, *Advancing Equal Access to Diagnostic Services: Recommendations on Standards for the Design of Medical Diagnostic Equipment for Adults with Disabilities. The final report of the Medical Diagnostic Equipment Accessibility Standards Advisory Committee*, December 6, 2013. Available at <https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report>.

⁷² *Id.* Other reasons for quality shortfalls identified were clinicians' failures to understand the values, preferences, needs, and expectations of persons with disabilities for their health care; financial barriers caused by insufficient or missing health insurance coverage and inaccessible buildings.

⁷³ *Id.*, at Section 2, Background. Available at <https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report/2-background>. The research publications and studies reviewed included: Andriacchi R., *Primary care for persons with disabilities: the internal medicine perspective*. *Am J Phys Med Rehabil.* 1997;76(3 Suppl):S17-20; Iezzoni L, *Blocked*. *Health Aff (Millwood)*. 2008;27(1):203-209. doi: 10.1377/hlthaff.27.1.203; Kirschner K, et al., *Structural impairments that limit access to health care for patients with disabilities*. *JAMA*. 2007;297(10):1121-1125; Drainoni M, et al., *Cross-Disability experience of barriers to health-care access: Consumer perspectives*. *Journal of Disability Policy Studies*. 2006;17(2):101-115; Iezzoni L, et al., *Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments*. *Oncology Nursing Forum*. 2010;37(6):711-717; Iezzoni L, et al., *Rural residents with disabilities*

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The mountain of empirical evidence reviewed gave voice to the struggles that persons with physical disabilities, particularly women with physical disabilities, were experiencing in receiving even basic care, and the existence of health disparities between persons with disabilities and those without. It was clear: if you are a person with a disability, and a person with a physical disability, you will likely not receive the same level of care as someone who is not disabled given the absence of accessible medical diagnostic equipment.

While the Access Board was developing the MDE Standards, the Department of Justice launched its “Barrier-Free Healthcare Initiative” on July 26, 2012.⁷⁴ While this new initiative was created to address accessibility barriers broadly, its emphasis was on ensuring those who are

confront substantial barriers to obtaining primary care. Health Serv Res. 2006;41(4 Pt 1):1258-1275; Iezzoni L, et al., *More than Ramps. A Guide to Improving Health Care Quality and Access for People with Disabilities.* New York: Oxford University Press; 2006; Iezzoni L, et al., *Implications of mobility impairment on the diagnosis and treatment of breast cancer.* Journal of Women's Health. 2011;20(1):45-52; Kroll T, et al., *Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: A qualitative inquiry.* Health Soc Care Community. 2006;14(4):284-293; Lishner DM, et al., *Access to primary health care among persons with disabilities in rural areas: A summary of the literature.* J Rural Health. 1996;12(1):45-5; Mele N, et al., *Access to breast cancer screening services for women with disabilities.* J Obstet Gynecol Neonatal Nurs. 2005;34(4):453-464; Morrison EH, et al., *Primary care for adults with physical disabilities: Perceptions from consumer and provider focus groups.* Fam Med. 2008;40(9):645-651; Scheer JM, et al., *Access barriers for persons with disabilities: The consumer's perspective.* J Disabil Policy Stud. 2003;14(4):221-230; Smeltzer SC, et al., *Perspectives of women with disabilities on reaching those who are hard to reach.* J Neurosci Nurs. 2007;39(3):163-171; Story MF, et al., *Perspectives of patients with disabilities on the accessibility of medical equipment: Examination tables, imaging equipment, medical chairs, and weight scales.* Disabil Health J. 2009;2(4):169-179.e1.; Bachman SS, et al., *Provider perceptions of their capacity to offer accessible health care for people with disabilities.* J Disabil Policy Stud. 2006;17(3):130-136; Centers for Disease Control and Prevention. *Environmental barriers to health care among persons with disabilities, Los Angeles county, California, 2002-2003.* Morbidity and Mortality Weekly Report. 2006;55(48):1300-1303; Mudrick N, et al., *Physical accessibility in primary health care settings: Results from California on-site reviews.* Disabil Health J. 2012;5(3):159-167; Lagu T, et al., *Access to subspecialty care for patients with mobility impairment: A survey.* Ann Intern Med. 2013;158(6):441-446.

⁷⁴ See, press release, Justice Department Announces Americans with Disabilities Act Barrier-free Health Care Initiative by US Attorney's Offices Nationwide, July 26, 2012. Available at: <https://www.justice.gov/opa/pr/justice-department-announces-americans-disabilities-act-barrier-free-health-care-initiative>

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Deaf or hard of hearing have access to medical information provided to them in a manner that is understandable to them.⁷⁵ And in the nearly 9 years since the launch of the initiative that has borne true as well over 75% of all enforcement actions undertaken by the Department of Justice in furtherance of this initiative address ineffective communication between healthcare providers and persons who are Deaf or hard of hearing.⁷⁶

After considerable delay, on January 9, 2017, the long-awaited MDE Standards were published in the Federal Register.⁷⁷ The Access Board divided the MDE Standards into separate technical criteria based on how the diagnostic equipment is used by the patient: (1) supine, prone, or side lying position; (2) seated position; (3) while seated in a wheelchair; and (4) standing position. For each category, the Access Board provided technical criteria to allow independent access to and ensure the diagnostic equipment was usable by patients with disabilities to the maximum extent possible. The technical requirements for diagnostic equipment used by patients in the supine, prone, or side-lying position and diagnostic equipment used by patients in the seated position focus on ensuring a patient can transfer from a mobility device onto the diagnostic equipment. The other category of requirements focus on the necessary technical requirements to allow a patient to use the diagnostic equipment while seated in their wheeled mobility device, or while standing, respectively.⁷⁸ As the Access Board noted, given the many barriers to healthcare that patients with mobility and communication disabilities encounter due

⁷⁵ *Id.*

⁷⁶ See, DOJ Barrier Free Healthcare Initiative, settlements and enforcement actions, <https://www.ada.gov/usao-agreements.htm>.

⁷⁷ 82 Fed. Reg. 2810 (January 9, 2017)

⁷⁸ *Id.*

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to inaccessible medical diagnostic equipment, if the MDE Standards are adopted by DOJ, individuals with disabilities will benefit from access to and use of diagnostic equipment meeting the MDE Standards, facilitating their ability to “. . . receive health care comparable to that received by their non-disabled counterparts . . .”⁷⁹

As the Access Board completed its work, all that needed to be done was for either the Department of Health and Human Services in its rulemaking authority under Section 1557, or the Department of Justice in its regulatory authority under the ADA, to adopt the standards and thereby make them enforceable, otherwise they were merely guidelines for healthcare providers and manufacturers of medical diagnostic equipment and furniture to voluntarily adopt; neither did. On December 26, 2017, the Department of Justice unceremoniously withdrew its previously announced advanced notice of proposed rulemaking for medical diagnostic equipment and furniture, along with the withdrawal of its proposed rulemaking for the accessibility of web information and next-generation 9-1-1.⁸⁰ The rationale for its withdrawal of the accessible diagnostic medical equipment and furniture proposed rule was to reevaluate whether the accessibility of non-fixed equipment and furniture is necessary and appropriate, incredulously disregarding the rationale for launching its Barrier-Free Healthcare Initiative, the underlying reasons for which it first announced its advanced notice of proposed rulemaking for accessible diagnostic medical equipment and furniture, and ignoring the MDE Standards Advisory

⁷⁹ *Id.*, at 2811.

⁸⁰ 82 Fed. Reg. 60932 (December 26, 2017) Announcing the withdrawal of DOJ’s previously announced Advance Notice of Proposed Rulemaking, entitled “Nondiscrimination on the Basis of Disability by State and Local Governments and Places of Public Accommodation; Equipment and Furniture.” 75 Fed. Reg. 43452 (July 26, 2010).

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Committee's significant findings. Since December 26, 2017, what, if anything, the Department of Justice has done to reassess the necessity of rules adopting the MDE standards is unknown.