# FROM INVALIDS TO INDEPENDENT CITIZENS: HOW VISIBILITY IMPACTED THE DISABLED COMMUNITY AND THEIR FIGHT FOR CIVIL RIGHTS FROM 1860 TO 1990.

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by
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#### **ABSTRACT**

From Invalids to Independent Citizens: How Visibility Impacted the Disabled Community and Their Fight for Civil Rights from 1860 to 1990.

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People with disabilities have often been ignored or forgotten throughout history. This thesis is about the changes in the visibility of individuals with disabilities in the United States and how this affected their civil rights from the post-Civil War era to the passage of the Americans with Disabilities Act (ADA) in 1990. Other scholars who have written about the passage of the ADA have focused solely on the legislative efforts of lobbying Congress, rather than a longer and broader movement for disability rights. However, this thesis shows that the ADA would not have been possible without the efforts of the disabled community to demand their public visibility and their refusal to be hidden, cast aside, or given fewer rights than other Americans.

In the late 19<sup>th</sup> and early 20<sup>th</sup> century, the disabled community did not have equal rights. Instead, they were purposefully excluded through legislation and social segregation. From the 1930s through the 1960s, the disabled community became more visible in society due to the polio epidemics and the return of veterans from World War II. These changes brought about an

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increased visibility in media and society and an increased sense of community among individuals with disabilities not seen in previous years. Around this time, there was an increase in early activism through organizations, some of which were created for individuals with disabilities, while individuals with disabilities created others. The former did not always consider the opinions of individuals with disabilities, while the latter helped the disabled fight for legal equality and equality of opportunity for themselves.

The mid-20<sup>th</sup> century laid the groundwork for future disability rights activists. When the Civil Rights Act of 1964 did not include individuals with disabilities in its protection from discrimination, the disabled community protested and created the Disability Rights Movement. Throughout the 1970s and 1990s, there was an increase in organizations created by and for individuals with disabilities and activism through public protests and demonstrations to fight for civil and legal rights in society and the courts. This increase in activism allowed for protective legislation to be passed, most of which was written by individuals with disabilities, which considered disabilities in terms of civil rights. This legislation led to the Americans with Disabilities Act of 1990, which filled in the gaps in the Civil Rights Act, and prohibited discrimination based on disability in all areas of public life.

## **DEDICATION**

To my friend Catherine who encouraged and commiserated with me throughout this thesis's research and writing process.

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#### INTRODUCTION

In the 1880s, the physically disabled were nothing more than "annoying nuisances." In 1990, the United States passed "the world's first declaration of equality for people with disabilities in any nation." Over a hundred years, the disabled community went from being second-class citizens to being guaranteed the same rights and protections other Americans enjoyed. From 1860 to 1990, this thesis examines the role visibility played in society in granting individuals with disabilities civil rights. The disabled community had gone from being hidden to the spotlight. This thesis will address three overarching themes: first, changes in the visibility of disabilities; second, changes in legislation; finally, changes in the agency by which individuals with disabilities acted for themselves, instead of relying on the federal government. Change happens gradually; it is not an overnight process. Any change thought to be sudden has roots in the past.

From 1860 to the 1920s, post-Civil War to Progressive Era, individuals with disabilities were isolated from society and seen as invalids, pests, burdens, or objects of ridicule. At this time, people with disabilities "did not see themselves as a community with shared interests or rights;" rather, they "[saw] themselves as others saw them," the sick family member with no future. Viewed as inferior and incapable of independence, people with disabilities were denied basic rights and excluded from public life. This exclusion was done through local legislation

<sup>&</sup>lt;sup>1</sup> "ANNOYING NUISANCES.: A LIST OF MINOR OFFENSES NOW PUNISHABLE UNDER THE REVISED ORDINANCE. WILL BE A PUBLIC BENEFIT," *Chicago Daily Tribune*, July 13, 1881, 8.

<sup>&</sup>lt;sup>2</sup> Justin Dart Jr., "ADA: Landmark Declaration of Equality," Worklife 3, no. 3 (1990): 1.

<sup>&</sup>lt;sup>3</sup> Hugh Gregory Gallagher, *Black Bird Fly Away: Disabled in an Able-bodied World*, (Arlington, VA: Vandamere Press, 1998), 9.

<sup>&</sup>lt;sup>4</sup> Susan M. Schweik, *The Ugly Laws: Disability in Public*, (New York: New York University Press, 2009), 4; Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (John Hopkins University Press, 2010), 1-3.

like the Ugly Laws, which banned the physically disabled from public areas to federal legislation, like the Immigration Acts. Individuals with disabilities were often segregated from society in another effort to keep them hidden. Institutions kept them out of the public eye for rehabilitative care, while freakshows drew attention to them on the public's terms. However, society treats disabilities differently based on the causes of the disability, such as disabled veterans. Other exceptions included Stephen Crane's *The Monster* and Helen Keller. The latter half of this period witnessed the rise of the Eugenics Movement. Individuals with disabilities were kept out of sight and out of mind.

As society progressed into the 1930s to 1960s, a rising sense of independence grew among disabled individuals. A new line of thinking also emerged that disabilities were not something to be pitied or a tragedy. Instead, it was "society's myths, fears, and stereotypes that most make being disabled difficult." Thanks to the highly publicized nature of polio-related disabilities, a rising sense of community began to form among disabled individuals and allowed networks to grow. This era also saw the end of the eugenics movement (thanks to Nazi Germany's eugenics program), the return of disabled veterans from World War II, and headway made into the deinstitutionalization movement. Numerous organizations were founded for individuals with disabilities to rehabilitate them and legislation passed focusing on rehabilitation. However, individuals with disabilities had begun to act for themselves with the foundation of the first cross-disability protest and organization. The disabled became more visible in society and fought to change the public's understanding of disabilities. People with disabilities demanded to be seen and heard.

<sup>&</sup>lt;sup>5</sup> Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1994), 5

<sup>&</sup>lt;sup>6</sup> Frieda Zames and Doris Zames Fleischer, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2001), 7.

Finally, these changes led to the start of the Disability Rights Movement, where the disabled community fought for their right to be seen, to be heard, and treated as equals. The movement began officially in the 1970s and culminated with the Americans with Disabilities Act of 1990. During this time many prominent disability rights activists founded various organizations (grassroot and national) that worked to change social perceptions and fight for civil rights. Nationwide, the fight for civil rights often took the form of protests. Whether local or national, protests and demonstrations were crucial to the passage of protective legislation such as the Americans with Disabilities Act (ADA) of 1990. Most legislation passed at this time for the disabled community was drafted by or received input from individuals with disabilities; the disabled community took agency for themselves from the government. Disability rights activists refused to back down and be satisfied with the bare minimum; they resolved to be fully known and fully human in the eyes of the law and society.

## 1. OUT OF SIGHT, OUT OF MIND

In the decades following the Civil War, laws and policies around the United States kept individuals with disabilities primarily out of public sight. The Gilded Age saw an increased number of disabled individuals with injuries and/or amputations which resulted from war or industrial accidents. Their public invisibility, forced upon them by a public unwilling and unable to accept and accommodate, was attained in various ways, but most obviously through legislation and segregation. Local, state, and federal legislation not only limited the freedom of individuals with disabilities to participate in the public sphere or enter the United States, but also banned them from being seen in public. Disabled individuals were often institutionalized in county or state-funded asylums, poorhouses, almshouses, or hospitals. While these institutions were supposed to rehabilitate or care for them, this was seldom the reality. Instead, these institutional warehouses functioned to segregate them from society.

The Progressive Era focused on intense social and political reform to improve society. It was an era of surveillance and containment for people considered deviant and degenerative, and the disabled were automatically lumped into these categories. Born and raised during this era, the Eugenics movement aimed to cull the undesirable and nurture the "ideal American citizen," or the ideal human. Other countries would later take inspiration from this movement, as seen in Nazi Germany in the 1940s. Local officials passed laws restricting domestic relations (parenting and marriage) for disabled individuals and forced sterilization laws nationwide. However, similar to how the Gilded Age was not a Golden Age, the Progressive Era was not progressive for all Americans, especially many disabled Americans. Disability disturbs; it contradicted the growing

<sup>&</sup>lt;sup>7</sup> Kim E. Nielsen, A Disability History of the United States, (Boston: Beacon Press, 2012),

ideas of American Independence and uniqueness during the Gilded Age and Progressive Era.

Disability was a problem to be fixed. The solution – hidden out of sight and out of mind.

#### 1.1 Legislation

In the latter half of the 19<sup>th</sup> century, legislators in various cities nationwide enacted laws that discriminated against physically disabled individuals. Known as the Ugly Laws, these regulations emerged after the Civil War with the rise of industrialization. The Ugly Laws made it illegal for the physically disabled to appear in public. These laws sought to manage beggars, primarily the unsightly or offensive (i.e., beggars with disabilities), and they were also known as "unsightly beggar ordinances." These ordinances regulated the appearance of disabilities until the beginning of the Disability Rights Movement in the 1970s. The most famous law, the Chicago City Code of 1881, read:

Any person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in this city shall not therein or thereon expose himself or herself to public view under penalty of one dollar for each offense. On the conviction of any person for a violation of this section, if it shall seem proper and just, the fine provided for may be suspended, and such person detained at the police station, where he shall be well cared for, until he can be committed to the county poor house.<sup>10</sup>

After this ordinance, a newspaper article stated that putting "crippled" beggars in a poorhouse out of sight "WILL BE A PUBLIC BENEFIT" since their physical appearance would be shocking to other people.<sup>11</sup> The City of Chicago later updated the ordinance in 1911 to ban

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<sup>&</sup>lt;sup>8</sup> Adrienne Phelps Coco, "Diseased, Maimed, Mutilated: Categorizations of Disability And An Ugly Law In Late Nineteenth Century Chicago," *Journal of Social History* 44, no. 1, (Fall 2010): 23-24; Schweik, *Ugly Laws*, 24.

<sup>&</sup>lt;sup>9</sup> Schweik, *Ugly Laws*, 6; Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 864.

<sup>&</sup>lt;sup>10</sup> The Municipal Code of Chicago: Comprising the Laws of Illinois Relating to the City of Chicago, and the Ordinances of the City Council, 1881, Law #1612, 377.

<sup>&</sup>lt;sup>11</sup> "ANNOYING NUISANCES," 8; Coco, "Diseased, Maimed, Mutilated," 26.

"exposure of diseased, mutilated, or deformed portions of the body." People with disabilities were to be made invisible, and the law sought to eliminate them from the public eye.

The Ugly Laws were a post-Civil War phenomenon that coincided with the rise of industry and related industrial accidents that resulted in disfigurement or deformities, such as missing limbs or fingers, blindness, deafness, burns and/or scarring. These injuries, often severe, became more prominent due to lack of safety protocol in the infancy of the Industrial Age.

Disabilities became more visible in society, provoking a sense of revulsion and pity. The language of these laws removed the "unsightly", disabled beggars from the street to be cared for out of sight at a poor house. <sup>13</sup> It is important to note that whether a disability was unsightly or not often corresponded to race, ethnicity, socioeconomic status, and the origins of the disability. <sup>14</sup>

The earliest known Ugly Law was enacted in San Francisco, CA, in 1867: "Order No. 873. To Prohibit Street Begging, and to Restrain Certain Persons from Appearing in Streets and Public Places." This order made a vague distinction between the infirm and unsightly, with only the latter deserving the full force of the law. Per this order, the unsightly beggar could face a harsh fine or be committed to an almshouse indefinitely. Portland, and other cities passed similar bans (Pennsylvania did so at a state level) and while the language may have differed the spirit remained the same. New Orleans, Louisiana also passed an ordinance in 1879 that banned disability through lengthy elaborations on types of misbehavior. One phrase in the long list of misbehaviors associated with disorderly rogues and vagabonds was "wandering abroad and

<sup>&</sup>lt;sup>12</sup> Schweik, *Ugly Laws*, 34.

<sup>&</sup>lt;sup>13</sup> Schweik, *Ugly Laws*, 34-35.

<sup>&</sup>lt;sup>14</sup> Nielsen, A Disability History, 89.

<sup>15</sup> Schweik, Ugly Laws, 24-25.

<sup>&</sup>lt;sup>16</sup> Schweik, Uglv Laws, 27.

<sup>&</sup>lt;sup>17</sup> Susan M. Schweik, "Kicked to the Curb: Ugly Law Then and Now," *Harvard Civil Rights-Civil Liberties Law Review Amicus* 46, (2011): 1-2.

endeavoring by the exposure of wounds or deformities to obtain and gather alms."<sup>18</sup> Although the rationale of the legislation was economic, it also prohibited people from appearing in public based on their physical appearance.

The Ugly Laws were not equally enforced across the country. In Chicago, it is unclear how many people arrested for begging or homelessness were physically disabled. However, New Orleans kept track of those detained for being "wounded vagabonds." Soon after Ordinance #5046 passed in New Orleans, the "corralling of cripples" began. In September 1883, the names of nine people arrested for violating the new ordinance and sent to the Shakespeare Alms House were recorded. Another example of these laws being enforced is the story of "Mother Hastings" in Portland, Oregon, who was given money to leave town after being told she was "too terrible a sight for the children to see," referring to her crippled hands, in 1917. These Ugly Laws were anti-beggar laws at their core. Although they technically applied to the entire population, those living in poverty were predominantly punished for exposure of disabilities in public. For many disabled individuals, mendicancy, or begging, was a means to survive and provide for themselves if their wages or pensions could not do so. However, with the passage of the Ugly Laws, mendicancy was no longer an option.

Excluding the disabled catalyzed excluding other undesirable groups.<sup>24</sup> For example, San Francisco designated Chinese immigrants as "public health intrusions" and sought to quarantine

<sup>&</sup>lt;sup>18</sup> Schweik, *Ugly Laws*, 33.

<sup>&</sup>lt;sup>19</sup> Schweik, *Ugly Laws*, 36-37; Coco, "Diseased, Maimed, Mutilated," 27.

<sup>&</sup>lt;sup>20</sup> "Corralling the Cripples," New Orleans Times-Picayune, Sept. 11, 1883, 2.

<sup>&</sup>lt;sup>21</sup> Schweik, *Ugly Laws*, 34-35.

<sup>&</sup>lt;sup>22</sup> "Love Blooms on Sidewalk," Los Angeles Times, 1917; Schweik, *Ugly Laws*, 148; Schweik, "Kicked to the Curb," 1-2.

<sup>&</sup>lt;sup>23</sup> "Annoying Nuisances," Chicago Tribune, July 13, 1881, 8.

<sup>&</sup>lt;sup>24</sup> Douglas C. Baynton, "Disability and the Justification of Inequality in American History," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky, (New York: New York University Press, 2001), 33.

them through the Ugly Laws. Chicago's Ugly Laws also partially responded to the increasing number of disabled immigrants.<sup>25</sup> From the unsightly beggar to the "undesirable immigrant," the rise of the Ugly Laws coincided with anti-immigration sentiments throughout the U.S.A, especially in the western states.<sup>26</sup>

While the Ugly Laws occurred on the municipal level, legislation excluding disabled individuals also happened at the federal level. The Immigration Act of 1882 prohibited entry to the country to any "lunatic, idiot, or anyone unable to take care of himself or herself without becoming a public charge."<sup>27</sup> In 1907, the law denied entry to those deemed "mentally or physically defective, such mental or physical being of a nature which may affect the ability of such alien to earn a living."<sup>28</sup> The use of diction such as *defect* or *defective* in these laws could refer to any moral, intellectual, or physical abnormality, whether real or perceived. Some states along the Atlantic would search almshouses for disabled immigrants "supported at the public's expense" and deport them back to their home country.<sup>29</sup> Many individuals were denied entry into the country due to disabilities believed to be inherent to specific ethnicities.<sup>30</sup> Slavs were "feebleminded," and Jews were predisposed to "insanities." The criteria for those likely to be a public charge were subjective and determined at the discretion of government officials. It reflected society's desire to exclude and reduce the number of disabilities visible.

<sup>&</sup>lt;sup>25</sup> Schweik, *Ugly Laws*, 30.

<sup>&</sup>lt;sup>26</sup> "UNDESIRABLE IMMIGRANTS: THE SHOCKING OBJECT THAT CRAWLED INTO CASTLE GARDEN YESTERDAY." *New York Times*, Nov. 06, 1879, 3; Schweik, *Ugly Laws*, 167.

<sup>&</sup>lt;sup>27</sup> Immigration Act of 1882, Pub. L. No. 47-376, § 2, 22 Stat. 214

<sup>&</sup>lt;sup>28</sup> Immigration Act of 1907, Pub. L. No. 59-69, 34 Stat. 898; Baynton, "Disability and the Justification of Inequality," 45.

<sup>&</sup>lt;sup>29</sup> "Alien Paupers And Lunatics", *The New York Times*, Feb. 26, 1894, 4.

<sup>&</sup>lt;sup>30</sup> Douglas C. Baynton, "Defect: A Selective Reinterpretation of American Immigration History" in *Civil Disabilities*, ed. by Nancy J. Hirschmann and Beth Linker (Philadelphia: University of Pennsylvania Press 2015), 48-49

<sup>&</sup>lt;sup>31</sup> Baynton, "Defect," 60-61.

The Ugly Laws prevented the physically handicapped from participating in society and immigration laws targeted disabled immigrants. However, for the less visible disabilities there were local laws that restricted a disabled person's civil rights that were guaranteed to other Americans. States could deny or restrict a mentally disabled individual from the right to enter into contracts; often applied to "deaf mutes...[who] was presumed to be an idiot." Mentally disabled individuals (or insane persons) could not enter courts or hold public office. The right to vote was also limited, since many states passed laws that prevented or restricted the insane or *mentally retarded* from voting. Inaccessible buildings or polls often prevented the physically handicapped from being able to vote as well. While these did not outright ban individuals with disabilities from the public eye like the Ugly Laws, they restricted their ability to participate in society to the extent able-bodied Americans could.

#### 1.2 Segregation

Another reality that the disabled faced, outside of targeted legislation, was their involuntary institutionalization into asylums, almshouses, hospitals, and other similar establishments. Society viewed individuals with disabilities as incapable of work and dependent on others to survive, influencing their institutionalization. Families were the first line of care for a "dependent," followed by the community; however, in the late 19<sup>th</sup> century, a shift occurred as the burden of care was transferred to the county and state.<sup>34</sup> Following the Civil War, many low-income families no longer had the financial means to care for a disabled relative, so they would

<sup>&</sup>lt;sup>32</sup> Maria Pearce Burgdorf and Robert Burgdorf Jr., "A History of Unequal Treatment: The Qualifications of Handicapped Persons as a Suspect Class under the Equal Protection Clause," *Santa Clara Law Review* 15, no. 4 (1975): 862.

<sup>&</sup>lt;sup>33</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 863; For more information see, "Mental Disability and The Right to Vote," *The Yale Law Journal* 88, no. 8 (July 1979): 1644-1644, and Kay Schriner, Lisa A. Ochs and Todd G. Shields, "The Last Suffrage Movement: Voting Rights for Persons with Cognitive and Emotional Disabilities," *Publius* 27, No. 3 (Summer, 1997): 75-96.

<sup>&</sup>lt;sup>34</sup> Nielsen, *A Disability History*, 66; Molly Ladd-Taylor, *Fixing the Poor: Eugenic Sterilization and Child Welfare in the Twentieth Century*, (Baltimore, MA: Johns Hopkins University Press 2017), 32.

often have them institutionalized.<sup>35</sup> Whether in long-term, state-run asylums or temporary, locally-run poorhouses or almshouses, the common factor in the incarceration methods of 19<sup>th</sup> century America "was [the] total exclusion of the disabled person from society."<sup>36</sup> This system lasted until the latter half of the 20<sup>th</sup> century.

Life was often worse in the almshouse or poorhouse than on the streets.<sup>37</sup> At the Cook County almshouse in Chicago, "the atmosphere necessarily [was] loaded with foul odors...and with the germs of various diseases—tuberculosis, syphilis...[and lacked] privies of proper size and in sufficient number...the ground all around the buildings is offensive both to the sight and to the smell."<sup>38</sup> In San Francisco, the Unsightly Ordinance distinguished between the infirm and the unsightly, yet both would be hidden from public view and treated the same way once incarcerated at the almshouse.<sup>39</sup> By 1884, Illinois's poorhouses housed 30,310 "disabled" individuals: 4,885 were lame or crippled; 1,648 were paralytic; 2,600 were epileptic; and 7,780 were "sick".<sup>40</sup> In a 1923 census survey, "63.7% of the inmates in the almshouses of the United States in 1910...had some physical or mental defect."<sup>41</sup> All were kept out of sight.

The almshouse system began in the early 19<sup>th</sup> century. By 1830, nearly all states mandated or encouraged the establishment of almshouses that would house the poor, sick, "insane," or handicapped.<sup>42</sup> Created as "a way of regulating dependent people thought to be disorderly," they kept the disabled confined and out of the public eye.<sup>43</sup> The typical almshouse

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<sup>&</sup>lt;sup>35</sup> Ladd-Taylor, *Fixing the Poor*, 34.

<sup>&</sup>lt;sup>36</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 886.

<sup>&</sup>lt;sup>37</sup> Coco, "Diseased, Maimed, Mutilated," 34.

<sup>&</sup>lt;sup>38</sup> Fifth Biennial Report of the Board of State Commissioners of Public Charities of the State of Illinois, 1878 (Springfield, 1879), 225

<sup>&</sup>lt;sup>39</sup> Schweik, *Ugly Laws*, 27.

<sup>&</sup>lt;sup>40</sup> Eighth Biennial Report of the Board of State Commissioners of Public Charities of the State of Illinois, 1884 (Springfield, 1885), 352; Coco, "Diseased, Maimed, Mutilated," 34.

<sup>&</sup>lt;sup>41</sup> Schweik, *Ugly Laws*, 67.

<sup>&</sup>lt;sup>42</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 885

<sup>&</sup>lt;sup>43</sup> Schweik, *Ugly Laws*, 27.

was usually locally funded and poorly administered by corrupt administrators, as seen with Cook County's almshouse in Chicago and the Shakespeare almshouse in New Orleans.<sup>44</sup> The Shakespeare almshouse was reported to have extremely high death rates and eventually shut down. Almshouses began their decline in 1890, and despite lasting well into the 20<sup>th</sup> century, they were abandoned to make way for state institutions.<sup>45</sup>

While the typical almshouse was locally funded, most state institutions, like asylums or hospitals, were funded by the state and charitable donations. These state institutions took many forms, claiming to rehabilitate or cure the disabled or feebleminded. However, in reality, they became little more than dehumanizing places of confinement. However, in reality, they rapid expansion in the early 20th century and correlated to the phasing out of almshouses. The almshouse was a temporary solution, but extreme supporters of state-funded institutional warehouses hoped for "life segregation for all handicapped persons." Their confinement was for the betterment of society. He

Many of these state institutions (which were supposed to care for the incarcerated individuals, many of whom were disabled) were inhumane due to a lack of funding, neglect, and building inaccessibility. Following the Civil War, state institutions were flooded with patients turning them into "human warehouses;" by the end of the century, brutality and corruption were

<sup>&</sup>lt;sup>44</sup> John R. Sutton, "The Political Economy of Madness: The Expansion of the Asylum in Progressive America," *American Sociological Review* 56, no. 5 (October 1, 1991): 666; Coco, "Diseased, Maimed, Mutilated," 34; Schweik, *Ugly Laws*, 34-35.

<sup>&</sup>lt;sup>45</sup> Schweik, *Ugly Laws*, 66; For more information on Almshouses, see Michael B. Katz, *In the Shadow of the Poorhouse: A Social History of Welfare in America* (New York: Basic Books, 1986).

<sup>&</sup>lt;sup>46</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 886-887.

<sup>&</sup>lt;sup>47</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 887.

<sup>&</sup>lt;sup>48</sup> Michael Anagnos, "Hindrances To The Welfare And Progress Of State Institutions" in *Proceedings of the Ninth Annual Conference of Charities and Corrections*, (Madison: Midland Publishing Company, 1883), 1.

commonplace.<sup>49</sup> Patients were alternatively neglected or abused, "often...restrained by camisoles and strait jackets and...locked into covered cribs at night."<sup>50</sup> Institutions were built for the caretakers, not the residents. Facilities had "locked living units" where the door handle was too high for children or physically handicapped to reach and required a caretaker to open.<sup>51</sup> State institutions dehumanized their involuntary residents.

The segregation of disabled individuals was not limited to only adults. Doctors and parents believed it was better for the "mentally retarded child" to be with "their kind" while the normal children lived regular lives. <sup>52</sup> Often, severely disabled children, mentally or physically, would be institutionalized for *their own good* despite the child never being consulted on this. Many people thought "children who are deformed should be put out of the way" and that it was "more detrimental for the healthy to be forced into contact with the deformed." <sup>53</sup> In other words, the "deformed" and healthy children should have separate but essentially equal residences. As African Americans of the era knew well, separate does not always mean equal.

Another form of segregation, freak shows, seems contradictory at first glance. Disabled individuals featured in freak shows were meant to be viewed and gawked at, but their visibility was limited to side shows and circuses; they still could not expose themselves openly in the public sphere. Freak shows were active in the United States throughout the 19<sup>th</sup> and early 20<sup>th</sup> centuries.<sup>54</sup> These shows were one of the few ways that individuals who were physically disabled

<sup>&</sup>lt;sup>49</sup> Laura I. Appleman, "Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration," *Duke Law Journal* 68, no.3 (November 26, 2018): 430; Sutton, "The Political Economy of Madness," 670-671.

<sup>&</sup>lt;sup>50</sup> Appleman, "Deviancy, Dependency, and Disability," 434.

<sup>&</sup>lt;sup>51</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 887.

<sup>&</sup>lt;sup>52</sup> Ladd-Taylor, *Fixing the Poor*, 190.

<sup>&</sup>lt;sup>53</sup> "WANTS RULER OVER CUPID," *Chicago Daily Tribune*, Jun 10, 1907, 1; "PLEAD FOR THE CRIPPLES," *Chicago Daily Tribune*, May 30, 1903, 8.

<sup>&</sup>lt;sup>54</sup> Brigham A. Fordham, "Dangerous Bodies: Freakshows, Expression, and Exploitation," *UCLA Entertainment Law Review* 14, no.2 (2007): 212-213.

(whether born that way or from accidents) could make a living besides begging or relying on charity. In 1881, the same year its Ugly Laws were enacted, the Chicago Municipal Code sanctioned the "exhibition of monsters or freaks of nature." While the exhibition of the deformed bodies of beggars was banned, those same bodies could be exhibited commercially, as entertainment, for a profit, and within a circumscribed space. Lavinia Warren, a dwarf exhibited her freakshows her entire life, stated "I belong to the public." Even when visible to the public, the bodies of disabled individuals were not their own.

Freak shows were advertised as educational or scientific exhibits on "human oddities." <sup>57</sup> They emphasized the otherness of individuals that differed from the norm due to race, ethnicity, or disability. The 'freaks' in these shows did not always have a physical disability or deformity, but many did. <sup>58</sup> P.T Barnum brought freak shows to their peak in the 19<sup>th</sup> century, emphasizing otherness via exoticism and aggrandized status. <sup>59</sup> Exotic "freaks" included the "savage African" or people from the Orient. <sup>60</sup> Exoticism presentations exaggerated stereotypes and emphasized the strangeness of other cultures or body types. Disabled "freaks" showcased included "people with microcephaly," "Siamese twins, or armless people." <sup>61</sup> While modern movies have attempted to romanticize these exhibitions, as seen in *The Greatest Showman*, the historical truth is that while these shows made a spectacle of the disabled, they revealed a dark side of human nature - the desire to gawk and mock those who were different. <sup>62</sup>

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<sup>&</sup>lt;sup>55</sup> Coco, "Diseased, Maimed, Mutilated," 30; Municipal Code of Chicago, (Chicago, 1881), 128.

<sup>&</sup>lt;sup>56</sup> Nielsen, A Disability History, 90.

<sup>&</sup>lt;sup>57</sup> Robert Bogdan, "The Exhibition Of Humans With Differences For Amusement And Profit," *Policy Studies Journal* 15, no 3 (March 1987): 538.

<sup>&</sup>lt;sup>58</sup> David A. Gerber, "Volition and Valorization in the Analysis of the 'Careers' of People Exhibited in Freak Shows," *Disability, Handicap, & Society* 7, no. 1 (1992): 62.

 <sup>&</sup>lt;sup>59</sup> Rosemarie Garland Thomson, Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature, (New York: Columbia University Press, 2017), 58; Bogdan, "The Exhibition Of Humans," 540.
 <sup>60</sup> Bogdan, "The Exhibition Of Humans," 540.

<sup>&</sup>lt;sup>61</sup> Bogdan, "The Exhibition Of Humans," 543; Fordham, "Dangerous Bodies," 211.

<sup>&</sup>lt;sup>62</sup> The Greatest Showman, directed by Michael Gracey (United States: Twentieth Century Fox, 2017).

#### 1.3 Exceptions & Media

This ostracization of the physically disabled was not uncommon during the 19<sup>th</sup> century, but a critique of it in the media was. Stephen Crane's novella *The Monster* explores the ostracization of Henry Johnson, a disabled African American man in a small town. His disability resulted from chemical burns when rescuing his employer's son from a burning building. Before the facial disfigurement, Henry was well-liked around town, but after the incident, he was suddenly viewed as a monster. Disability and race worked together to further ostracize and segregate him from the regular townspeople. Even the rescued boy treated Henry as an oddity or spectacle due to his disfigurement.<sup>63</sup> Throughout the work, Henry's appearance frightened and disgusted the average person. The doctor attempted to keep Henry out of sight to be cared for and segregated from the regular townspeople. Crane criticizes the reaction of the townspeople, which represents how American society shunned individuals with disabilities in this era.

Individuals with disabilities were to be kept out of the public sphere, and some believed it would be more humane to euthanize rather than rehabilitate them.<sup>64</sup>

Veterans were often exceptions to this norm. Disabled veterans held a unique status concerning how disabilities were perceived. Many cities made exceptions in their Ugly Laws for wounded veterans from the Civil War and later other conflicts like the Indian Wars and Spanish American War. Wartime made disability heroic.<sup>65</sup> A disability caused by the war was a status symbol and marker of proving oneself in service to the country. There are many instances where disabled veterans ran for state office, emphasizing their disability, usually an amputated arm or leg, and were very successful.<sup>66</sup> Another exception to the Ugly Law ordinance occurred in

<sup>&</sup>lt;sup>63</sup> Stephen Crane, *The Monster and Other Stories*, (New York: Harper, 1899), 3-106.

<sup>&</sup>lt;sup>64</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 887.

<sup>65</sup> Schweik, Ugly Laws, 149; Nielsen, A Disability History, 87.

<sup>&</sup>lt;sup>66</sup> Nielsen, A Disability History, 87.

Chicago after the Haymarket Riot on May 4, 1886. The same council that passed the Ugly Laws issued a "Resolution to Provide for Disabled Policemen," specifically for those injured by the riot.<sup>67</sup> These exceptions provide glimpses of hope in an otherwise hostile environment. These exceptions show that the public realized to some extent that disabilities are not the fault of the person with the disability. While the Ugly Laws discriminated against visible disabilities, exceptions were given to those who gained their disability honorably (i.e., white veterans).

Another contradiction in the treatment of individuals with physical disabilities was the treatment of industrial-related disabilities. For most of the 19<sup>th</sup> century, disfigured railroad workers occupied a unique status alongside disabled veterans. Before the 1870s, disabled workers were not considered inept or slow; a work-related disability was a sign of experience. Being maimed suggested that the man was a skilled laborer and was advantageous when searching for a job.<sup>68</sup> Railroad or factory managers sometimes reassigned a disabled individual to a lighter task or workload. Unfortunately, this did not last, and work-related disabilities shifted from a sign of experience to a "marker of incompetency, dependency, [and] immortality."<sup>69</sup> Now, disabled workers were viewed with suspicion by other workers and often considered inefficient and more susceptible to injury by the company. Economic competition and railroad brotherhood (a type of union) propaganda fueled this change.<sup>70</sup> Despite their unique status, workers injured or killed were not guaranteed compensation for themselves or their dependents; many received little to nothing.<sup>71</sup>

<sup>&</sup>lt;sup>67</sup> Schweik, *Ugly Laws*, 60; Joseph Kirkland, "Among the Poor of Chicago," *Scribner's* 12, no. 1 (July 1892), 233.

<sup>&</sup>lt;sup>68</sup> John Williams-Searle, "Cold Charity: Manhood, Brotherhood, and the Transformation of Disability, 1870-1900," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky, (New York: New York University Press, 2001), 163; Coco, "Diseased, Maimed, Mutilated," 28

<sup>&</sup>lt;sup>69</sup> Williams-Searle, "Cold Charity," 163.

<sup>&</sup>lt;sup>70</sup> Williams-Searle, "Cold Charity," 162-163.

<sup>&</sup>lt;sup>71</sup> Crystal Eastman, Work Accidents and The Law (New York: Charities Publication Committee, 1910), 126.

While individuals with disabilities were to be kept out of sight in most instances, there were exceptions. One such exception was an individual rather than a group of people. Helen Keller, the deaf, blind, and mute girl, became a world-famous writer and activist for not only the Deaf and Blind, but also women, the working class, and people of color. She was very well-known while alive, and even today she is still a household name in the twenty-first century. Born in Tuscumbia, Alabama, in 1880, she went blind, deaf, and mute at 19 months after contracting a life-threatening fever. It is suspected to have been Scarlet Fever, which was occurring in pandemics at the time, and in severe cases, could cause permanent deafness. <sup>72</sup> Unlike many other parents, her mother refused to institutionalize Helen and instead sought a way to educate her daughter.

Helen Keller was a highly visible figure with very prominent disabilities and also a well-known disability activist. Keller was taught by Annie Sullivan, a graduate of the Perkins Institute for the Blind, and Keller eventually herself attended the Perkins Institute. She graduated from Radcliffe College, where she had become interested in politics. Keller was the first deafblind graduate from Radcliffe College (now known as Harvard University). She was extremely active in politics, and joined the American Socialist Party in 1909; however, regarding disabilities, she often undermined "disability as a viable political category for herself and others." Keller politicized disability as a "personal affliction spawned by social and economic injustices" thus disability was a consequence of class inequalities.<sup>74</sup>

Keller's activism did not see disability as a civil rights issue. She focused on combating the belief that a disability rendered an individual dependent and incapable of work. She refuted

<sup>&</sup>lt;sup>72</sup> Meredith Eliassen, *Helen Keller: a Life in American History* (Santa Barbara: ABC-CLIO, LLC, 2021), 26-27.

Kim Nielsen, "Helen Keller and the Politics of Civic Fitness," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky, (New York: New York University Press, 2001), 270-71.
 Nielsen, "Helen Keller and the Politics," 273.

the idea that blind people were incapable of work. She believed that work would "raise blind people from 'dependence to self-respecting citizenship' and allow them to become 'useful blind people.'"<sup>75</sup> Keller equated work with citizenship; even so, this equation did not necessarily translate to have political rights. Keller did not believe that her disability disqualified her from participating in politics even though American society often believed this true.<sup>76</sup>

In terms of visibility, she was extremely visible in American Society and internationally; she had traveled across the nation and to over thirty different countries by her death. Keller published *The Story of My Life*, her first book and volume of her autobiography in 1903. A prolific writer, she wrote fourteen books, over 400 essays, and speeches on various topics. <sup>77</sup> In 1919, Keller assisted in the foundation of the American foundation for Overseas Blind (later known as Helen Keller International). <sup>78</sup> The same year, Helen Keller was featured in *Deliverance*, a "powerful motion picture...[that] portrays the life of...a woman who has mastered language and science." <sup>79</sup> This film told the story of Keller's life. In 1920, Keller helped found the American Civil Liberties Union (ACLU) which fought to protect civil rights in the courts. <sup>80</sup> In 1924, Keller began her work as a spokesperson for the American Federation of the Blind (AFB) and toured the nation giving speeches: eventually touring internationally for the AFB and Helen Keller International. <sup>81</sup> She would work with the AFB for the next forty years. She met a dozen United States Presidents throughout her life, from Grover Cleveland to John F. Kennedy.

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<sup>&</sup>lt;sup>75</sup> Nielsen, "Helen Keller and the Politics," 271.

<sup>&</sup>lt;sup>76</sup> Kim E. Nielson, *The Radical Lives of Helen Keller* (New York: New York University Press, 2004), 15-16.

U.S. Congress, Senate, Committee on the Judiciary, Helen Keller: Report (to Accompany S. Con. Res. 39), 84th
 Cong., 1st sess., 1955, S. Rep. 616, 1-2.; Nielson, The Radical Lives, 6-7; For more info on some of Helen Keller's writings, see Kim E. Nielson, Helen Keller: Selected Writings (New York: New York University Press, 2005).
 M. Robert Barnett, "Helen Keller and the American Foundation for the Blind," Journal of Visual Impairment and

<sup>&</sup>lt;sup>78</sup> M. Robert Barnett, "Helen Keller and the American Foundation for the Blind," *Journal of Visual Impairment and Blindness* 62, no. 7 (September 1968): 206-207; "Dulles Calls for Aid to Overseas Blind," *The Brooklyn Daily Eagle*, Apr. 21, 1946, pg. 1.

<sup>&</sup>lt;sup>79</sup> "Helen Keller Sees; The World Is Blind," *The Capitol Times* (Madison, Wisconsin), Dec. 9, 1919, pg. 8

<sup>&</sup>lt;sup>80</sup> Associated Press, "Organization Will Bring Back Free Speech," Detroit Free Press, Jan 26, 1920, pg. 11.

<sup>81</sup> Nielson, The Radical Lives, 50; Eliassen, Helen Keller, 199.

Even though, Keller is a controversial figure concerning disability advocacy; she remains a highly visible figure who went against the current perceptions of disability during her time.

#### 1.4 Progressive Era & Eugenics

Eugenics, a new form of social engineering, was the belief (and study) that the way to improve society was through selective human breeding practices. The goal was to increase the number of desirable characteristics and limit the population of undesirable or defective characteristics. Begin and undesirable traits were fluid and subjective; however, any disability was resolutely undesirable. Eugenics, coined in the 1880s by Sir Francis Galton, was "the study of agencies under social control that may improve or impair . . . future generations either physically or mentally." Eugenics' drew its scientific backing from the works of Gregor Mendel and Charles Darwin, rooted on the basis of Social Darwinism. Eugenics was a matter of "survival of the fittest, not...survival of the unfittest," as the latter supposedly *dragged* society down and backwards. Begin and the social control that unfittest, as the latter supposedly *dragged* society down and backwards. Begin and the social control that may improve or impair . . . Survival of the fittest, not...survival of the unfittest," as the latter supposedly *dragged* society

The eugenics movement is marked by a stark belief that mental and physical disabilities were the root of all social problems and the fear of the increasing number of disabilities in modern society. Prominent studies, at the time, linked disability and immorality showcasing generations of "defective, degenerative, and criminal persons," in the Juke's and the Kallikaks family tree.<sup>85</sup> In a prime example of correlation does not equal causation, these studies were later proven false, but the stigma of disability due to immorality remained. The spread of hereditary disabilities or handicapping conditions was considered the most crucial threat to American

<sup>82</sup> Nielsen, A Disability History, 100-101.

<sup>&</sup>lt;sup>83</sup> Robert L. Burgdorf Jr. and Marcia Pearce Burgdorf, "The Wicked Witch Is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons," *Temple Law Quarterly* 50, no. 4 (1977): 997.

<sup>84</sup> William Graham Sumner, *The Challenge of the Facts and other Essays*, ed. by Albert Galloway Keller (New Haven: Yale University Press, 1914), .

<sup>&</sup>lt;sup>85</sup> "The Juke Family," Chicago Tribune, February 18, 1877, p. 10; Robert L. Dugdale, The Jukes (New York, 1970), 11, 30; Burgdorf Jr. and Burgdorf, "Wicked Witch," 997-998.

Society during the Progressive Era. There were many ideas on controlling the increasing rate of "degenerates, defectives", and disabled individuals. The proposed solutions included euthanasia, forced sterilization laws, segregation, and prohibitions on marriage and sexual relations of "defective" individuals. Unfortunately, these solutions were implemented at some level or practiced throughout the United States. Ultimately the American Eugenics Society decided that only restrictive marriage laws, sterilization, and segregation of defective individuals capable of reproduction were realistically feasible.<sup>86</sup>

Segregation of disabled individuals was not unusual, as seen with the numerous mental institutions and asylums littering America's landscape at this time. <sup>87</sup> Since hereditary genetics is a factor regarding some disabilities, laws were passed to prohibit people with disabilities from marrying. Thirty-seven states and the District of Columbia restricted or prohibited the right of "the mentally retarded persons to marry." Some states included the physically handicapped, and at least seventeen states prohibited individuals with epilepsy to marry. A local Kentucky court declared, "A person 'of unsound mind,' an idiot... is as incapable as a dead body of being a husband or a wife in a legal, rational, or moral sense." Despite attempts to restrict marriage, it became apparent that "the unfit reproduce their kind regardless of marriage laws." This left sterilization as the only realistic solution.

<sup>&</sup>lt;sup>86</sup> Burgdorf Jr. and Burgdorf, "Wicked Witch," 998-999.

<sup>&</sup>lt;sup>87</sup> Sterilization could be used as a get-out-of-institution-free card, so they were no longer segregated or hidden from public life. However, they were only released after their ability to reproduce and potentially increase the disabled population was no longer possible. For more information, see

<sup>&</sup>lt;sup>88</sup> Jeffrey M. Shaman, "Persons Who Are Mentally Retarded: Their Right to Marry and Have Children," *Family Law Quarterly* 12, no. 1 (Spring 1978): 62.

<sup>&</sup>lt;sup>89</sup> Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 861.

<sup>&</sup>lt;sup>90</sup> Hastings H. Hart, "A Working Program for the Extinction of the Defective Delinquent," *The Survey* 30, no. 1 (1913): 277.

However, sterilization of disabled individuals only became feasible at the end of the 19<sup>th</sup> century with the development of vasectomy (for males) and salpingectomy (for females).<sup>91</sup> Sterilization became the standard practice in the medical field. Beginning with Indiana in 1907, over thirty states passed forced-sterilization laws by the 1930s, and only three states struck down the laws as unconstitutional.<sup>92</sup> The model law created by Harry Laughlin, eugenics advocate, defined "socially inadequate classes" of people very broadly:

(1) Feebleminded; (2) Insane, (including the psychopathic); (3) Criminalistic (including the delinquent and wayward); (4) Epileptic; (5) Inebriate (including drug habitues); (6) Diseased (including the tuberculous, the syphilitic, the leprous, and other with chronic, infectious, and legally segregable diseases); (7) Blind (including those with seriously impaired vision); (8) Deaf (including those with seriously impaired hearing); (9) Deformed (including the crippled); and (10) Dependent (including orphans, ne'er-dowells, the homeless, tramps, and paupers). 93

Many states that passed forced sterilization laws included all or many of the groups defined by Laughlin above.

However, many individuals targeted for sterilization did not passively acquiesce; some took their cases to court with varying degrees of success. Before 1927, sterilization laws that reached state courts were ruled unconstitutional on state and federal grounds. 94 Some courts considered it cruel and unusual punishment, which belonged to "the Dark Ages." In 1913, the New Jersey Supreme Court ruled in Smith v. Board of Examiners of the Feeble-Minded that the law ordering Alice Smiths, a poor woman with epilepsy, sterilization violated the Fourteenth Amendment since it was not applied equally, but only those in poverty or public institutions.<sup>96</sup> The New Jersey Supreme Court did not answer whether forced sterilization was constitutional.

<sup>91</sup> Burgdorf Jr. and Burgdorf, "Wicked Witch," 999.

<sup>&</sup>lt;sup>92</sup> Nielsen, A Disability History, 113; Burgdorf Jr. and Burgdorf, "Wicked Witch," 1000.

<sup>&</sup>lt;sup>93</sup> Nielsen, A Disability History, 113-115; Henry Laughlin, Eugenical Sterilization in the United States (Chicago: Pyscho-pathic Laboratory of the Municipal Court of Chicago, 1922), 446-47.

<sup>&</sup>lt;sup>94</sup> Victoria Nourse, "Buck v Bell: A Constitutional Tragedy from a Lost World," Pepperdine Law Review 39, no. 101, (2011): 102.

<sup>95</sup> Nourse, "Buck v Bell," 103.

<sup>&</sup>lt;sup>96</sup> Nielsen, A Disability History, 116-117; Burgdorf and Burgdorf Jr., "A History of Unequal Treatment," 861.

However, in 1927, the United States Supreme Court ruled in *Buck v Bell* that forced sterilization laws were constitutional and did not violate the Fourteenth Amendment. After all, according to Justice Holmes, "three generations of imbeciles are enough." Even into the twenty-first century, this decision has yet to be overturned by the Supreme Court.

97 Lombardo, Three Generations, No Imbeciles," 169-170.

## 2. TO BE SEEN, TO BE HEARD

In the early 20<sup>th</sup> century, particularly beginning in the 1920s and 1930s, there was an increase in disability activism, albeit it was not cohesive. Hugh Gallagher, a disability rights activist in the early 1960s, attributes this to the fact that "the disabled did not see themselves as a community with shared interests or rights...no such thing as 'disability culture.' At this time disabilities were only a medical condition, not a unifying socio-political condition. Instead of a shared community, there were the handicapped, the mentally ill, the Deaf/Blind, and other specific groups, some of which had higher visibility points in America early than others, as noted in "Out of Sight, Out of Mind." However, this would change. Gallagher believed there was change approaching America's disabled population grounded in the polio epidemics, veterans, early activism in organizations, and legislation. These developments brought disabilities to the forefront of the public eye and could not be avoided. They demanded to be seen and their voices heard.

#### 2.1 Polio

The polio epidemics swept across America in waves from the 1890s to the 1950s. Polio, first called "infantile paralysis" (and later poliomyelitis), was a highly contagious disease primarily seen in children. For most, polio was simply an intestinal virus; however, for others, it would spread to the nervous system destroying spinal cord cells and resulted in paralysis (full or partial). Without a vaccine until the 1950s and no cure for survivors, poliomyelitis left many victims disabled. Polio was not the only disease that could result in a disability, such as scarlet fever which could cause deafness or blindness. Yet, polio was one of the most feared diseases of childhood, and although it could be fatal, ironically that was not what parents or society feared

the most. Instead, it was the possibility of their children being disabled that terrified so many.

Afterall, many believed it was better to be dead than disabled.

Polio was not a new disease, with visual evidence going back to ancient Egypt and the classical world. However, with modern sanitation and better hygiene, the United States witnessed polio's "shift from an endemic disease, which infrequently occurred [...] to a disease of epidemic proportions." Children were not exposed to the virus as newborns and did not develop a natural immunity. This lack of exposure resulted in an epidemic crisis, the most severe occurring between 1916 and 1952, as children and adults with no immunity fell victim to the virus. Polio increased its age range in victims and its severity as the 20<sup>th</sup> century continued; "the older one contracted the disease, the more likely it was to be paralytic." It was not always possible to immediately tell if an illness was Polio, and the potential resulting paralysis could not be entirely determined till the virus had run its course. In the 1950s, Jonas Salk developed the polio vaccine and introduced it to the public, and by 1979, any new polio cases had been eliminated in the United States. However, since a vaccine is not a cure, paralyzed survivors remained paralyzed.

The polio epidemic drastically increased the visibility of disabilities in the United States. Polio was photogenic; its effects were visual, from the iron lungs to paralyzed survivors using braces or wheelchairs. Yet in the early 20<sup>th</sup> century, most polio survivors were kept hidden. Polio was shameful; many kept silent about their disability or suffered medical neglect or abuse as they were isolated from public life.<sup>101</sup> Further showcasing the beliefs regarding disabilities in the late

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<sup>&</sup>lt;sup>98</sup> Julie K. Silver, *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*, (New Haven: Yale University Press, 2001), 1.

<sup>&</sup>lt;sup>99</sup> Daniel J. Wilson, *Living with Polio: The Epidemic and Its Survivors* (Chicago: University of Chicago Press, 2005), 3.

<sup>&</sup>lt;sup>100</sup> Silver, Post-Polio Syndrome, 1-3.

<sup>&</sup>lt;sup>101</sup> Amy L. Fairchild, "The Polio Narratives: Dialogues with FDR," *Bulletin of the History of Medicine* 75, no. 3 (2001), 497-498; Gallagher, *Blackbird*, 8.

19<sup>th</sup> and early 20<sup>th</sup> century, when disability was defined as an inability to work that clashed with American ideals of independence. Those with severe disabilities, often caused by polio, were "invalids" incapable of independence and no longer members of American society.<sup>102</sup>

However, the perception of polio changed with the election of the 32<sup>nd</sup> President of the United States, Franklin Delano Roosevelt (FDR), a polio survivor. <sup>103</sup> In the summer of 1921, FDR contracted polio, leaving him paralyzed from the waist down and reliant on a wheelchair for mobility. In 1932, FDR was elected president, becoming the first president with such a visible disability. However, FDR's visibility is slightly contradictory since his disability was not widely known nor publicized until after his death. There are only two photos of him in a wheelchair despite how significant a factor it was in his life. Instead, FDR created a narrative of overcoming polio and, subsequently, his disability by purposefully creating an illusion of walking and standing with the help of others. <sup>104</sup> FDR's false narrative of overcoming a disability shifted public perception. Perceptions of polio changed from shame to recovery, and the public falsely believed that a disability could be overcome with enough effort (especially physical disabilities). <sup>105</sup> This narrative aligned with the medical model of disabilities, which focuses on disability as a *defect* to be fixed or cured so an individual could be more *normal*.

During his presidency, FDR established the National Foundation for Infantile Paralysis (NFIP) and its fundraising branch March for Dimes, in 1938. The NFIP funded research to eradicate polio for good (such as Dr. Jonas Salk's research into a vaccine) and helped pay for the care of children, adolescents, and adults with polio. March for Dimes, a very well-oiled publicity

<sup>&</sup>lt;sup>102</sup> Daniel Holland, "Franklin D. Roosevelt's Shangri-La: Foreshadowing the Independent Living Movement in Warm Springs, Georgia, 1926–1945" *Disability & Society* 21, no 5 (November 2006), 515.

<sup>&</sup>lt;sup>103</sup> Zames and Fleischer, *The Disability Rights Movement*, 3.

<sup>&</sup>lt;sup>104</sup> Hugh Gallagher, introduction to FDR's Splendid Deception, (New York: Dodd, Mead & Co., 1985), xiii.

<sup>&</sup>lt;sup>105</sup> Fairchild, "The Polio Narratives," 499-500.

machine, held massive annual fundraisers using the president's popularity and other celebrities, such as Marilyn Monroe or Elvis Presley, to reach the public.<sup>106</sup> They enlisted the "radio...to fight infantile paralysis."<sup>107</sup> They published newsletters, posters, and magazine and newspaper articles to keep the public updated on the most recent scientific findings on polio.

March for Dimes, alongside similar organizations, often used a "poster child" in their fund-raising charities, especially after the 1940s. A poster child "refers to a child with a disease or disability whose picture was used on posters and other media in the campaign for a particular charity to encourage people to give." Posters often made the disability evident via wheelchairs and braces. These children would also attend events in person, often accompanied by celebrities. Children were used for all fundraising campaigns, while adults, except veterans, were underrepresented. Children garnered sympathy, and these ads would claim to cure children of their disability if people donated to the charity.

Outside of FDR and March for Dimes, polio also led to the development of a shared community due to the actions of one individual: Gini Laurie. While not disabled by polio but deeply affected by its consequences (having lost her siblings to the virus), Laurie volunteered at the Toomey Pavilion Respiratory (or Polio Rehabilitation) Center in Cleveland, Ohio, in the late 1950s. 109 While volunteering there, she noticed polio survivors had "two vital needs: people and information" after leaving rehabilitative care. 110 In 1958, Laurie began to produce the Toomey J Gazette (later the Rehabilitation Gazette) newsletter, which connected people and shared information as they left hospital care. This newsletter inspired many future disability activists

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<sup>106</sup> Wilson, Living with Polio, 3-4; Robert Bogdan, Martin Elks, and James Knoll, Picturing Disability: Beggar, Freak, Citizen and Other Photographic Rhetoric, (Syracuse: Syracuse University Press, 2012), 51-52.

<sup>&</sup>lt;sup>107</sup> "Radio Enlists To Fight Infantile Paralysis," *The President's Birthday Magazine*, Jan. 30, 1937, https://www.disabilitymuseum.org/dhm/lib/detail.html?id=2151.

<sup>&</sup>lt;sup>108</sup> Bogdan, Elks, and Knoll, *Picturing Disability*, 45-46.

<sup>&</sup>lt;sup>109</sup> Shapiro, No Pity, 64.

<sup>&</sup>lt;sup>110</sup> Joan L. Headley, "Independent Living: The Role of Gini Laurie," *Rehabilitation Gazette* 38, no 1 (1998): 2.

and showed they were not alone in their struggles. The Rehabilitation Gazette was a grassroots publication that became "an early voice for disability rights." Laurie later established the Polio Network News (now Post-Polio Health) for polio survivors suffering from Post-Polio Syndrome (PPS). 112

While polio was probably the most significant contributor to the visibility of disabilities, it was not the only one. Advancements in medicine and medical technology played an essential role as well. One example is the iron lung, a negative pressure ventilator primarily used to treat polio patients, which helped many severely paralyzed polio survivors breathe. It significantly extended their lifespan and quality of life. Also prompted by polio and FDR was the development of rehabilitative medical practices, such as Warm Springs. In 1926, FDR founded the Warm Springs Hydrotherapeutic Center in Warm Springs, GA, a wheelchair-friendly residential rehabilitation community for people with disabilities from polio. The goal was to rehabilitate individuals with disabilities. Another significant medical development during World War II was the creation of antibiotics. Individuals with disabilities could now be treated for injuries or diseases' that could have quickly worsened their condition or killed them.<sup>113</sup>

#### 2.2 Veterans & World War II

World War II (WWII) played a significant factor in increasing the visibility of disabled people. The end of WWII resulted in numerous veterans returning home, many of whom had become disabled during the war. There was an increase in veterans' organizations that sought to protect and promote the civil rights of veterans with disabilities and legislation meant to provide

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<sup>&</sup>lt;sup>111</sup> Julia Sain, et al, "IL 201: History & Philosophy of the Independent Living Movement: A National Teleconference Participant's Manual," *IL NET: an ILRU/NCIL National Training and Technical Assistance Project*, (August 8, 2002): 67.

<sup>&</sup>lt;sup>112</sup> For information on Post-Polio Syndrome see, Joan L. Headley, "What is Post-Polio Syndrome?" Post-Polio Health International, 2017.

<sup>&</sup>lt;sup>113</sup> Hugh Gallagher, *Blackbird Fly Away*, 8-10.

vocational training and rehabilitation services.<sup>114</sup> Disabled war veterans prompted improvements in medical technology (like prosthetics) and garnered public attention; their return "force[d] the community to immediate action."<sup>115</sup> They also had an increased presence in the media. In 1946, *The Best Years of Our Lives* was released, and the film detailed the difficulties veterans faced when adjusting to life after the war. One of the main characters in the movie was a disabled veteran, and the actor that was cast, Harold Russell, was a disabled veteran who had lost both hands during the war. This film was the first to feature a severely disabled actor in a major role on film; it broke new ground on the "realistic visualization of severe [a] disability" in film.<sup>116</sup>

World War II not only increased public visibility of disabilities but also stopped the eugenics movement in America in its tracks. During WWII, Nazi Germany, inspired by the American Eugenics Movement, took it a step from forced sterilization to euthanasia. Although, not to say that Nazi Germany did not conduct involuntary and voluntary sterilization. Before WWII, Nazi Germany recorded the forced sterilization of 350,000 people with mental or physical disabilities (real and perceived). While euthanasia was considered a solution in America at one point, it was ultimately deemed unrealistic; the more reasonable options were life segregation and sterilization.

Nazi eugenics programs were centralized and decentralized, enacted by doctors and health officials. Nazis began with children. The "children campaign" made it mandatory to report any child suffering from "idiocy, Down's Syndrome, microcephaly, hydrocephaly, spastic

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<sup>&</sup>lt;sup>114</sup> David A. Gerber, "Introduction: Finding Disabled Veterans in History" in *Disabled Veterans in History*, rev. ed., ed. David A. Gerber (Ann Arbor: University of Michigan Press, 2012), 27.

<sup>&</sup>lt;sup>115</sup> Nielsen, A Disability History, 127.

<sup>&</sup>lt;sup>116</sup> Best Years of Our Lives, directed William Wyler, performances by Harold Russell (Samuel Goldwyn Productions, 1946), Film; David A. Gerber, "Heroes and Misfits: The Troubled Social Reintegration of Disabled Veterans in The Best Years of Our Lives," in *Disabled Veterans in History*, Rev, ed., ed. David A. Gerber (Ann Arbor: University of Michigan Press, 2012), 71.

<sup>117</sup> Nicholas Stargardt, *The German War: A Nation Under Arms 1939-1945*, (New York: Basic Books, 2015), 82

paralysis or missing limbs."<sup>119</sup> Some parents requested the Nazi government to euthanize their kids. Through drugs and starvation, around 5,000 children were killed. Next were the adult patients in asylums, so a secret program, codenamed T-4, was enacted. Approved by Hitler, operation T-4 sought out patients "deemed unworthy of life," which was determined by the likelihood of the individual ever contributing to society through work. <sup>120</sup> Some doctors and health officials considered these actions "mercy killing" and allowed society legitimate means to dispose of "useless ballast existences." <sup>121</sup> The official program lasted from 1939 to 1941, although its official end did not "bring an end to the killing of the disabled and insane." By the end of WWII, it has been estimated that Nazi's killed anywhere between 120,000 and 275,000 individuals with physical or mental disabilities. <sup>122</sup> After Hitler died and the Nazis lost, certain subjects became taboo in Germany and were not talked about; the principles of eugenics and euthanasia were among these subjects. <sup>123</sup>

Americans were not unaware of what was occurring in Nazi Germany. In the early 1930s, a few American eugenicists believed that Nazi's policies were made in the best interest of eugenicists in "civilized countries." <sup>124</sup> In July of 1942, the American Journal of Psychiatry published two articles on euthanizing "retarded" children: one opposed and one in favor. The article, in favor, believed children with disabilities should be relieved from "the agony of living" and alluded that "euthanasia, like sterilization, would [eventually] become a widely adopted practice" in the United States. <sup>125</sup> However, for the most part, Nazi eugenics was universally

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<sup>&</sup>lt;sup>119</sup> Hugh Gregory Gallagher, *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich*, (New York: H. Holt, 1990), 118; Stargardt, *The German War*, 82.

<sup>120</sup> Stargardt, The German War, 82-83.

<sup>121</sup> Stargardt, The German War, 84.

<sup>&</sup>lt;sup>122</sup> Gallagher, By Trust Betrayed, 117-119.

<sup>&</sup>lt;sup>123</sup> Gallagher, By Trust Betrayed, 248.

<sup>&</sup>lt;sup>124</sup> Paul Popenoe, "THE GERMAN STERILIZATION LAW," *Journal of Heredity* 25, no. 7 (July 1934): 260.

<sup>&</sup>lt;sup>125</sup> Foster Kennedy, "Social Control of the Congenital Defective: Education, Sterilization, Euthanasia," *American Journal of Psychiatry* 99, no. 1 (July 1942): 13-14; Gallagher, *By Trust Betrayed*, 94-95.

condemned by American newspapers. One article referred to German doctors as "quacks" and criticized Nazi eugenics as an "amazing retrogression" in medicine. One writer denounced Nazi eugenics as an "inhuman[e] doctrine," while the Catholic Church condemned the "peculiar Nazi methods of eugenics" as animal-like. The eugenics movement in America had begun to wane in the 1920s and was briefly revived by Nazi eugenics in the early 1930s; by the end of the 1940s, the public view of eugenics, especially Nazi eugenics, was one of complete abhorrence. The Eugenics movement was past its prime, and public reception of the horrors wrought by Nazi's eugenics was the final nail in the coffin.

## 2.3 Early Activism in Organizations

In 1919, an Ohio businessman Edgar Allen established an organization for "crippled children." After losing his son in an accident, he became aware of two issues in the medical field: inadequate emergency medical facilities and a need for expert care for children with disabilities. It was not uncommon for poor medical care to create a disability, especially in light of economic inequalities. So, Allen organized the construction of new hospitals in his town; one was the Gates Hospital for Crippled Children. He realized that children with disabilities were often hidden from public view (since it was believed to be the result of sin in the family), which led to the Ohio Society for Crippled Children. 128 In 1921, this organization became known as the National Society for Crippled Children, now known as Easterseals, and sought to speak and act on behalf of individuals with disabilities. Ultimately, it was very similar to March for Dimes as it was one of the big National Health Service Charities in the United States at the time.

<sup>&</sup>lt;sup>126</sup> "Nazified Medicine: German Doctors are Falling Back on Hitlers Eugenics Ideas," *New York Times*, Dec. 6, 1942, pg. E11.

<sup>&</sup>lt;sup>127</sup> Joseph Breig, "One Man's Opinion." *Pittsburgh Sun-Telegraph*, Feb. 23, 1943; Religious News Service, "The Week in Religion." *Nashville Banner*, Dec. 11, 1942.

<sup>&</sup>lt;sup>128</sup> Laurie Block, "Inventing The Poster Child," *Beyond Affliction: The Disability History Project*, National Public Radio, 1998; Pat Boone and Easter Seals Society, *The Human Touch: The Story of Easter Seals* (New York, NY: Wieser & Wieser Inc, 1991), 20-22.

This organization began in Elyria, Ohio but quickly grew as it spread to other counties in the state. Initially, they were funded partially by Ohio legislation, individual memberships, and Ohio rotary clubs; however, as word spread and they expanded, they had to look to other tactics. Thus, Easterseals was born. The plan was to sell seals (small decorative stamps or miniature posters) during Easter since the "rehabilitation of crippled children means a new life and activity." These seals were a visible representation of "crippled" children in need of aid; unlike disabled adults, children were subjects of charity and pity. The seals "spurred the unprecedented expansion of the society...[and] growth of a nationwide movement [for] people with disabilities." These seals brought awareness to issues individuals with disabilities faced. Easterseals focused on the rehabilitation of children and, eventually, others with disabilities as well. During WWII, they encouraged using disabled individuals as "an important source of labor supply for an all-out war effort." Although this did not guarantee that individuals with disabilities would keep their job at the war's end.

One of the first organizations to challenge the public perception of disability (especially as an inability to work) was the League of the Physically Handicapped. Formed in New York City during the Great Depression (1930s), they protested government and private employment discrimination. At the same time that FDR hid his disability, the League broadcasted theirs and the discrimination they faced. Their main target was the Works Progress Administration (WPA), created by FDR's New Deal, which was supposed to provide jobs to anyone unemployed. However, individuals with disabilities quickly realized that *anyone* did not include those with disabilities (as well as other minority groups). The legislation categorized those with disabilities

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<sup>&</sup>lt;sup>129</sup> Boone and Easter Seals Society, *The Human Touch*, 38.

<sup>&</sup>lt;sup>130</sup> Boone and Easter Seals Society, *The Human Touch*, 39.

<sup>&</sup>lt;sup>131</sup> Nielsen, A Disability History, 148.

as unemployable and created a system where any disabled individual's job application was stamped with "' PH' (physically handicapped)."<sup>132</sup> These applications would then be rejected.

This system left disabled individuals to rely on local relief, such as the NYC Emergency Relief Bureau (ERB), which also automatically rejected disabled individuals for relief. <sup>133</sup> The League took issue with these discriminatory practices and made them well known. The League began their protest at the ERB office in NYC. Their methods? Sit-ins and picket lines. Sit-ins were peaceful or non-violent protests involving occupying an area and refusing to leave until the demands were met. While the ERB attempted to starve them out and isolate them to get them to go, they ultimately failed. The sit-in lasted for nine days. At one point, Director Knauth of ERB met with them and offered charity and segregated workshops which were rejected. The League claimed they did not want charity; they wanted work. Or, in the words of the New York Times, "Three Camping in Relief Office Promise to Continue Siege – Spurn City's Home Aid." <sup>134</sup> Various other protestors occasionally joined during this sit-in, making it highly visible.

The League continued to organize sit-ins at New York's ERB and WPA offices. They camped on the lawn of WPA headquarters in Washington, D.C, which did not pan out as hoped for the League. However, the League's actions ultimately led to the creation of 1500 jobs in New York City. The League faded to the background sometime in 1938. They failed to

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<sup>&</sup>lt;sup>132</sup> Zames and Fleischer, *The Disability Rights Movement*, 5.

<sup>&</sup>lt;sup>133</sup> Paul K. Longmore and David Goldberger, "The League of the Physically Handicapped and the Great Depression: A Case Study in the New Disability History," *The Journal of American History* 87, no 3 (December 8, 2000), 898. <sup>134</sup> "CRIPPLES SEE KNAUTH, BUT FAIL TO GET JOBS: THREE CAMPING IN RELIEF OFFICE PROMISE TO CONTINUE SIEGE -- SPURN CITY'S HOME AID," *The New York Times*, Jun 04, 1935.

<sup>&</sup>lt;sup>135</sup> "PLEA BY DISABLED PUT TO WPA CHIEF: NEW YORK GROUP, CAMPING IN WASHINGTON, WILL CONSULT WILLIAMS AGAIN TODAY CHARGE 'DISCRIMINATION' THEY ARE TOLD LAW ALLOWS NO SPECIAL CONSIDERATION, BUT PROPOSED CENSUS MAY HELP," *The New York Times,* Aug 17, 1937.

<sup>&</sup>lt;sup>136</sup> Zames and Fleischer, *Disability Rights Movement*, 5-7; Shapiro, *No Pity*, 64; Sain, et al, "IL 201," 37-38; Longmore and Goldberger, "The League of the Physically Handicapped" 893.

redirect federal action, change the narrative, or leave any ongoing cohesive activism base behind.

They set a precedent, and they forced conversations about the fate of the disabled.

Created around the same time as the League, Jacob tenBroek established the National Federation for the Blind (NFB). Working to "promote the economic and social welfare of the blind," the NFB led the fight for rights of those with visual disabilities and pioneered independence for the blind. They advocated for "white cane laws," which made it safer for blind individuals "who travel with aid of this device. These canes had become a symbol of independence and the social and economic integration of the blind. Thanks to the NFB's efforts, October 15th was designated as White Cane Awareness Day. The NFB had state affiliates that followed national guidelines but operated independently. The NFB also funded a braille newspaper, the *Braille Monitor* (previously known as *All Story*). Like the Deaf community, the NFB was not interested in cross-disability alliances, since sometimes their interests conflicted with other disability groups. While the NFB only worked for those with visual disabilities, they helped establish a narrative of independence for individuals with visual disabilities.

Other organizations that protested job discrimination alongside the League were the National Fraternal Society of the Deaf (NFSD), founded in 1901, and the National Association of the Deaf (NAD), founded in 1880. The NFSD was an insurance company tailored more for the average citizen and worker that was "of, by, and for" deaf people.<sup>141</sup> In comparison, NAD sought

<sup>&</sup>lt;sup>137</sup> National Federation of the Blind Inc., "Constitution," *The Braille Monitor*, October 1966, <a href="https://nfb.org/images/nfb/publications/bm/bm66/bm66-oct.html">https://nfb.org/images/nfb/publications/bm/bm66/bm66-oct.html</a>.

<sup>&</sup>lt;sup>138</sup> Jacobus tenBroek, "The Right to Live in the World: The Disabled in the Law of Torts," *California Law Review* 54, no. 2 (May 1966): 847.

tenBroek, "The Right to Live in the World," 847.

<sup>&</sup>lt;sup>140</sup> Barbara Piece, "Telling Our Story: Through Publications," in *Building the Lives We Want: The Seventy-Fifth Anniversary History of the National Federation of the Blind*, ed. by Deborah Stein (National Federation of the Blind, 2015). eBook

<sup>&</sup>lt;sup>141</sup> Susan Burch, Signs of Resistance: American Deaf Cultural History, 1900 to World War II (New York: New York University Press, 2004), 111.

to defend the entire communities' rights in the public sphere, yet in practice, catered to the educated urban elite. He are Both encouraged social hierarchies within the community reminiscent of "mainstream... American" society. He wisibility of disabilities.. Residential schools, first established in the early 19th century for and by deaf people in the United States, and the Deaf community emphasized their normality as a separate "cultural and linguistic minority group" with "full citizenship potential."

The Deaf community was hit hard by the Great Depression. They had difficulty finding jobs and were usually among the first laid off if cutbacks happened. The WPA also categorized them as unemployable regardless of any previous vocational or skill training. Similar to the League, they fought against this discrimination. Most Deaf organizations and workers accepted the *unemployable* label for individuals with disabilities as long as they were not included in that category. According to Deaf leaders and organizations, deaf people were not disabled; they were a linguistic minority. They wished to separate themselves from "the truly disabled," often rejecting cross-disability alliances like the League.<sup>145</sup>

However, one NFSD and NAD member, Paul Strachan, disagreed with the leaders in the Deaf community on their refusal to work with other disabled individuals outside the Deaf. Eventually kicked out of those organizations, Strachan founded the American Federation of the Physically Handicapped (AFPH), the first national cross-disability activist organization. Strachan "understood disability as a right's issue - not one of social welfare or the individual" and focused on how social structures excluded individuals with disabilities.<sup>146</sup> The AFPH argued that people

<sup>&</sup>lt;sup>142</sup> Burch, Signs of Resistance, 111-112.

<sup>&</sup>lt;sup>143</sup> Burch, Signs of Resistance, 126.

<sup>&</sup>lt;sup>144</sup> Michael Higgins and Amy M. Lieberman, "Deaf Students as a Linguistic and Cultural Minority: Shifting Perspectives and Implications for Teaching and Learning." *Journal of Education* 196, no. 1 (2016): 9: Nielsen, *A Disability History*, 134-136.

<sup>&</sup>lt;sup>145</sup> Nielsen, A Disability History, 134-136.

<sup>&</sup>lt;sup>146</sup> Nielsen, A Disability History, 134

with disabilities had civil rights, including access to public life. They pushed for accessible building policies, better work safety measures, and economic security. Unlike March for Dimes or Easter Seals, which focused on "medical rehabilitation and needs-based charity...focused exclusively on altering the individual," the AFPH sought to change social and employer attitudes towards individuals with disabilities.<sup>147</sup>

The AFPH, mainly funded by labor unions, worked with them and disability activists to bring about government programs for those with disabilities, such as National Employment of the Physical Handicapped Week (NEPHWEEK). President Harry S. Truman signed Public Law 176 on August 11, 1945, and established the first full week in October each year as NEPHWEEK. He AFPH had groups (or lodges) in eighty-nine cities. They hosted biennial conventions on a national level and were extremely visible on a state and local level. Strachan and the AFPH spoke before Congress and advocated establishing a "federal agency for handicapped [individuals]." Alongside the creation of NEPH was the President's Committee on Employment of the Handicapped, which worked with the National Easter Seals Society and disabled veterans to create national standards for "barrier-free" buildings. Barrier-free meant that the buildings would be accessible and usable by individuals with physical disabilities. The American National Standard Institute published these national standards and would become the basis of many architectural access codes. However, many buildings remained inaccessible until it was federally mandated.

<sup>&</sup>lt;sup>147</sup> Nielsen, A Disability History, 152.

<sup>&</sup>lt;sup>148</sup> Nielsen, *A Disability History*, 152; "The WORK of the AMERICAN FEDERATION OF THE PHYSICALLY HANDICAPPED, INC," Report, <a href="https://library.uta.edu/txdisabilityhistory/doc/20001886">https://library.uta.edu/txdisabilityhistory/doc/20001886</a>.

<sup>&</sup>lt;sup>149</sup> "A.F.P.H Bulletin," Newsletter, November 1949, https://library.uta.edu/txdisabilityhistory/doc/20001872.

<sup>&</sup>lt;sup>150</sup> Rehabilitation and Employment of Handicapped Citizens, S. 2570, 83<sup>rd</sup> Cong., 2<sup>nd</sup> Sess., Congressional Record (April 21, 1954), 1, <a href="https://library.uta.edu/txdisabilityhistory/doc/20001874">https://library.uta.edu/txdisabilityhistory/doc/20001874</a>.

Organizations for individuals with disabilities were very localized and community-based; however, many of these organizations found each other and collectivized. This development led to the beginnings of the deinstitutionalization movement, especially for children with mental or cognitive disabilities. One of these was the New Jersey Parents Group for Retarded Children, which was started by a New Jersey housewife who hoped this organization would "be the first chapter in a nationwide organization." By 1952, many of these parent groups in different states merged to form the National Association for Retarded Children (later named the National Association of Retarded Citizens and now known as The ARC). 152 This action was a complete departure from standard treatment towards cognitive disabilities, as many doctors had routinely encouraged parents to institutionalize children with mental retardation. Despite this, parents began to organize and advocate for their children – rejecting the stigma associated with cognitive disabilities. This stance could also be seen in media, specifically, The Child Who Never Grew by Pearl Buck (the only female to win the Pulitzer Prize and the Nobel Prize) and Angel Unaware by Dale Evans (a television/movie star and evangelical Christian). Both stories were written about their daughters who had cognitive disabilities, but they do not present the children as shameful or a punishment from God. Instead, both portrayed their daughters as innocent and a gift from God.<sup>153</sup>

The National Mental Health Foundation was founded by WWII "conscientious objectors" who were assigned to public service at state mental hospitals and training schools for individuals with cognitive and developmental disabilities. State hospitals were often understaffed; while the

<sup>&</sup>lt;sup>151</sup> Nielsen, A Disability History, 142.

<sup>&</sup>lt;sup>152</sup> Richard K. Scotch, "'Nothing About Us Without Us:' Disability Rights in America," *OAH Magazine of History* 23, no. 3, (July 2009): 18.

<sup>&</sup>lt;sup>153</sup> Nielsen, *A Disability History*, 142-143; Pearl S. Buck, *The Child Who Never Grew* (New York: J. Day Co., 1950); Dale Evans, *Angel Unaware* (Westwood, NJ: Revell, 1953).

staff was severely overworked. Shaken by the brutality towards patients, these conscientious objectors were appalled by the conditions in these institutions. They brought these facilities' abusive conditions and treatments to the attention of local and national media, community leaders, academics, and prominent influencers in American popular culture and politics. Their experiences were documented in the 1947 book, *Out of Sight, Out of Mind*, which showcased the lived experiences of institutionalized individuals; similarly showcased in Burton Blatt's exposé *Christmas in Purgatory* (1966). Burton Blatt, a professor at Boston University, hoped to reform these institutions, but ultimately deinstitutionalization was the only feasible solution.

Following the end of WWII, numerous different organizations created for and by disabled veterans formed in the United States. Such as the Disabled American Veterans organization, Paralyzed Veterans of America, and the Blind Veterans of America (BVA), the latter of which is very similar to the AFPH in welcoming all blind veterans, regardless of race or religion. The BVA, founded in 1945, advocated for better rehabilitation, employment programs, and physical accessibility and viewed disability as a civil rights issue. Paralyzed Veterans of America (PVA) was founded in 1946 by veterans with spinal cord injuries and sought to promote and protect the civil rights of disabled veterans. They published *The Paraplegia News* in 1951, founded by John M. Price (a paralyzed war veteran), a newspaper dedicated to "the interest of and for the benefit of paraplegics...civilian and veteran." The "main focus [of the newspaper] is on [improving] the daily life of individuals with spinal cord injuries" or wheelchair users. 158

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<sup>&</sup>lt;sup>154</sup> Nielsen, A Disability History, 144-145.

<sup>&</sup>lt;sup>155</sup> Frank Leon Wright, Out of Sight, Out of Mind: A Graphic Picture of Present-day Institutional Care of the Mentally Ill in America, Based on More than Two Thousand Eye-witness Reports (Philadelphia: National Mental Health Foundation, 1947); Burton Blatt and Fred Kaplan, Christmas in Purgatory: A Photographic Essay on Mental Retardation (1966), (Syracuse NY: Human Policy Press, 1974).

<sup>&</sup>lt;sup>156</sup> Nielsen, A Disability History, 146.

<sup>&</sup>lt;sup>157</sup> Helen Brainard Smith, "Seen and Heard," *The Ridgewood NJ Herald News*, Feb. 20, 1958, pg. 28; "Pushbutton Warfare Scares Mexicans; Paralyzed Veteran Aids Paraplegics," *The Wilmington Morning Star*, May 31, 1947, p. 1. <sup>158</sup> "Magazine has wheelchair sports covered," *The Record* (Hackensack, New Jersey), Aug. 22, 1999. Pg. 14.

## 2.4 Legislation

During the 1930s to 1960s, legislation about individuals with disabilities was less concerned with guaranteeing or protecting their civil rights or against discrimination. Instead, most legislation (federal policies and programs) took a medical-based approach toward disability. The goal was rehabilitation in order to be as *normal* as possible. During this time frame, legislation was enacted that helped lay the groundwork for the deinstitutionalization of individuals with disabilities from the state-funded institutional asylums or warehouses. Legislation was passed concerning civil rights; however, it skipped over the rights of individuals with disabilities and only covered discrimination based on skin color. This direction would inspire disability activists as they fought for their civil rights in the 1970s.

In the 1910s, Congress passed the Smith-Hughes Act Vocational Rehabilitation Act (1917) and the Smith-Sears Veterans Rehabilitation Act, which established a Federal-State program responsible for the vocational rehabilitation of disabled veterans, plus job training and employment for disabled WWI veterans. The 1920 Smith-Fess Act (or Civilian Vocational Rehabilitation Act) extended this rehabilitation program to include civilians with disabilities. These did not approach the civil rights issue for individuals with disabilities; instead they focused on federal assistance to obtain jobs. Congress, in the 1930s, passed two acts regarding the employment of the blind and economic opportunities. First, the Randolph-Sheppard Act of 1936 recognized that blind individuals could have jobs and allowed the state to license qualified individuals to operate vending stands in federal buildings. Second, the Wagner-O'Day Act in

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<sup>&</sup>lt;sup>159</sup> David Carleton, "The Smith-Hughes Act (February 23, 1917)" in *Landmark Congressional Laws on Education* (Greenwood Publishing Group, 2002), 63-65; Evangeline Thurber, "Rehabilitation of World War I Veterans in District No. 12," *Pacific Historical Review* 15, no. 1 (1946): 68-9; Reuben D. Cahn, "Civilian Vocational Rehabilitation," *Journal of Political Economy* 32, no. 6 (December 1924): 666.

<sup>&</sup>lt;sup>160</sup> James Ledbetter and Timothy L. Field, "A Brief History of Vocational Rehabilitation Legislation," *Psychosocial Rehabilitation Journal* 2, no. 3 (1978): 35.

<sup>&</sup>lt;sup>161</sup> Randolph-Shepard Act, U.S. Code 20 (1936), § 107 et seq.

1938 required the government to purchase specific products from workshops for blind individuals. Rehabilitation and economic stability were the goals.

Following WWII, Congress passed the Barden-Lafollette Act of 1943 (or Vocational Rehabilitation Amendments), which expanded the efforts of the previous acts by "providing manual vocational training, higher-education opportunities, and physical rehabilitation services." This direction increased the Rehabilitation program's budget and allowed for services offered to mentally ill individuals instead of just those with physical disabilities. In 1954, Congress revised the Vocational Amendment Act and reshaped the roles of the federal-state program. It also established a working relationship between public and private rehabilitation services and other various improvements. Later in 1965, Congress expanded services to individuals with socially handicapped conditions, removed economic need as a requirement for services, and established the National Commission on Architectural Barriers. In 1967, Congress used the act to support the construction and operation of the National Center for Deaf/Blind Youth and Adults. Ultimately, these laws provided resources for individuals with disabilities to obtain jobs or governmental aid but did nothing in granting civil rights.

Sometimes Congress passed legislation for individuals with disabilities that had unforeseen consequences. The Social Security Act of 1935, part of FDR's New Deal, established an income maintenance system that targeted individuals with an "inability to engage in substantial gainful work," or individuals with disabilities. At first, this only included blind individuals and disabled children; however, this would increase. In the 1950s, Social Security

<sup>&</sup>lt;sup>162</sup> Javits-Wagner-O'Day Act, U.S. Code 41 (1971), §§ 8501-8506.

<sup>&</sup>lt;sup>163</sup> Nielsen, A Disability History, 150; "Handicapped Workers," Monthly Labor Review 60, no. 6 (1945): 1231-32.

<sup>&</sup>lt;sup>164</sup> Vocational Rehabilitation Amendments of 1954, Pub. L. 565, U.S. Statute at Large 68 (1954): 652-665; Vocational Rehabilitation Amendments of 1965, Pub. L. 89-333, U.S. Statute at Large 79 (1965): 1289.

<sup>&</sup>lt;sup>165</sup> Vocational Rehabilitation Amendments of 1967, Pub. L. 90-99, U.S. Statute at Large 81 (1967): 250.

<sup>&</sup>lt;sup>166</sup> Social Security Amendments of 1954, Pub. L. 83-761, U.S. Statutes at Large 83 (1954): 1080.

Amendments established a federal-state aid program for disabled individuals, included financial protection for workers forced to leave the workforce due to disability, extended benefits to dependents of disabled workers, and eliminated age restrictions for disabled workers.<sup>167</sup>

However, this act had many unintended consequences since it kept many disabled people unemployed, contrary to the goal of the Vocational Rehabilitation Act since benefits would be rescinded if they earned above a set limit below the national poverty level.<sup>168</sup> This made the Social Security Act a catch-22 for individuals with disabilities.

At the same time legislation expanded rehabilitation services, Congress also passed legislation allowing the deinstitutionalization movement to gain traction and focused on individuals with mental disabilities. In 1946, the Hill-Burton Act was passed and authorized federal grants to states to create hospitals, public health centers, and facilities for rehabilitating individuals with disabilities. <sup>169</sup> The National Mental Health Act, which established the National Institute of Mental Health, was enacted in 1946. In the 1960s, President Kennedy created the President's Panel on Mental Retardation and called for the number of individuals confined to residential asylums for the mentally ill to be reduced, aiding the deinstitutionalization movement. <sup>170</sup> In 1966, this panel became a committee on mental retardation (established by President Johnson) and was later renamed the President's Committee for People with Intellectual Disabilities. Following these developments, Congress passed the Mental Retardation Facilities and Community Health Centers Construction Act (or Community Mental Health Act), which

<sup>&</sup>lt;sup>167</sup> Social Security Amendments of 1954, 1080.

<sup>&</sup>lt;sup>168</sup> Evan J. Kemp Jr., "Stop 'Caring for' the Disabled" *The Washington Post*, June 7, 1981; For more information on how this legislation is essentially a poverty trap see, David C. Stapleton et al., "Dismantling the Poverty Trap: Disability Policy for the Twenty-First Century" *The Milbank Quarterly* 84, no. 4 (Dec 2006): 701-732.

<sup>169</sup> *Hill-Burton Act of 1946*, Pub. L. 79-725, 60 Stat. 1040 (1946).

<sup>&</sup>lt;sup>170</sup> John F. Kennedy, 1961, "Statement by the President Regarding the Need for a National Plan in Mental Retardation," (transcript, National Archives).

authorized grants for nonprofit mental health centers (private and public).<sup>171</sup> These actions led to the end of institutional warehouses in the United States.

In 1964, President Johnson signed the Civil Rights Act of 1964, which prohibited discrimination based on race, religion, ethnicity, national origin, and creed. Disability was not included. Previously implemented legislation provided government aid and employment opportunities for individuals with disabilities. Nevertheless, individuals with disabilities were still not protected from discrimination or disenfranchisement, despite being the largest minority group in the United States. At the same time, there was evidence of changing perceptions towards disabilities, seen in the end of the eugenics movement and deinstitutionalization.

### 2.5 Conclusion

Individuals with disabilities in the United States were in a transition period as changes in society, legislation, and perception led to different organizations and media that increased the visibility of disabilities. Despite no cohesive disability community, the seeds of one were beginning to grow as different organizations worked together for a common interest. Changes in societal perceptions of disability were also abundant, leading to deinstitutionalization and the end of the eugenic movement (albeit aided by the horror of Nazi eugenics). Individuals with disabilities demanded to be seen and heard, and laid the groundwork for civil rights during this time. In the latter half of the 20<sup>th</sup> century, the United States was in a civil rights revolution; disability activists of the 1970s and 80s learned and used strategies from the civil rights activists of the 50s and 60s.

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<sup>&</sup>lt;sup>171</sup> Mental Retardation Facilities and Community Health Centers Construction Act of 1963, Pub. L. 88-164, U.S. Statutes at Large 77 (1963): 284.

# 3. FULLY KNOWN. FULLY HUMAN.

The passage of the Civil Rights Act of 1964 prohibited discrimination based on race, religion, sex, or ethnicity, but not disability. Rather than discourage them, this act led to increased effort by individuals with disabilities to fight for the rights for which they had been passed over. Disability rights activists had realized that they would have to fight for their rights, same as other minorities before them. Inspired and energized by the efforts of civil rights activists, disability rights activists established organizations, organized protests, and lobbied and helped draft protective legislation. Disability rights activists realized they needed to take agency for themselves in changing societal and governmental perceptions of disability and the disabled community. Thus, the Disability Rights Movements was born. It was time for individuals with disabilities to be fully known and fully human in the eyes of the law and society.

## 3.1 Organizations & Movements

Many movements began with one individual's actions; in the Independent Living Movement's case, this was Edward L. Roberts. Ed Roberts contracted polio at fourteen in 1953 and was left paralyzed from the neck down (except for two fingers and a few toes). Roberts began his work in self-advocacy in his fight for acceptance at the University of California at Berkeley. He was admitted in 1962, although the university described his admittance as "experimental," while newspaper headlines read "Helpless Cripple Attends U.C. Classes." Despite the insulting headline, it inspired hope among the disabled, leading to an increase of severely disabled students applying and attending U.C. Berkeley. Roberts and other disabled

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<sup>&</sup>lt;sup>172</sup> Shapiro, *No Pity*, 44-45.

<sup>&</sup>lt;sup>173</sup> "A Story of Burlingame Boy and His Heroism," *The Times (San Mateo, California)*, October 24, 1962, pg. 15.

<sup>&</sup>lt;sup>174</sup> Sain et al., "IL 201," 37-38.

students created the "Rolling Quads," an informal student organization that formed into a political activist coalition by the end of the 1960s. <sup>175</sup> Roberts helped establish the Physically Disabled Students Program (PDSP), essentially an anti-dropout program run by and for students with disabilities. However, the PDSP expanded to assist individuals with disabilities in the surrounding community. <sup>176</sup> Roberts was the first student with visible severe disabilities to attend UC Berkeley, but he intended not to be the last. He was successful.

Robert founded the Center for Independent Living (CIL) in Berkeley in 1972. Having grown out of the PDSP and former student members, this center focused on "people with severe disabilities having attendant services...[where] each individual—not the aide—decided for themselves what to eat, what to wear, and when to go to bed."<sup>177</sup> Berkeley's CIL was a model "for independence, self-advocacy, and peer-support programs" that quickly spread nationwide. <sup>178</sup> It also provided a model for "advocacy-based organizations" as their "bylaws said that at least 51% of the staff and Board had to be people with disabilities, or it would be the same old oppression."<sup>179</sup> They wanted to prevent what happened to the President's Commission on National Employment of the Handicapped (PCEH), which Strachan claimed "fill[ed] up...with a lot of 'do-gooders, social welfare workers, and the like,' most of whom...WILL DO ANYTHING IN THE WORLD FOR THE HANDICAPPED, EXCEPT, GET OFF OUR BACKS!"<sup>180</sup> Centers for Independent Living began to appear throughout the nation as local

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<sup>&</sup>lt;sup>175</sup> Scot Danforth, "Becoming the Rolling Quads: Disability Politics at the University of California, Berkeley, in the 1960s." History of Education Quarterly 58, no. 4 (2018): 506–36.

<sup>&</sup>lt;sup>176</sup> Danforth, "Becoming the Rolling Quads," 510-511; Fred Pelka, What We Have Done: An Oral History of the Disability Rights Movement (University of Massachusetts Press 2012), 197-198.

<sup>&</sup>lt;sup>177</sup> Stephanie Francis Ward, "Action for Access," ABA Journal 104, no. 1 (January 2018): 44.

<sup>&</sup>lt;sup>178</sup> Richard K. Scotch, "The Disabilities Rights Movement: An Overview," in *Disabilities: Teen Rights and Freedoms*, edited by David M. Haugen and Susan Musser, (Farmington Hills, MI: Greenhaven Press, 2014), 23. <sup>179</sup> "Ed Roberts (1939-1995)," The Ability Center, Jan. 21, 2020, https://abilitycenter.org/ed-roberts-1939-1995/.

<sup>&</sup>lt;sup>180</sup> Nielsen, A Disability History, 153.

organizations. By the end of the 1980s, there were over 300 Centers for Independent Living established in the United States. 181

Berkeley's CIL lit the spark that grew into a national movement with its own "independent living philosophy." At its core, this was a cross-disability philosophy rooted in the then-radical notion that disabled individuals were the experts on their experience and knew what they needed best. Roberts, often called the "Father of the Independent Living Movement," changed the narrative set for individuals with disabilities on measuring independence. Roberts "redefined independence as the control a disabled person had over his life." In contrast to the medical model of disability which equated mobility with independence. This movement spread like wildfire and redefined societal perceptions of disability and connected individuals with different disabilities into a shared community.

The "barrier-free" movement continued to make strides across the nation. Comprised of national and grassroots organizations, this movement focused on removing architectural barriers for the handicapped and disabled. However, the local grassroot organizations needed to be brought to light, rather than the movements of large national groups previously mentioned. Ronald Mace, a disabled architect and disability advocate in North Carolina, established Barrier Free Environments Inc. (BFE), which advocated "for accessibility in buildings and products." BFE provided technical assistance and consulting for architectural accessibility issues on a state and federal level. 86 While BFE did operate on a national level, it is not as widely recognized for

<sup>&</sup>lt;sup>181</sup> Richard K. Scotch, "Politics and Policy in the History of the Disability Rights Movement," *The Milbank Quarterly* 67, suppl. 2, pt. 2 (1986): 394.

<sup>&</sup>lt;sup>182</sup> Sain et al., "IL 201," 24.

<sup>&</sup>lt;sup>183</sup> Pelka, *What We Have Done*, 113; Sandy Kleffman, "Ed Roberts, Advocate for the Disabled, Dies," *The Sacramento Bee*, Mar. 16, 1995, pg. 20.

<sup>&</sup>lt;sup>184</sup> Shapiro, No Pity, 51.

<sup>&</sup>lt;sup>185</sup> Sain et al., "IL 201," 68.

<sup>&</sup>lt;sup>186</sup> Aimi Hamraie, *Building Access: Universal Design and Politics of Disability*, (Minneapolis: University of Minnesota Press, 2017), 175-222.

its contribution to the barrier-free movement. Barrier Free Environments Inc helped to develop and implement "state building codes, national and federal design standards, and construction regulations for appropriate accessible housing" and other buildings."<sup>187</sup> They also testified in front of Congress regarding issues with the Fair Housing Amendments Act of 1987.

In Frederick County, Maryland, Cara Clow (disabled by polio as a toddler) joined the Disability Rights Movement and fought locally for accessible public spaces in 1973. In 1976, Clow and her husband organized the Disabled Citizens of Frederick County United and focused on "architectural and attitudinal barriers." The Able-Disabled Club (a local group in Lima, Ohio) also pushed to eliminate architectural barriers. In Florida, a local group "declared itself on the WARPATH (World Association to Remove Prejudice Against the Handicapped) to abolish barriers in public transportation." Grassroot organizations appeared nationwide, fighting to eliminate barriers for people with disabilities in architecture, transportation, education, and employment.

Local and grassroots organizations gained traction as national networks began forming for individuals with disabilities, first through "national meetings of the President's Committee on the National Employ the Handicapped Week" and then through self-advocacy groups like the American Coalition of Citizens with Disabilities (ACCD). The ACCD was founded on April 30th, 1975, by Lex Frieden, Fred Fay, Judy Heumann, and other prominent disability rights activists. ACCD was an "organization of organizations" that included "national, disability-specific...[and] locally disability-led organizations." ACCD occasionally referred to as "the

<sup>&</sup>lt;sup>187</sup> U.S. Congress, Senate, Committee on the Judiciary, Subcommittee on the Constitution, *Fair Housing Amendment Act of 1987: Hearings before the Subcommittee on the Constitution of the Committee on the Judiciary*, 100<sup>th</sup> Cong., 1<sup>st</sup> Sess., 1987, 464-466.

<sup>&</sup>lt;sup>188</sup> Nielsen, A Disability History, 161.

<sup>&</sup>lt;sup>189</sup> Nielsen, A Disability History, 167.

<sup>&</sup>lt;sup>190</sup> Scotch, "Nothing About Us Without Us," 19.

<sup>&</sup>lt;sup>191</sup> Lex Frieden, "Roots of the Movement That Produced the ADA," HLRe: Off the Record 5, no. 2 (2015), 138.

handicapped lobby," represented "the first attempt to organize a united front among disparate interest groups." 192 Created, governed, and administered by individuals with disabilities, the ACCD facilitated the creation of fifty statewide and hundreds of local coalitions. The ACCD closed its doors in 1983 due to a lack of funding. However, it still greatly impacted the visibility of the disability rights movement with its influence on legislation, protests, and the disabled community.<sup>193</sup>

There was a growth in legal organizations that focused on protecting the legal rights of individuals with disabilities: National Center for Law and the Handicapped (NCHL) and the Disability Rights Education and Defense Fund (DREDF). Founded in 1971, the National Center for Law and the Handicapped (located at the University of Notre Dame in South Bend, Indiana) was the first legal advocacy center for people with disabilities in the United States. 194 One of its founders was Robert Burgdorf Jr., the "drafter of the original ADA bill," who had been partially paralyzed by polio. 195 The NCHL provided advocacy for people with intellectual, mental, and physical disabilities. One of NCHL's earliest cases was Colorado Association for Retarded Children v. State of Colorado, "a class action suit brought in federal court on behalf of a statewide class of children with disabilities against the state and all the individual school districts for failing to provide a free public education to the plaintiffs." 196 NCHL worked on special education issues, cases focusing on community residential services, and the sterilization of

<sup>&</sup>lt;sup>192</sup> Steven V. Roberts, "Handicapped Are Feeling New Strength in Congress," *The New York Times*, Mar 13, 1979, pg. 8. <sup>193</sup> Frieden, "Roots of the Movement," 138-140.

<sup>&</sup>lt;sup>194</sup> Sain et al., "IL 201," 68; Ward, "Action for Access," 47.

<sup>&</sup>lt;sup>195</sup> U.S. Congress, House of Representatives, Committee on Education and Labor, ADA Restoration Act of 2007: Hearings before the Committee on Education and Labor, 110th Cong., 2nd sess., 2007, 11;

<sup>&</sup>lt;sup>196</sup> Robert Burgdorf Jr., "Pioneering Disability Rights," Notre Dame Magazine (Winter 2016-17), https://magazine.nd.edu/stories/pioneering-disability-rights/.

disabled children. The NCHL lasted for less than a decade due to budget cuts, but many of its "alumni" made further strides in advocacy for the disability rights movement. 197

In 1979, the Disability Rights Education and Defense Fund (DREDF), modeled on the NAACP's legal defense fund, evolved from the Berkeley CIL's Disability Law Resource Center. Cofounded by disability activists Patrisha Wright and Mary Lou Breslin, DREDF would become the nation's leading disability rights advocacy center. Patricia Wright, a legally blond lobbyist, served as the Director of Government affairs for DREDF and established an office in Washington D.C. Wright led the congressional negotiating team representing Americans with disabilities throughout the ADA's legislative process and was instrumental in the enactment of disability rights legislation. PAEDF Although not well-known to the average American, DREDF participated in "much of the landmark litigation and lobbying of the 1980s and 1990s," thus extremely visible in the legal field and congress.

DREDF played an active role in litigation regarding Section 504 regulations; one of the first pieces of protective legislation regarding disability discrimination. In *Southeastern Community College v. Davis*, the Supreme Court ruled that denying Francis Davis, a hard of hearing licensed practical nurse, admittance to a registered nurse program did not violate Section 504. Attorneys at DREDF realized that the Supreme Court Justices did not understand the issue, so they waited for their next chance. This chance arrived once *Consolidated Rail Corp. v. Darrone* reached the Supreme Court. DREDF filed an amicus brief supporting the petitioner that educated the Court on discriminatory employment practices and the importance of Section 504

<sup>&</sup>lt;sup>197</sup> Burgdorf Jr., "Pioneering Disability Rights."

<sup>198</sup> Pelka, What We Have Done, 339; Ward, "Action for Access," 47; Scotch, "Nothing About Us Without Us," 20.

<sup>&</sup>lt;sup>199</sup> Pat Wright, "The Culmination of Decades of Struggle," *Worklife* 3, no. 3 (1990): 14; Pelka, *What We Have Done*, 461-64.

<sup>&</sup>lt;sup>200</sup> Sain et al., "IL 201," 59.

regulations.<sup>201</sup> DREDF's goal was to transition the Supreme Court from viewing "disability as part of the 'medical model'...in terms of sickness and benefits" to "view[ing] disability in terms of civil rights."<sup>202</sup> DREDF's activism in the courts and government were essential to the passage of the Americans with Disabilities Act.

The National Council on Disability (NCD), originally named the National Council on the Handicapped, was founded in 1978 as a small advisory body to the Department of HEW, then the Department of Education, and eventually became an independent agency in 1984. The NCD acted as an advisory board on disability policy for all levels of government and private sectors. Their primary mission was "to review federal laws and programs affecting people with disabilities and to make recommendations to the president and Congress" on improving those laws and programs.<sup>203</sup> To provide these recommendations, they consulted various disability organizations, local and national.

In 1982, Justin Dart, on behalf of the council, traveled to all fifty states (using his wealth to do so) and met with disabled activists to get an underlying sense of the most pressing issue: "defining [the] protection of rights."<sup>204</sup> Dart, a paralyzed wheelchair user, had been appointed the Vice-chair of the National Council of the Handicapped (later the National Council on Disability) by President Ronald Reagan. During this tour of the states, Dart compiled evidence from disabled communities to ascertain the issues they faced. This compiled evidence was known as the "discrimination diaries;" these "diaries" provided evidence and support for the NCDs

Ward, "Action for Access," 47-48; "Southeastern Community College v. Davis," Oyez, Accessed March 1, 2023. https://www.ovez.org/cases/1978/78-711.

<sup>&</sup>lt;sup>202</sup> Kathi Wolfe, "Disability Rights Group: 30 Years as a Force for Change," *Independence Today*, Dec. 19, 2012, <a href="https://dredf.org/disability-rights-group-30-years-as-a-force-for-change/">https://dredf.org/disability-rights-group-30-years-as-a-force-for-change/</a>.

<sup>&</sup>lt;sup>203</sup> Burgdorf Jr., "Pioneering Disability Rights"; Lex Friedan, et al, "National Council on Disability: 20 Years of Independence," *National Council on Disability*, July 26, 2004, 5-6.
<sup>204</sup> Shapiro, *No Pity*, 108.

recommendations.<sup>205</sup> They conducted a national poll or survey "to obtain data on disabled people's experiences and attitudes that would provide a clear information framework of NCD's recommendations on public policy for disabled people," which would later be published as *The ICD Survey of Disabled Americans: Bringing Disabled Americans Into the Mainstream*.<sup>206</sup>

The NCD comprised their preliminary data findings, analysis, and suggestions into the following reports. In 1986, the NCD published *Toward Independence*, which proposed that Congress "enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap."<sup>207</sup> The name proposed for this law was the Americans with Disabilities Act. In 1988, the NCD published *On the Threshold of Independence*, which reviewed *Toward Independence's* reception and achievements made in the areas addressed in the previous report. *On the Threshold* also included one of the first drafts of the Americans with Disabilities Act. The NCD compiled the research necessary to draft the

Summer camps for individuals with disabilities profoundly impacted disability rights activism, specifically Camp Jened. Camp Jened was a two-month "summer getaway and rehabilitation center for teenagers and adults with disabilities" in Hunter, New York. This summer camp was one of the few for teenagers with disabilities, and people traveled from across the country to join. They offered a rehabilitation program alongside standard camp activities and,

<sup>&</sup>lt;sup>205</sup> Justin Dart, Jr., interview, *In Their Own Words: An ADA History*, Administration for Community Living and HHS Office for Civil Rights, October 20, 1999.

<sup>&</sup>lt;sup>206</sup> Friedan, et al, "National Council on Disability," 13.

<sup>&</sup>lt;sup>207</sup> On the Threshold of Independence, National Council on the Handicapped: Report to the President and to the Congress of the United States (January 1988), <a href="https://ncd.gov/publications/1988/jan1988">https://ncd.gov/publications/1988/jan1988</a>.

<sup>&</sup>lt;sup>208</sup> Friedan, et al, "National Council on Disability," 13-17.

<sup>&</sup>lt;sup>209</sup> Eddie Comeaux, Danielle Mireles, and Anna Acha, "Dis/abled Student Campusmaking: Sites of New Possibility" *Education Sciences* 11, no. 11 (2021): 9.

most importantly, a sense of community. This camp connected teenagers with disabilities and built a community. Members of this community, inspired by the freedom and accessibility, "wanted to have more" and "to change the world out there." This camp is also where three prominent disability rights activists would first meet: Judy Heumann, Bobbi Linn, and Frieda Tankus. Camp Jened was not the only one of its kind, such as Easter Seal's Camp Daddy Allen, however it was a crucial turning point for the disability rights movement. Camp Jened inspired hope in a better world among adolescents with disabilities, many of whom who would later become disability rights activists upon entering adulthood. 211

Change does not occur on a grand stage but locally; this was the case for student organizations on college campuses. Three organizations whose founders attended Camp Jened increased the visibility of disability activism in higher education: SOFEDUP, HIM, and PUSH. SOFEDUP (or Student Organization for Every Disability United for Progress) was founded at Brooklyn College in 1970 by Frieda Tankus and other disabled students. SOFEDUP brought attention to campus inaccessibility and provided accommodations for students with disabilities. HIM (or Handicapped Integration Movement) was founded by Judy Heumann and other disabled students at Long Island University (LIU), Brooklyn Campus. Born from LIU's Disabled Student Program (which advocated for campus accessibility and advised students with disabilities), HIM demanded equal rights and accessibility in higher education. In 1969, HIM organized a conference at the university to raise awareness about discrimination towards individuals with disabilities. PUSH (or People United in Support of the Handicapped) was founded by disabled

<sup>&</sup>lt;sup>210</sup> Ward, "Action For Access," 43; Lindsey Patterson, "Points of Access: Rehabilitation Centers, Summer Camps, and Student Life in the Making of Disability Activism, 1960-1973," *Journal of Social History* 46, No. 2 (Winter 2012): 481.

<sup>&</sup>lt;sup>211</sup> For more information on Camp Jened, see *Crip Camp: A Disability Revolution*, directed by James Lebrecht and Nicole Newman, (2020; Los Gatos, CA: Netflix).

students at Hofstra University, including leader Bobbi Linn. PUSH fought to ensure equal opportunities for disabled students and make the dorms accessible to wheelchair users.<sup>212</sup>

#### 3.2 Protests

In 1969, Judy Heumann was denied her teaching license by the New York Board of Education; simply because she "couldn't walk." The following year she was the plaintiff in *Heumann v. Board of Education of the City of New York*, "one of the earliest disability-based employment discrimination lawsuits in the nation" in 1970. The court ruled in her favor and inspired Heumann to found Disabled in Action (DIA), one of the first cross-disability political activist organizations, with members of SOFEDUP, HIM, PUSH, and those who shared similar experiences. They tackled various issues, from ending sheltered workshops and institutionalization to public protests. The DIA organized numerous protests, most notably the Section 504 Sit-ins. The DIA's militant activism led to the overriding of President Nixon's veto of the Rehabilitation Act of 1973 and the enforcement of Section 504.

Some of the most important protests of the 1970s were due to the Rehabilitation Act of 1973 (or "Rehab Act") and Section 504. Primarily considered a spending bill, this act authorized federal aid to individuals with disabilities. The Nixon administration vetoed the bill twice, claiming the act was a "waste [of] taxpayer dollars." Modeled off of the Civil Rights Act of 1964, Section 504 of this Act prohibited the discrimination of individuals with disabilities in "any program or activity receiving federal financial assistance" "solely by reason of his [or her]

<sup>&</sup>lt;sup>212</sup> Patterson, "Points of Access, "482-483.

<sup>&</sup>lt;sup>213</sup> Ward, "Action For Access," 43; "You Can Be President, Not Teacher, With Polio," *Daily News* (New York, New York), Apr. 5, 1970, pg. 82.

<sup>&</sup>lt;sup>214</sup> Pelka, *What Have We Done*, 126; Andrew H. Malcolm, "Women in Wheel Chair Sues to Become Teacher," *The New York Times*, May 27, 1970, pg. 33.

<sup>&</sup>lt;sup>215</sup> Patterson, "Points of Access," 484.

<sup>&</sup>lt;sup>216</sup> Judith Heumann, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist* (Boston: Beacon Press, 2020), 64; Pelka, *What Have We Done*, 138.

<sup>&</sup>lt;sup>217</sup> Ward, "Action for Access," 45.

handicap."<sup>218</sup> Section 504 was the first federal civil rights law that protected individuals with disabilities and the most critical piece of legislation enacted during the Disability Rights Movement before the passage of the ADA.

Nixon's veto of the Rehabilitation Act in October 1972 led to protests nationwide, including the DIA demonstration at Madison Avenue in New York City. On November 2nd, 1972, Heumann, Bobby Muller (a paraplegic Vietnam veteran), and fifty fellow activists wheeled themselves into the middle of Manhattan's Madison Avenue, faced the oncoming cars, and stopped; they shut down traffic. The New York police "stood and watched, unable to move or arrest the protesters because their vehicles were not equipped for disabled passengers." After the hour-long demonstration on Madison Ave, the DIA protestors moved to Nixon's re-election campaign headquarters in New York. They occupied the office till midnight – four days before the election. The DIA members demanded that Nixon explain his veto, which he did not; when Congress passed a revised version, he vetoed the bill again. In response, DIA held a march with 150 disability activists in Washington, D.C. 222 DIA organized demonstrations at the Lincoln Memorial, Federal Plaza, and different parts of the nation for eleven months. 223

The bill was reintroduced and made effective September 27th, 1973.

The enactment of the Rehabilitation Act of 1973 was a stride forward for the disability rights movement. However, fearing the potential scope of Section 504, Congress, and presidential administrations began to postpone releasing regulations for Section 504. Regulations

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<sup>&</sup>lt;sup>218</sup> Scotch, "Nothing About Us Without Us," 20; *The Rehabilitation Act of 1973*, Pub. L. 93-112 §504, 87 Stat. 355 (1973), <a href="https://www.eeoc.gov/rehabilitation-act-1973-original-text">https://www.eeoc.gov/rehabilitation-act-1973-original-text</a>.

<sup>&</sup>lt;sup>219</sup> Zames and Fleischer, *Disability Rights Movement*, 49.

<sup>&</sup>lt;sup>220</sup> Heumann, *Being Heumann*, 68; Chava Willig Levy, *A People's History of the Independent Living Movement* (Lawrence: Research and Training Center on Independent Living, 1988), 15; Sain et al., "IL 20l," 27-28; "Disabled Tie Up Traffic Here To Protest Nixon Aid-Bill Vote," *The New York Times*, Nov. 3, 1972, pg. 43.

<sup>&</sup>lt;sup>221</sup> Patterson, "Points of Access," 473.

<sup>&</sup>lt;sup>222</sup> Scotch, "Politics and Policy," 388.

<sup>&</sup>lt;sup>223</sup> Ward, "Action for Access," 46; "Disabled Tie Up Traffic."

for 504 were drafted by senate aides, Department of Health, Education and welfare (HEW), and disability rights advocates. The Ford Administration took a couple of years to draft these regulations and left office with them unsigned; then the Carter administration delayed signing them. Disability advocates gave the Carter administration until April 4, 1997, to issue regulations. In response, the Section 504 protests, organized by the DIA and other disability activists, began on April 5, 1977. Activists staged sit-ins and demonstrations in nine different HEW offices around the country; most ended up dispersing within 24-hours except for the one in San Francisco, California.<sup>224</sup>

Lasting twenty-five days, the San Francisco 504 demonstration was "the longest peaceful occupation of a federal building" in United States history. April 5, 1977, Heumann and other leading disability rights activists held a rally outside the steps of the San Francisco Federal building. Around two to three hundred activists with different disabilities from different social and racial backgrounds attended the rally. After entering the HEW office, Heumann declared "we're not leaving until we get assurances." Seventy-five people (activists and personal attendants) committed to staying; this action was not easy as many required daily medications or personal assistance which not everyone had. They were able to secure food from the Salvation Army and local organizations. Next day's headline read "An Occupation Army of Cripples Has Taken Over the San Francisco Federal Building." They held a press conference to share their story, when they learned that the D.C. protestors had been starved out, with no access to food, medication, or phones.

<sup>&</sup>lt;sup>224</sup> Sain et al., "IL 201," 54-55; Linda Hamilton Krieger, "Afterword: Socio-Legal Backlash," *Berkeley Journal of Employment & Labor Law* 21, no. 1 (2000): 489-490; "Disabled in San Francisco Vow to Continue Sit-in," *New York Times*, April 17, 1977, pg. 29.

<sup>&</sup>lt;sup>225</sup> Heumann, Being Heumann, 96.

<sup>&</sup>lt;sup>226</sup> Heumann, Being Heumann, 103.

<sup>&</sup>lt;sup>227</sup> Heumann, Being Heumann, 105-6.

San Francisco protestors were outraged; ten activists participated in a hunger strike in solidarity. The next day HEW shutdown the San Francisco Federal Building, cutting access to water and blocking landlines. Fortunately, the activists had access to the news and two pay phones, so they called their supporters to organize a vigil outside the building to call attention. Protestors used sign language to communicate with deaf protestors outside holding vigil to relay any announcements and messages. The issue of food remained, but not for long. Brad Lomax, a young protestor and member of the Black Panthers, "formed a bridge between civil rights movements." On the third night, the Black Panthers forced their way past security into the building with dinner for every protester; the Panthers continued to provide food and other provisions for the rest of the protest. One activist later stated, "without that food, the sit-in would have collapsed." Support from local grassroot organizations and other activists made the San Francisco 504 sit-in possible.

San Francisco's 504 Sit-in gained national media attention as labor unions, churches, and civil rights groups endorsed the protest. Local stores and the Black Panthers provided food, local pharmacies provided medication, and the Butterfly Brigade smuggled in walkie-talkies. Mayor George Moscone provided air mattresses and hoses with showerheads.<sup>232</sup> Politicians (local and federal) also voiced their support or provided provisions. Ed Roberts, the state Director of Rehabilitation, blessed the protest. He stated, "We have to keep up the pressure" since federal officials "have underestimated the commitment of this group."<sup>233</sup> Roberts also stated they "were

<sup>&</sup>lt;sup>228</sup> Ward "Action for Access," 46.

<sup>&</sup>lt;sup>229</sup> Eileen AJ Connelly, "Overlooked No More: Brad Lomax, a Bridge Between Civil Rights Movements," The New York Times, July 20, 2020, https://www.nytimes.com/2020/07/08/obituaries/brad-lomax-overlooked.html.

<sup>&</sup>lt;sup>230</sup> Heumann, *Being Heumann*, 113-14.

<sup>&</sup>lt;sup>231</sup> Susan Schweik, "Lomax's Matrix: Disability, Solidarity, and the Black Power of 504," Disability Studies Quarterly 31, no. 1 (2011), <a href="https://dsq-sds.org/article/view/1371/1539">https://dsq-sds.org/article/view/1371/1539</a>.

<sup>&</sup>lt;sup>232</sup> Heumann, *Being Heumann*, 110, 119-120; Shapiro, *No Pity*, 67.

<sup>&</sup>lt;sup>233</sup> Shapiro, *No Pity*, 67.

considered vegetables a few years ago, but now the vegetables are rising."<sup>234</sup> Governor Brown of California urged President Carter to sign the 504 regulations.<sup>235</sup> Democratic representatives Phillip Burton and George Miller supported the protesters' demands after holding a congressional hearing.<sup>236</sup> The "outpouring of community support" for the 504 Sit-in was crucial for how long the sit-in lasted. On April 28, 1977, twenty-five days later, the 504 regulations were signed into law as the HEW and the Carter Administration caved in to a protest with no sign of stopping. The Section 504 Sit-in was one of the earliest cross-disability protests that started the Disability Rights Movement in the 1970s.

One of the most visible protest organizations was the American Disabled for Accessible Public Transit (ADAPT) in Denver, Colorado, founded by wheelchair users from a Denver independent living center in 1978. ADAPT fought for accessible transportation in Denver in July 1978 by surrounding two city buses; these protests continued for four years. For seven years, ADAPT fought against the American Public Transit Association (APTA) and local public transit authorities nationwide to protest the lack of accessible public transport. <sup>237</sup> In 1983, ADAPT confronted APTA at their national convention and demanded that APTA take a stance on accessible public transit. APTA refused, so ADAPT "promised to confront the transportation group whenever possible," a promise the members of ADAPT kept. <sup>238</sup> At every conference APTA held, ADAPT was there as well.

Inspired by the bus boycotts of the Civil Rights movement, ADAPT engaged in civil disobedience protests, such as blocking roads and chaining themselves or their wheelchairs to

<sup>&</sup>lt;sup>234</sup> "Disabled in San Francisco Vow to Continue Sit-in," New York Times, April 17, 1977, pg. 29.

<sup>&</sup>lt;sup>235</sup> Heumann, Being Heumann, 110; Shapiro, No Pity, 67.

<sup>&</sup>lt;sup>236</sup> "Disabled in San Francisco Vow to Continue Sit-in."

<sup>&</sup>lt;sup>237</sup> Scotch, "Nothing About Us Without Us," 22; James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Berkeley, CA: University of California Press, 2000), 126.

<sup>&</sup>lt;sup>238</sup> Jim Neubacher, "Access showdown at Rustler's Roost," *Detroit Free Press*, Apr 26, 1987, pg. 122

buses.<sup>239</sup> Protestors would crawl up the stairs of buses with the slogan "WE WILL RIDE!"<sup>240</sup> One activist stated, "Black people fought for the right to ride in the front of the bus. We're fighting for the right to get on the bus."<sup>241</sup> Many ADAPT protestors took inspiration from Rosa Parks, a famous civil rights activist. In Chicago in 1984, activists blocked a downtown street to protest the Chicago Transit Authority's purchase of new buses without lifts; "every protester wore a name tag that said, 'My name is Rosa Parks."<sup>242</sup> Like Section 504 protests, ADAPT would stage sit-ins and takeovers in federal buildings or politicians' offices proposing legislation limiting accessible public transit.

ADAPT's actions often resulted in mass arrests by local police, although "it was not a simple process." Police cars, or "paddy wagons," were frequently inaccessible to wheelchair users, so they could not transfer the protestors to jail. If they found a way, jails would often be inaccessible as well. These mass arrests forced cities to consider the injustice of inaccessible public transit, while the police had to obtain "lift-equipped paddy wagons" to arrest the protestors in wheelchairs. Une to ADAPTS's "philosophy of civil disobedience and mass arrests," they were often avoided by other disability activists and regarded as a "militant fringe group." Eventually by 1990, ADAPT reached "an agreement with UMTA [Urban Mass Transportation Administration... to mandate 100 percent lift-equipped buses in all future purchases." On one hand ADAPT had limited success, but the visible nature of their demonstrations forced police and society to consider the injustices of inaccessible transportation.

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<sup>&</sup>lt;sup>239</sup> Shapiro, *No Pity*, 128; Sain et al., "IL 201," 57.

<sup>&</sup>lt;sup>240</sup> Scotch, "Nothing About Us Without Us," 20.

<sup>&</sup>lt;sup>241</sup> Shapiro, *No Pity*, 128.

<sup>&</sup>lt;sup>242</sup> Susan Ann Silverstein, "humanrights heroes: Relentless Riders: ADAPT" *Human Rights* 34, no. 3 (Summer 2007): 26.

<sup>&</sup>lt;sup>243</sup> Sain et al., "IL 201," 57.

<sup>&</sup>lt;sup>244</sup> Shapiro, *No Pity*, 128; Neubacher, "Access Showdown at Rustlers Roost."

<sup>&</sup>lt;sup>245</sup> Shapiro, No Pity, 130.

<sup>&</sup>lt;sup>246</sup> Pelka, What Have We Done, 515.

Throughout the 1960s to 1990, many protests began on a small scale, specifically on college campuses, throughout the disability rights movement. Some were only visible on a local scale, while some garnered national attention. In the late 1960s, the "Rolling Quads" advocated for ramps and accessible architecture in Berkeley, CA, but were often pushed to the wayside. The rumor goes that one night, the "Rolling Quads" and other activists went around the city "smashing sidewalks with sledgehammers and pouring new curb cuts with bags of cement or asphalt."<sup>247</sup> It remains unconfirmed whether or not this happened at UCB. Still, the destruction of inaccessible curbs, or "curb cuts," by disabled students and activists did occur in other parts of the nation at college campuses and local cities.<sup>248</sup>

Berkeley University was a hotspot for activism at this time, from civil rights activism to protests against the Vietnam War, so the numerous protests led by disabled students were no surprise.<sup>249</sup> On the east coast, SOFEDUP worked with Brooklyn College's student government to occupy the President of Brooklyn College's office, John Kneller, to demand that the campus be made accessible. Kneller then committed to making new buildings accessible and created the Dean's Committee on the Disabled.<sup>250</sup> Protests occurred on college campuses nationwide, including the Gallaudet student protests of March 1988.

Gallaudet University, a federally chartered university established in 1864, "prided itself on preparing deaf students for the hearing world" and was the "world's only liberal arts college for the Deaf."<sup>251</sup> The Gallaudet student protests, sometimes called "Gallaudet campus takeover...[or] Gallaudet revolt," occurred after the previous hearing president resigned. <sup>252</sup> The

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<sup>252</sup> Shapiro, No Pity, 75.

<sup>&</sup>lt;sup>247</sup> Comeaux, Mireles, and Acha, "Dis/abled Student Campusmaking," 9; Hamraie, *Building Access*, 95.

<sup>&</sup>lt;sup>248</sup> Patterson, "Points of Access," 480.

<sup>&</sup>lt;sup>249</sup> Danforth, "Becoming the Rolling Quads," 514-16.

<sup>&</sup>lt;sup>250</sup> Patterson, "Points of Access," 482.

<sup>&</sup>lt;sup>251</sup> Shapiro, *No Pity*, 74; Pelka, *What Have We Done*, 367; Molly Sinclair, "Echoes of deaf student's victory still being heard across country," *The Miami Herald*, Sep 30, 1988, pg. 35.

committee tasked to replace him completely bypassed the two Deaf candidates and chose only the hearing candidate, Elisabeth Zinser, who also did not know American Sign Language (ASL).<sup>253</sup> Gallaudet's Board of Trustees Chairman, Jane Bassett Spilman, claimed that "neither of the other two candidates [had] the breadth of her experience."<sup>254</sup> In other words, the two candidates who knew ASL and were deaf, did not have hearing experience Spilman believed necessary to be president of a university for the Deaf. Students and alumni, who had advocated for a Deaf president in previous months, were incensed and made their stance known.

The "DEAF PRESIDENT NOW!" protest began on March 6th, 1988.<sup>255</sup> On the morning of March 6th, five hundred students and alumni marched from campus to the Mayflower Hotel, where the Gallaudet's Board of Trustees were said to be. The students signed and shouted speeches. Spilman stated that "Deaf people were not ready to function in the hearing world" to the representatives of the protesting students, although she later denied this statement.<sup>256</sup> In response, the students took over the campus. They blocked campus entrances and roads with hotwired university buses and cars, "forcing the cancellations of classes." Gallaudet Provost escaped angry protestors through a hole in a chain-link fence; employees were told to stay home.

Protesting students, staff, and faculty sent the chairman a list of demands and called for an assembly. They demanded "Zinser's resignation, the appointment of a Deaf president, the resignation of Spilman as board chairman, and the reorganization of the board to include 51 percent deaf membership." Spilman agreed to hold an assembly yet rejected their demands.

Over 1000 students attended, who upon learning that Spilman rejected their demands marched to

<sup>&</sup>lt;sup>253</sup> "Deaf Student Protest: Hearing women gets presidency," *Herald and Review* (Decatur, IL), Mar 7, 1988, pg. 9. <sup>254</sup> "Deaf Student Protest."

<sup>&</sup>lt;sup>255</sup> Pelka, What Have We Done, 367.

<sup>&</sup>lt;sup>256</sup> Shapiro, No Pity. 78.

<sup>&</sup>lt;sup>257</sup> "College students continue push for deaf president," *The Times* (Streator, IL), Mar 8, 1988, pg. 14.

<sup>&</sup>lt;sup>258</sup> Sinclair, "Echoes of deaf student's victory."

the Capitol and White House, yelling and signing in protest. Classes resumed the next day, but 90% of the student body boycotted them. Protestors burned effigies of Spilman and Zinser; students held another protest rally with 1500 members at a statue on campus.<sup>259</sup> Gallaudet students resolved to keep Zinser off campus; they searched incoming campus vehicles at the barricades and laid on the ground to prevent helicopter arrival. Protests were no longer peaceful marches or sit-ins; student activists became increasingly radical as demonstrations continued.

The protest garnered national attention as students and alumni at other deaf schools nationwide protested, sent support, or came in person to help. The local business sent provisions for food and banners or offered pro bono representation. Students organized their protest, creating the Deaf President Now Committee, and gained the support of NAD and Congress. The students took their cause to Congress, where many politicians, including Vice President George Bush, encouraged the school to name a Deaf president, while many representatives urged Zinser to resign. Ultimately, Zinser resigned in the face of "the extraordinary social movement of deaf people," while newspaper's proclaimed "Hearing President Quits as Deaf Students Cheer!" The protest still did not end, as three thousand students and supporters marched to the U.S. Capitol chanting "Deaf President Now," "No Hearing President," and "Deaf Power." Eventually, Spilman resigned but maintained her stance on a hearing president until the end. Gallaudet's Dean of the College of Arts and Sciences, King Jordan (a deaf candidate), was nominated. After 124 years, Jordan became Gallaudet University's first Deaf president.

<sup>&</sup>lt;sup>259</sup> Shapiro, *No Pity*, 78-80.

<sup>&</sup>lt;sup>260</sup> "Deaf Student Protest."

<sup>&</sup>lt;sup>261</sup> Diane Duston, "Hearing president quits as deaf student cheer," *Standard-Speaker* (Hazleton, Pennsylvania), Mar 12, 1988, pg. 15.

<sup>&</sup>lt;sup>262</sup> Duston, "Hearing president quits."

<sup>&</sup>lt;sup>263</sup> Shapiro, *No Pity*, 80-83.

The "Deaf President Now" (DPN) protest, lasting eight days, was "a defining moment for the disability rights movement." Referred to as "the Selma of the Deaf," the Gallaudet protests and events following were still talked about in newspapers six months later. In this case, Selma references a keystone moment during the civil rights movement, the march from Selma, Alabama to Montgomery, Alabama. Like Selma for African Americans, Gallaudet raised awareness and set the ball rolling for other events within the Deaf community. 265

On a national scale, the Gallaudet student protest solidified disability as a civil rights issue in the national consciousness of disabled and non-disabled Americans. <sup>266</sup> There was a new spirit of cooperation between the Deaf community, as they recognized "they share so much with people who are blind, who have cerebral palsy, and [they] need to all work together." <sup>267</sup> DPN changed the "climate of opinion" regarding disability, while positive publicity created a "favorable climate of opinion within Congress" for this change. <sup>268</sup> This change allowed for the passage of the Americans with Disabilities Act of 1990, introduced only two months after the Gallaudet protests. Lex Frieden, a member of the National Council on the Handicapped, claimed that the ADA "would not have happened without Gallaudet raising people's consciousness." <sup>269</sup> Gallaudet's protest set the stage for the final push leading to the passage of the Americans with Disabilities Act.

The most successful and visible moment that catalyzed the passage of the ADA was the "Capitol Crawl" on March 12, 1990. Occurring on the first day of ADAPT's Wheels of Justice campaign, the capitol crawl cemented the disability rights movement in public memory. This

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<sup>&</sup>lt;sup>264</sup> Shapiro, No Pity, 75.

<sup>&</sup>lt;sup>265</sup> Sinclair, "Echoes of deaf student's victory."

<sup>&</sup>lt;sup>266</sup> Shapiro, *No Pity*, 74-75.

<sup>&</sup>lt;sup>267</sup> Sinclair, "Echoes of deaf student's victory."

<sup>&</sup>lt;sup>268</sup> John B. Christiansen and Sharon N. Barnartt, *Deaf President Now! The 1988 Revolution at Gallaudet University*, (Gallaudet University Press, 1995), 213.

<sup>&</sup>lt;sup>269</sup> Shapiro, *No Pity*, 75.

march was not the first-time disability rights activists marched on Capitol Hill. In May 1972, Judy Heumann and 100 other disabled activists led a three-mile march on Capitol Hill. Their objective was "to lobby Congress to amend the 1964 Civil Rights Law to include physical handicaps...on the list of prohibitions against discrimination."<sup>270</sup> Although the first time was unsuccessful, this would not ring true for the Wheels of Justice March.

Early morning on March 12, 1990, ADAPT activists and supporters gathered at the White House to begin "their spring campaign 'Wheels of Justice," with a march to U.S. Capitol Hill to pressure Congress into passing the ADA.<sup>271</sup> The event started with around 500 people (many of whom were in wheelchairs) and grew as they marched up Pennsylvania Ave; the march ended at the U.S. Capitol building with about 700 people. Even though 700 was a small number compared to the number of disabled Americans in the nation or other civil rights protests, "disability marches never attracted large numbers" due to economic, transportation, and architectural barriers.<sup>272</sup> Stretched over a mile long and disrupting traffic, the protestors, with posters and signs chanted, "What Do We Want?" "Our ADA" "When Do We Want It?" "Now!"<sup>273</sup> Americans representing different disabilities and professions had come together for a single protest.

Once at the base of Capitol Hill, protestors listened to speeches by leading disability activists, including Justin Dart Jr., the Chair of the PCEH, and Michael Auberger, the co-founder of ADAPT. Dart hailed the protestors as "pioneer patriots" who "will struggle for however long it takes for the same civil rights other Americans have."<sup>274</sup> Auberger spoke on "the grim

<sup>270</sup> "Wheel Chairs Marched to Capitol," *The Colombia Record*, May 6, 1972.

<sup>&</sup>lt;sup>271</sup> Tom Collins, "'Wheels of Justice' March," March 1990, Tom Collins Collections. <a href="http://tomolincollection.com/?p=1">http://tomolincollection.com/?p=1</a>.

<sup>&</sup>lt;sup>272</sup> Shapiro, No Pity, 131; Pelka, What Have We Done, 516.

<sup>&</sup>lt;sup>273</sup> Collins, "'Wheels of Justice' March."

<sup>&</sup>lt;sup>274</sup> Shapiro, *No Pity*, 132.

symbolism of the inaccessible Capitol building" as the steps before them represented "the history of discrimination and indignities heaped on disabled Americans." He stated that the preamble to the Constitution did not specify "We the able-bodied people" but "We the people;" the crowd responded with "Access is our civil right." The Empowered by his speech, ADAPT demonstrators and other activists threw themselves from their wheelchairs and began crawling up the steps one by one. The most visible image of this crawl-up was of an "eight-year-old...struggling forwards on her hands and knees," who proclaimed, "I'll take all night if I have to!" Literally on their hands and knees, these Americans with disabilities were demanding civil rights.

## 3.3 Legislation

Before the passage of the Americans with Disabilities Act, some legislation helped to increase the visibility of individuals with disabilities and increase their access to the public sphere. Beginning in the 1970s, individuals with disabilities began actively lobbying for and drafting legislation for themselves and the disabled community. The growth of the disabled community was encouraged by the public policy, and as they grew they then affected public policy. Through their efforts, disability transformed into a civil rights issue on the congressional level. Instead of being the beneficiaries of government agency as seen in "To Be Seen, To Be Heard," the disabled community and leading activists took agency for themselves. No longer content to be acted upon, they decided to take action on the federal level.

Hugh Gregory Gallagher, a disability rights activists paralyzed by polio, drafted the language of the Architectural Barriers Act of 1968 while he worked as an aide to Sen E.L. "Bob"

<sup>277</sup> Shapiro, *No Pity*, 133; "Disabled Protest at Capitol Hill," *The Times* (Shreveport, Louisiana), Mar 13, 1990, pg. 3.

<sup>&</sup>lt;sup>275</sup> Krieger, "Afterword," 490; Shapiro, No Pity, 132.

<sup>&</sup>lt;sup>276</sup> Shapiro, *No Pity*, 133.

<sup>3. &</sup>lt;sup>278</sup> Richard K. Scotch, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, (Philadelphia: Temple University Press, 2009), 7.

Barlett (D-Alaska) on Capitol Hill. He drew upon his experiences with inaccessible architecture in university and Washington, D.C. In 1968, Congress passed the Architectural Barriers Act (ABA), which stated that any buildings constructed with federal funds or leased by federal agencies should be accessible to everyone, no matter if they were disabled or not. This legislation led to installing the first ramps on the Library of Congress, Smithsonian museums, other federal buildings, and non-government facilities. According to Senator Majority Leader Bob Dole (R-Kan), Gallagher "successfully place[d] disability rights on Congress' agenda for the first time."<sup>279</sup> This legislation was the first to treat the issue of disability rights as a civil rights issue and laid the foundations for the Americans with Disabilities Act of 1990.<sup>280</sup> This legislation allowed individuals equal access to the public sphere, albeit limited to only federally funded or leased buildings constructed or renovated after 1968. However, the ABA could not enforce these standards until 1973.

Amended in 1970, the Urban Mass Transportation Act of 1964 now "declared... that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services." This legislation established a grant and loan system for eligible jurisdictions; it required federally funded mass transit systems to be accessible to individuals with disabilities. However, this only provided construction costs, not operating costs, and did not contain any "provision of enforcement." In 1974, President Ford passed the National Mass Transportation Assistance Act, which expanded the Urban Mass Transit Act to provide a six-year operating assistance program for mass transit to follow the policy of

<sup>&</sup>lt;sup>279</sup> Adam Bernstein, "Hugh Gallagher Dies; Crusaded for Disabled," *The Washington Post*, July 26, 2004.

<sup>&</sup>lt;sup>280</sup> Gallagher, *Black Bird*, 107; *Architectural Barriers Act of 1968*, Public Law 90-480, https://www.govinfo.gov/content/pkg/COMPS-10651/pdf/COMPS-10651.pdf.

<sup>&</sup>lt;sup>281</sup> Urban Mass Transportation Assistance Act of 1970, Public Law 91-453, U.S. Statute at Large 84 (1970): 967.

<sup>&</sup>lt;sup>282</sup> Elmer C. Bartels, "Travel problem for the disabled," *The Boston Globe*, Jun. 29, 1975, pg. 113.

<sup>&</sup>lt;sup>283</sup> Sain et al., "IL 201," 67-68.

accessibility.<sup>284</sup> Individuals with disabilities, in theory, had the freedom to travel with the elimination of barriers. However, the transit industry successfully blocked the implementation of certain aspects, such as lifts on buses, for two decades; although, they were challenged frequently by ADAPT. <sup>285</sup> Many buses and forms of public transportation remain functionally inaccessible even into the 21<sup>st</sup> century.

The Rehabilitation Act of 1973 was the first legislation to address equal access for individuals with disabilities by removing architectural, employment, and transportation barriers. The Rehab Act traces back to the vocational rehabilitation acts enacted post-WWI, that treated disabilities as the individual's fault and something to cure. However, this legislation marked a turn from "charity to civil rights" with how disabilities were viewed. The most critical sections regarding the visibility of disabilities and disability rights are Sections 501 through 504. First, Section 501 concerned the "employment of handicapped individuals" in federal agencies and established a committee for that purpose. The Architectural and Transportation Barriers Compliance Board, established by Section 502, sought to enforce and "ensure compliance" with the Architectural Barriers Act of 1968. Section 503 prohibited federal contractors or subcontractors from discriminating against individuals with disabilities; instead, they should "take affirmative action to employ...qualified handicapped individuals." Section 504, while originally thought to be legislative afterthought, was quietly inserted by congressional senior staff at the behest "of [the disabled community's] champion senators." Previous attempts to

<sup>&</sup>lt;sup>284</sup> Bartels, "Travel problem for the disabled," pg. 113.

<sup>&</sup>lt;sup>285</sup> Silverstein, "Relentless Riders," 26.

<sup>&</sup>lt;sup>286</sup> Bianca G. Chamusco, "Revitalizing the Law That "Preceded the Movement": Associational Discrimination and the Rehabilitation Act of 1973," *The University of Chicago Law Review* 84, No. 3 (Summer 2017): 1288-89.

<sup>&</sup>lt;sup>287</sup> The Rehabilitation Act of 1973, §501.

<sup>&</sup>lt;sup>288</sup> The Rehabilitation Act of 1973, §502.

<sup>&</sup>lt;sup>289</sup> The Rehabilitation Act of 1973, §503.

<sup>&</sup>lt;sup>290</sup> Heumann, Being Heumann, 64.

amend the Civil Rights Act of 1964 to include disability were unsuccessful, so it was easier to add Section 504 which had been modeled off the Civil Rights Act to the end of the Rehabilitation Act.<sup>291</sup>

Judy Heumann played a role in developing the Education for All Handicapped Children Act (EHA) of 1975, later renamed the Individuals with Disabilities Education Act (IDEA) in 1990. Judy Heumann was a legislative intern on Capitol Hill, when the issue of ensuring quality education for children with disabilities arose. Heumann's "background and activism gave [her] knowledge and expertise" others lacked, so when asked for her input she advocated to "close down special-ed schools and get disabled students into the classroom." The EHA was clear that "all handicapped children between the ages of three and twenty-one have the right to a free appropriate education" in the "least restrictive environments." Before the EHA, children with disabilities (physical or mental) were rejected or barred from attending schools and kept home. If able to participate in school, disabled children remained segregated from *non-disabled* children. A least restrictive environment meant educating students with disabilities alongside non-disabled students as much as possible rather than segregating them.

The EHA was enacted in response to the SCOTUS ruling in *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania (PARC v. Commonwealth)* (1971) and lobbying by parents. In *PARC*, the Court affirmed "the right to education at the public expense and due process for children with disabilities," striking down the Pennsylvania statute that permitted school districts to discriminate against developmentally disabled students.<sup>294</sup> The

<sup>&</sup>lt;sup>291</sup> Nielsen, *A Disability History*, 166; Chamusco, "Revitalizing the Law," 1290-91.

<sup>&</sup>lt;sup>292</sup> Heumann, *Being Heumann*, 75; Scotch, "Politics and Policy," 391.

<sup>&</sup>lt;sup>293</sup> Shapiro, No Pity, 166-167; Education of All Handicapped Children Act of 1975, Public Law 94-142, U.S. Statutes at Large 89 (1975): 792.

<sup>&</sup>lt;sup>294</sup> Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971).

following year, the U.S. District Court for the District of Columbia heard *Miller v. Board of Education of the District of Columbia* (1972). It ruled that children with disabilities are entitled to education, and the district could not exclude them from "publicly-supported education [based on] a claim of insufficient resources."<sup>295</sup> A lesser-known effect, but *Miller* also led to the desegregation of d/Deaf education.<sup>296</sup>

In 1954, *Brown v Board of Education* ruled that racial segregation violated equal educational opportunity as "separate facilities are inherently unequal." *PARC* and *Miller* relied on the argument made and the precedent set in *Brown* regarding discrimination in public education. The *PARC* and *Miller* cases (as well as the *Brown* precedent) "formed the foundation for" the EHA; its creation, subsequently increased the visibility of children with disabilities in public education. <sup>298</sup> Children with disabilities could now attend public schools instead of hospital-schools or special schools.

Strides towards civil rights for disabled Americans continued in federal legislation. Some laws were passed as a reaction to the treatment of individuals with disabilities within institutions or state schools and hospitals. Congress passed the Developmental Disabilities Amendments of 1975, which expanded services for individuals with "mental retardation [or] cerebral palsy" and established a network of state protection and advocacy agencies to protect their rights.<sup>299</sup> In 1980, Congress passed the Civil Rights of Institutionalized Persons Act (CRIPA) which

<sup>&</sup>lt;sup>295</sup> Nathanial Ross, "Mills v Board of Education of District of Colombia (1972)," *The Embryo Project Encyclopedia*, June 14, 2022, <a href="https://embryo.asu.edu/pages/mills-v-board-education-district-columbia-1972">https://embryo.asu.edu/pages/mills-v-board-education-district-columbia-1972</a>; *Miller v. Board of Education of District of Columbia*, 106 F. Supp. 988 (D.D.C. 1952).

<sup>&</sup>lt;sup>296</sup> Comeaux, Mireles, and Acha, "Dis/abled Student Campusmaking," 6.

<sup>&</sup>lt;sup>297</sup> Oliver Brown, et al. v Board of Education of Topeka, et al., 347 U.S. 483 (1954) (Warren, C.J., majority).

<sup>&</sup>lt;sup>298</sup> Darvin L. Miller and Marilee A. Miller, "The Education for All Handicapped Act: How Well Does It Accomplish Its Goal of Promoting the Least Restrictive Environment for Education?," *DePaul Law Review* 28, no. 2 (Winter 1979): 330.

<sup>&</sup>lt;sup>299</sup> Congress.gov, "S.462 - 94th Congress (1975-1976): Developmentally Disabled Assistance and Bill of Rights Act," June 2, 1975, https://www.congress.gov/bill/94th-congress/senate-bill/462/summary/00.

authorizes the attorney general "to investigate and initiate lawsuits on behalf of persons deprived of fundamental constitutional and federal statutory rights in state institutions;" including institutions for the "mentally ill, chronically ill, or handicapped."<sup>300</sup> Both acts passed in response to the horrific mistreatment of disabled patients at Willowbrook on Staten Island, where "5,000 residents [remained in] locked, bare dayrooms reek with the odors of neglect."<sup>301</sup> In addition to organizations representing service providers and parents of disabled children promoting the legislation.<sup>302</sup>

Concerning the right to vote, Congress passed the Voting Accessibility for the Elderly and Handicapped Act (VAHEA) of 1984 which required all polling facilities for federal elections be accessible to elderly and handicapped voters. VAHEA also required that polling facilities have registration and voting aids, such as printed instructions or telecommunication devices for the deaf.<sup>303</sup> This act removed the architectural barrier to voting that individuals with disabilities faced, however it would not be until the passage of the Americans of Disabilities Act would the disabled community no longer be disenfranchised.

In 1986, Congress passed the Air Carrier Access Act (ACAA), which continued efforts to make transportation accessible and usable to individuals with disabilities. Congress passed this legislation in response to the Supreme Court's narrow interpretation of Section 504 in the *United States Department of Transportation (DOT) v. Paralyzed Veterans of America*, which held that "Section 504 is not applicable to commercial airlines." The ACAA amended Section 404 of

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<sup>&</sup>lt;sup>300</sup> American Bar Association, "Staff Report on the Institutionalized Mentally Disabled and a Response from the Justice Department," *Mental and Physical Disability Law Reporter* 9, No. 2 (March-April 1985): 155-156; Congress.gov, "H.R.10 - 96th Congress (1979-1980): Civil Rights of Institutionalized Persons Act," May 23, 1980, https://www.congress.gov/bill/96th-congress/house-bill/10.

<sup>&</sup>lt;sup>301</sup> Bruce Frankel, "Of Promises Forgotten," *Mount Vernon Argus* (White Plains, New York), Feb. 1, 1981, pg. 73. <sup>302</sup> Scotch, "Politics and Policy," 391.

<sup>&</sup>lt;sup>303</sup> Voting Accessibility for the Elderly and the Handicapped Act of 1984, Pub. L. 98-435, U.S. Statutes at Large 98 (1984): 1678.

<sup>&</sup>lt;sup>304</sup> United States Department of Transportation (DOT) v. Paralyzed Veterans of America, 477 U.S. 597 (1986).

the Federal Aviation Act of 1958 and declared that "no air carrier may discriminate against any handicapped individual...by reason of such handicap," thus providing equal access to air transportation services.<sup>305</sup>

Ronald Mace, a paralyzed architect and wheelchair user, helped to produce the first building code for accessibility in the nation, which became mandatory in North Carolina in 1973 and served as an example for other states' building codes. Mace's work in accessible design influenced the Fair Housing Amendment Act of 1988 (an extension of the Civil Rights Act of 1968), which "prohibited real estate and housing industries from discriminating on the basis of disability," and protected families with children. After the act's passage, Mace stated in an interview, "we have laws to prevent [discrimination and physical barriers] now, I helped draft those laws. The Fair Housing Act required multifamily housing (built after February 1991) to include the "minimal accessibility standards for those with physical disabilities. The law required "newly constructed multi-family homes" to include "access to common areas and adaptive design features. Passage of the Fair Housing Amendment Acts was also "the first step into extending disability anti-discrimination protection to the private sector. This set the foundations for the ADA, which would apply to both public and private sectors.

This prior legislation ultimately led to the passage of the Americans with Disabilities Act (ADA) in 1990. On July 26, 1990, thousands of activists, who fought for the ADA, gathered to witness a historic moment in the disability rights movement. The Americans with Disabilities

<sup>305</sup> Air Carrier Access Act of 1986, Public Law 99-435, U.S. Statutes at Large 100 (1986): 1080.

<sup>&</sup>lt;sup>306</sup> "Handicapped Guidelines Cause Spilt," *The Los Angeles Times*, May 6, 1990, pg. K2; *Fair Housing Amendments Act of 1988*, Public Law 100-430, *U.S. Statutes at Large* 102 (1988): 1619-20; Scotch, "Politics and Policy," 398.

<sup>307</sup> Steven Litt, "Breaking Down Barriers, stubbornly, by design," *The News and Observer*, August 7, 1988.

<sup>308 &</sup>quot;Handicapped Guidelines Cause Spilt."

<sup>&</sup>lt;sup>309</sup> James A Kushner, "The Fair Housing Amendments Act of 1988: The Second Generation of Fair Housing," *Vanderbilt Law Review* 42, no. 4 (1989): 1093.

<sup>&</sup>lt;sup>310</sup> Chai R. Feldblum, "Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?," *Berkeley Journal of Employment & Labor* 21, no. 1 (2000): 126.

Act (ADA) was passed and signed into law by President George W. Bush. The purpose of the ADA can be summed up into four points:

1. to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; 2. to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities; 3. to ensure that the federal government plays a central role in enforcing the standards established in this act on behalf of individuals with disabilities; and 4. to invoke the sweep of congressional authority, including the power to enforce the Fourteenth Amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.<sup>311</sup>

The ADA covers five sections: Employment, Public Services (in State and Local Government), Public Accommodations and Services by Private Entities, Telecommunications, and Miscellaneous Provisions.<sup>312</sup> The ADA guaranteed the disabled community the same rights enjoyed by other minorities.

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<sup>&</sup>lt;sup>311</sup> Peter C. Bishop and Augustus J. Jones Jr., "Implementing the Americans with Disabilities Act of 1990: Assessing the Variables of Success," *Public Administration Review* 53, No. 2 (Mar. - Apr. 1993): 122. 
<sup>312</sup> "An Overview of the American with Disabilities Act" ADA National Network, 2017, https://adata.org/factsheet/ADA-overview.

## **CONCLUSION**

The late 19<sup>th</sup> century witnessed individuals with disabilities (whether physical, mental, or cognitive) segregated and hidden from society. Whereas the late 20<sup>th</sup> century watched as President Bush proclaimed, "let the shameful wall of exclusion finally come tumbling down" as the Americans with Disabilities Act was signed into law.<sup>313</sup> In the eyes of the law "no longer [were] people with disabilities...second class citizens."<sup>314</sup> While many disability rights activists were optimistic, others refused to stop in their fight since, after everything it took to get here, this could not be solved solely by signing a piece of paper. The ADA was not the end of the movement, but according to Dart, "[the] ADA is only the beginning. It is not a solution. Rather, it is an essential foundation" for future solutions.<sup>315</sup> Heumann stated, "we must continue to struggle"<sup>316</sup> for equality as others responded to ADA's passage: "show me, show us our rights are guaranteed."<sup>317</sup> Disability rights activists won the battle for the Americans with Disabilities Act, but the fight was not yet over.

Not four years later, the ADA came under fire by the far right. Described as "senseless, arbitrary," and "a huge cost," opponents of the ADA called for amendments to or the repeal of ADA and the Individuals with Disabilities Act (IDEA).<sup>318</sup> Although, the calls for repeal were unsuccessful, the ADA was now under threat in the Courts. For nearly two decades, the Courts took a narrow interpretation of disability, restricting the scope of the ADA's mandate. Unlike

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<sup>&</sup>lt;sup>313</sup> George W. Bush, "President Bush: 'Let the Shameful Wall of Exclusion Finally Come Tumbling Down," *Worklife* 3, no. 3 (1990): 9.

<sup>&</sup>lt;sup>314</sup> "Independence Day I," Worklife 3, no. 3 (1990): 6.

<sup>315</sup> Dart Jr., "ADA: Landmark," 1.

<sup>&</sup>lt;sup>316</sup> Judy Heumann, "We Must Continue to Struggle," Worklife 3, no. 3 (1990): 25.

<sup>&</sup>lt;sup>317</sup> Ron Drach, "Show Me," Worklife 3, no. 3 (1990): 25.

<sup>&</sup>lt;sup>318</sup> Fred Fay, "The Testament of Justin Dart," *Mainstream Magazine*, March 1998, 24-25.

how courts took a broad view of "handicapped" for Section 504, the Courts had decided that "individuals with a range of impairments—from epilepsy to diabetes to manic depression—do not have disabilities under the ADA."<sup>319</sup> Despite the fact, these disabilities had previously been covered under Section 504. In 2008, Congress passed the ADA Amendment Acts (ADAAA) which aimed to "carry out the ADA's objectives...by reinstating a broad scope of protection;" essentially this expanded the definition of disability.<sup>320</sup>

Similar to other civil rights legislation, the ADA has been attacked in courts and ignored in practice. However, it still holds power thanks to the vigilance and activism of individuals with disabilities and their allies. 321 Most disability rights activism, at least the well-publicized actions, took place in the San Francisco Bay Area or Washington, D.C., although there were exceptions. Even still, the disability rights movement did not cement itself into the national consciousness like the civil rights movement, the gay rights movement, or women's movement, all of which were far more visible and cohesive. It can be argued that the visibility of disabled individuals was more prominent in the federal and legislative arenas. Especially since, anti-discrimination legislation for disabled people quickly moved through Congress, as disability lobbyists were extremely active and effective on pushing this legislation through. 322 In the end, the ADA would not exist without the visible activism (on a local and nation level) from disabled individuals, whose actions resulted in the Disability Rights Movement. 323

The Americans with Disabilities Act of 1990 was not only the culmination of the Disability Rights Movement, but of the efforts of individuals with disabilities over a hundred

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<sup>&</sup>lt;sup>319</sup> Elizabeth F. Emens, "Disabling Attitudes: U.S. Disability Law and the ADA Amendments Act," *The American Journal of Comparative Law* 60, no. 1 (2012): 206; Feldblum, "Definition of Disability," 93.

<sup>&</sup>lt;sup>320</sup> Americans with Disabilities Amendments Act of 2008, Pub. L. 110-325, 122 Stat. 3553 (2008) (codified at 42 U.S.C. § 12101 et seq.).

<sup>&</sup>lt;sup>321</sup> Nielsen, A Disability History, 181.

<sup>322</sup> Krieger, "Afterword," 490; Nielson, A Disability History, 137; Scotch, "Politics and Policy," 386.

<sup>&</sup>lt;sup>323</sup> Nielsen, A Disability History, 181.

years in the United States to be treated as equal citizens. It was the result of changes of perceptions of disability. From the medical to socio-political model within the disabled community. From viewing themselves as invalids to independent citizens. Although the average American still had negative perceptions disabilities and knew nothing about the importance of the Americans with Disability Act. In a survey, only eighteen percent of those questioned about the ADA were aware of the law's existence and sixteen percent of respondents declared "people with disabilities are an inconvenience." This attitude carries over to the twenty-first century, especially with mental or cognitive disabilities; the fight to change underlying perceptions of disability is not yet over for the disabled community.

In the 19<sup>th</sup> century, individuals with disabilities were ostracized and excluded from society; overall, a forgotten and ignored minority. In the late 20<sup>th</sup> century, individuals with disabilities were now protected under federal law, and "entitled to an equal opportunity to participate in the American dream" like other minorities.<sup>325</sup> From legislation that banned individuals with physical disabilities from public areas, under threat of arrest or fine, to legislation that prohibited discrimination on the basis of disability in public and private sectors. The ADA represents the changes in legislation for and by individuals with disabilities from post-Civil War era to the passage of the ADA in the late 20<sup>th</sup> century. Changes enacted as the disabled community took agency for themselves over the course of the century, instead of waiting on the government to enact the change they needed. However, the battle for the Americans with Disabilities Act was won, but as mentioned previously, the war is not over.

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<sup>324</sup> Krieger, "Afterword," 491.

<sup>325</sup> Senator Orrin Hatch, "The Time Has Come," Worklife 3, no. 3 (1990): 14.

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