From Crippled to Disabled: The Legal Empowerment of Americans with Disabilities

Michael Ashley Stein
REVIEW ESSAY

FROM CRIPPLED TO DISABLED: THE LEGAL EMPOWERMENT OF AMERICANS WITH DISABILITIES


Michael Ashley Stein *

INTRODUCTION

In the midst of the social turmoil of the late 1960s, Leonard Kriegel published a biting essay about his experiences as a disabled American. In anguish, he wrote that despite the surrounding political upheaval and revision, "The cripple is conspicuous by his absence from [inclusive social] programs.... [T]he cripple is still asked to accept definitions of what he is, and of what he should be, imposed on him from outside his experience." More than twenty years later, poised to sign into law the Americans with Disabilities Act (ADA), President George Bush proclaimed

* President, National Disabled Bar Association; Adjunct Assistant Professor of Law, New York University School of Law. Copyright 1994, Michael Ashley Stein. I am grateful to Martha Field, Alain Kodsi, Tami Lefko, Martha Minow, Gerald Torres, Jonathan Weiss, and David Wilkins for their comments on earlier drafts of this piece. My work on this project was made possible by assistance from Harvard Law School’s Program on the Legal Profession; I am indebted to David Wilkins for his warmth and support. This review is dedicated to the memory of Terrence J. (T.J.) O’Rourke, former president of the American Coalition of Citizens with Disabilities, and publisher of disability-related books. In 1977, T.J. helped spearhead a 25 day sit-in demonstration by people with disabilities at then-HEW Secretary Joseph A. Califano’s office. Their courageous civil disobedience resulted in Califano signing into law § 504’s regulations, which made it illegal for any institution receiving federal funding to discriminate against individuals “solely by reason of... handicap.” See Joseph P. Shapiro, No Pity: People with Disabilities Forging a New Civil Rights Movement 64-70 (1993). For a detailed account of the 1977 sit-in, see Richard K. Scotch, From Good Will to Civil Rights: Transforming Federal Disability Policy 111-16 (1984).


2 42 U.S.C. §§ 12,101-12,213 (Supp. II 1990). The ADA provides major new federal rights to disabled people by barring discrimination based on disability in the areas of employment, public accommodations and service, transportation, and telecommunications. For an especially thorough and
that "the shameful wall of exclusion [must] finally come tumbling down" and make way for "a bright new era of equality, independence and freedom." No Pity: People with Disabilities Forging a New Civil Rights Movement (No Pity), an exceptional book by Joseph P. Shapiro, chronicles the evolution of the disability rights movement and the trailblazing efforts of some of the individuals who, by challenging many of American society's misperceptions about people with disabilities, eventually made possible promulgation of the ADA.


8 The phraseology relating to individuals with disabilities has undergone significant evolution over the last five years, with many disability rights advocates asserting the same empowerment inherent in self-identification as that claimed by women and people of color. Thus, the terms "invalid" and "crippled" have been largely replaced by "disabled" and "with disabilities." Other common nomenclatures include "physically challenged," "otherwise abled," "differently abled," and most recently, "handi-abled" and "handi-capable." This evolution continues. For example, many individuals with disabilities are uncomfortable with the above terminologies. In fact, some militant disability rights advocates even promote use of the term "crip" for the same shock value that enures from use of parallel terms by some militant African-Americans. See Shapiro, supra note 4, at 33-34. Regardless of the lack of consensus, the fact that people with disabilities are active in the reappropriation of words to redefine themselves is a sign of a new and thriving group identity." Id. at 34 (quoting Brandeis University sociology professor Irving Kenneth Zola). The proper terminology for individuals with disabilities has proven to be the subject of much examination. See, e.g., California Governor's Comm. for Employment of the Handicapped, Language Guide on Disability (1987); Research and Training Ctr. on Indep. Living, Guidelines for Reporting and Writing About People with Disabilities (1987); Martha Minow, When Difference Has Its Home: Group Homes for the Mentally Retarded, Equal Protection and Legal Treatment of Difference, 22 Harv. C.R.-C.L. L. Rev. 111, 169-73 (1987) (discussing the controversy over labeling theory). As noted by the ADA committee reports, because "[m]any individuals with disabilities object to the use of such terms as 'handicapped person' or 'the handicapped,'" Congress has adopted the use of the terms "disabled" or "with disabilities." See H.R. Rep. No. 485, 101st Cong., 2d Sess., pt. 2, at 51 (1990); S. Rep. No. 116, 101st Cong., 1st Sess. 21 (1989).
In supporting passage of the ADA, Senator Edward M. Kennedy promoted the legislation's enactment as "an emancipation proclamation" for disabled Americans. Such enfranchisement was urgently needed and long overdue. Prior to the ADA's enactment, studies on the status of Americans with disabilities, both by advocates of disability rights and by mainstream (and therefore "disinterested") organizations, found overwhelming evidence of "massive, society-wide discrimination" against people with disabilities. For example, in 1980, Professor Robert Burgdorf, a disabled legal scholar and disability rights advocate, wrote:

The history of society's formal methods for dealing with handicapped people can be summed up in two words: segregation and inequality. Individuals with handicapping conditions have faced an almost universal conspiracy to shunt them aside from the mainstream of society and to deny them an equal share of benefits and opportunities available to others. . . . At every juncture, the handicapped person has met with attempts to "push" him or her aside and to withhold that which is taken for granted by other persons.

Ten years later, the National Council for the Handicapped found that "[t]he severity and pervasiveness of discrimination against people with dis-
abilities is well documented" and comprises a "major obstacle to achieving the societal goals of equal opportunity and full participation of individuals with disabilities."\(^{12}\)

The 1983 United States Commission on Civil Rights (Civil Rights Commission) reported similar findings: "Historically, society has tended to isolate and segregate handicapped people. Despite some improvements, particularly in the last two decades, discrimination against handicapped persons continues to be a serious and pervasive social problem."\(^{13}\) The Civil Rights Commission’s conclusion was echoed four years later by testimony presented before the United States Senate that "[b]y almost any definition . . . disabled Americans are uniquely underprivileged and disadvantaged. They are much poorer, much less well educated and have much less social life, enjoy fewer amenities and have a lower level of life-satisfaction than other Americans."\(^{14}\)

Each of these findings was in turn reinforced by an independent nationwide poll of Americans with disabilities conducted in 1986 by Louis Harris and Associates.\(^{15}\) That survey, entitled the International Center for the Disabled Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream (ICD Survey), found that two-thirds of working age

---

12 NATIONAL COUNCIL ON THE HANDICAPPED, TOWARD INDEPENDENCE at A-3 (1986).
individuals with disabilities are unemployed, while two-thirds of non-working disabled individuals want to work. In addition, during the year prior to the ICD Survey, nearly two-thirds of individuals with disabilities did not attend movies; three-fourths of the disabled population did not see live theater or music performances; two-thirds of disabled people had not attended sporting events; seventeen percent did not eat in restaurants; and thirteen percent had not shopped in grocery stores.

Shapiro illustrates that the systemic exclusion of individuals with disabilities from mainstream American society reported by the ICD Survey both has its origin in, and is bolstered by, a mythology that has persisted—even through the time of the ADA's enactment—which casts individuals with disabilities in two alternative yet dichotomous roles: the pitiable poster child and the inspirational “supercrip.”

Because of its emotional appeal, “No other symbol of disability is more beloved by Americans than the cute and courageous poster child” who smiles through his or her “tragic” fate. The pitiable poster child “is a surefire tug at our hearts,” an image that was created to inspire the donation of charity by instilling potential donors with pity for unfortunate children. One former poster child who has spoken out about her experiences is Cyndi Jones, editor and publisher of the national disability magazine, Mainstream. At age five, Jones was selected as the St. Louis March of Dimes “poster girl.” Her image—outfitted in a frilly party dress, smiling with pluck, and holding gamely onto her crutches—was subsequently painted on a large billboard in the downtown area, after

---

16 See ICD Survey, supra note 15, at 47.
17 Id. at 50-51.
18 Id. at 37, 39.
19 Id.
20 Id.
21 Id.
22 Id.
23 See ICD Survey, supra note 15.
24 See Shapiro, supra note 4, at 328.
25 Id. at 12-15.
26 Id. at 15-16.
27 Id. at 12.
28 Id.
29 Id.
which she was asked to appear on the nationally televised Muscular Dystrophy telethon.\textsuperscript{30} There, at a producer's direction, she cast aside her metal crutches and wobbled a few heart-rending steps before falling helplessly to the stage floor.\textsuperscript{31}

"[T]he 'supercrap' is the flip side of the pitiable poster child."\textsuperscript{32} If science, supported by telethon money, could not cure the scourge of disability, "then society would expect them to cure themselves. It would take hard work, determination, and pluck. . . . The worthy cripple was expected to overcome his or her disability."\textsuperscript{33} As Marilynn Phillips, a Morgan State University professor of folklore and former poster child observes, "It was the Horatio Alger cripple story. . . . You were expected to be jumping up stairs, even if you used a wheelchair. You were expected to be doing anything you had to do, even if it meant collapsing at the end of the day."\textsuperscript{34} Two supercrips who achieved widespread media exposure for "overcoming" their conditions were Mark Wellman, a paraplegic park ranger who climbed granite peaks in Yosemite National Park, and cancer survivor Terry Fox, who ran across Canada on an artificial leg.\textsuperscript{35}

The pitiable poster child/inspirational supercrap dual mythology depicted by Shapiro continues to exist, as the recent mass media reporting of the circumstances of two disabled individuals vividly demonstrates. The role of pitiable poster child was filled in this instance by a double cameo: adorable nine-year-old twin sisters, each of whom has cerebral palsy and uses a wheelchair. During a televised question and answer period with President Bill Clinton, Anastasia Samoza asked the President to intercede on behalf of her twin sister Alba—a speech-impaired quadriplegic—so that Alba could join her in her own regular school classes. Addressing President Clinton, Anastasia explained that her sister "uses a computer to speak. . . . I would like her to be in a regular class just like me."\textsuperscript{36} The press reported that, moved nearly to tears, the President paused a few

\textsuperscript{30} Id. at 13.
\textsuperscript{31} Id. The result of using pitiable poster child imagery is impressive: the annual Labor Day Telethon has to date raised over one billion dollars. \textit{See id.} at 21.
\textsuperscript{32} Id. at 16.
\textsuperscript{33} Id. at 15.
\textsuperscript{34} Id.
\textsuperscript{35} Id. at 17.
\textsuperscript{36} Timothy Clifford, \textit{No Easy Answers; Meet the Prez: Kids Have a Lot on Their Minds}, \textit{Newsday}, Feb. 21, 1993, at 7.
moments to regain his composure before saying simply “[w]ow.” Newspapers covering this event only briefly mentioned the other children who had participated in the question and answer period, but almost uniformly printed pictures of one or both of the adorable, poster-worthy children sitting with the President.

When professional athlete Dennis Byrd collided with a teammate during a football game and broke his neck, he took on the role of the super-crip who, with sufficient gumption, can overcome any disability. Articles on Byrd’s condition contained testimony by friends and family that Byrd had sufficient willpower to overcome his predicament. After months of rehabilitation, when Byrd was able to take a few steps with the aid of a cane, a press conference was held. Ensuing articles lauded Byrd’s desire, which alone seemed responsible for achieving his triumph, and a book entitled Rise and Walk: The Trial and Triumph of Dennis Byrd is soon to be released.

37 Id.
38 See, e.g., Clinton Takes Questions from a Young Audience, N.Y. TIMES, Feb. 21, 1993, at A1; Clifford, supra note 36, at 7; Raymond Hernandez, A Little Girl Speaks, and a Nation Listens, N.Y. TIMES, Feb. 22, 1993, at B2. Anastasia’s wish was eventually granted. See, e.g., Susan Harrigan, Little Girl Gets Her Wish; Twin Sister To Attend Regular Classes Too, NEWSDAY, June 9, 1993, at 4. Follow-up coverage of the Samoza twins’ victory also included a photograph of the two girls. See id.
39 See, e.g., Timothy W. Smith, Byrd’s Landscape Is Faith and Fortitude, N.Y. TIMES, Mar. 12, 1993, at B7 (quoting Byrd’s high school football coach as saying “[e]verything Dennis accomplished he worked hard for . . . . [H]e’ll always be a winner at whatever he does”).
41 See, e.g., Timothy W. Smith, Byrd Defies the Odds To Take His Biggest Steps, N.Y. TIMES, Feb. 12, 1993, at B9 (quoting Byrd as saying “I knew I could do it . . . . I can’t say that I’m amazed because it’s something I had set in my heart to accomplish”). Pulitzer-prize winning sportswriter Dave Anderson was more in sync with the progressive attitudes of the disabled community. See Dave Anderson, Sports of the Times; When the Wheels Become Your Legs, N.Y. TIMES, Dec. 6, 1992, § 8, at 2 (noting that even if Byrd was to become a wheelchair user, like other athletes before him, “there’s a life out there just waiting for him to live it”); see also Not All Can Walk Again, N.Y. TIMES, Apr. 4, 1993, § 8, at 11 (letter from the mother of a quadriplegic noting that although the reporting of Dennis Byrd’s progress was “inspiring and heartwarming,” it is important to remember that “the quality of an individual has nothing to do with the rapidity of healing of a spinal cord injury”). After Byrd progressed to walking without the assistance of a cane, he set out to establish a camp for less fortunate “wheelchair-bound children.” See Byrd Walking Without Help of a Cane, N.Y. TIMES, May 12, 1993, at B8.
The contrasting images of pitiable poster child and supercrip do not, however, properly characterize the lives of most people with disabilities. A more accurate description is that members of the disabled community are, on the whole, otherwise ordinary people trying to live otherwise ordinary lives. Unfortunately, since very few disabled people can achieve the status of supercrip—how many people climb mountains or run across continents?—most have been relegated to the realm of the poster child: the world of pity. In fact, a 1991 Louis Harris and Associates study found that seventy-four percent of Americans felt pity toward disabled individuals.43

Shapiro writes that treating the disabled with pity creates among mainstream society what Justin Dart, Jr., a post-polio paraplegic who became one of the leading proponents of the ADA,44 termed a “subhuman perception that existed of people with disabilities.”45 Because the logical extension of this pity-filled atmosphere is that disability is a hindrance and therefore people with disabilities are beholden to mainstream society for assistance, it also encourages acquiescence among disabled people at times when complaint would be more appropriate. While a field correspondent for National Public Radio, paraplegic John Hockenberry never informed his Washington-based supervisors about his disability,46 even though there were no accessible restrooms at his offices.47 Hockenberry felt uncomfortable about addressing his disability and claiming his rights after a lifetime of having to make due on his own.48 Instead, “he had tried to ignore such slights and limits by concentrating on personal achievement” and not raising the issue of his disability.49 Hockenberry is not alone in his feelings.50

44 See infra notes 68-73 and accompanying text.
46 Shapiro, supra note 4, at 109.
46 Id. at 19.
47 Id. at 331.
48 Id. at 332.
49 Id. at 331. After the ADA’s passage, Hockenberry became an assertive disability rights advocate who demanded that he be treated equally. See id. at 331-32; see also John Hockenberry, Limited Seating on Broadway, N.Y. TIMES, Apr. 13, 1992, at A19 (taking the owners of the Virginia Theater to task for their deplorable treatment of him). Hockenberry is now a correspondent on ABC’s “Day1One,” and regularly appears on camera using his wheelchair.
50 While attending law school, I did not complain about the absence of accessible kitchen and laundry facilities in my dormitory hall or the inaccessible nature of the building that housed the law review offices. Like Hockenberry, I was happy just to be able to participate, regardless of the
Given these prevailing conditions and perceptions effecting Americans with disabilities, Senator Kennedy's use of the term "emancipation proclamation" in reference to the ADA's passage seems understated. Nevertheless, it was against these often oppressive conditions that the individuals whose stories are chronicled in No Pity set forth to reform America's thinking and achieve a measure of respect and empowerment for their fellow Americans with disabilities.

II.

Shapiro has written a sensitive, well-researched, and insightful book that recounts the origin and development of the disability rights movement as reflected by the incredible life journeys of many of its leaders.

As a staunch friend of the disabled community, it is fitting that Shapiro should have written No Pity. Shapiro first became interested in disability rights when he received a telephone call from a public relations woman who worked for the Multiple Sclerosis Society about the person who had been chosen as their "Man of the Year." The "Man of the Year" had flown to New York to accept the award, staying in a hotel across the street from the club where he was to be honored. Because the street lacked curb cuts, and because taxi drivers could not lift his battery-powered wheelchair, the Multiple Sclerosis Society had to hire a special van with a hydraulic lift to take their honoree across a single street. Although Shapiro did not report this incident, he became sufficiently interested in disability rights to attend meetings of President Ronald Reagan's appointed National Council on the Handicapped, which at the time was drafting an early version of the ADA. Over the next five years, Shapiro ensured that national attention was given to disability rights issues by writing stories for his magazine, U.S. News & World Report, which related the concerns of the disabled community. Many of those stories, which were culled

from the more than two thousand interviews Shapiro conducted,\(^{66}\) form the basis of this work.\(^{66}\)

In *No Pity*, Shapiro adroitly tells how a handful of individuals spanning the spectrum of disability labored to obtain basic human dignities, and eventually civil rights, against prevailing societal misperceptions about their respective abilities.\(^{67}\) Among the people whose struggles are depicted are individuals with physical\(^{68}\) and developmental\(^{69}\) disabilities, autism,\(^{60}\) and hearing impairments.\(^{61}\) Shapiro separately presents these individuals' stories in a series of chapters, each of which describes either the struggles of an isolated individual or the actions of a specific disability rights movement.

Anecdotal in nature, Shapiro's narrative is unique in its perspective. In *No Pity*, he portrays with great sensitivity and insight a number of battles that were waged in the campaign to empower Americans with disabilities. Most remarkably, Shapiro describes these struggles from the perspective of the involved (themselves disabled) disability rights advocates, thereby lending new depth and meaning to events whose significance, while recognized by the disabled community, may have escaped that of mainstream

---

\(^{66}\) See Shapiro, *supra* note 4, at 10.  
\(^{66}\) Compare Shapiro, *Disabling 'Jerry's Kids,' supra* note 54 (relating disabled peoples' indignation for telethons which inspire pity for people with disabilities) with the account of Evan Kemp's attempts to recast the telethon format away from the exploitation of pity, Shapiro, *Trial by Radio, supra* note 54 (portraying spiteful treatment on a radio call-in show of a pregnant disabled journalist whose child had an even chance of being likewise disabled), and the identical account of Bree Walker Lampley, Shapiro, *supra* note 4, at 38-40.  
\(^{67}\) See supra notes 10-51 and accompanying text.  
\(^{68}\) See, e.g., Shapiro, *supra* note 4, at 41-73.  
\(^{69}\) *Id.* at 186-210.  
\(^{60}\) *Id.* at 144-58.  
\(^{61}\) *Id.* at 74-104. Sadly, Shapiro almost never mentions vision-impaired or vertically challenged people, even though their story comprises an important part of the disability rights mosaic. Their absence is both surprising and disappointing.
society. This book is, however, more than a skillful chronicle of individual stories. It is also a groundbreaking work that helps introduce able-bodied Americans to their forty-three million disabled neighbors in a way that will foster increased understanding by refocusing mainstream society’s perception of the disabled away from charity and toward equality.

In *No Pity*, Shapiro traces the transformation of the disability rights movement from the parallel but uncoordinated efforts of individual disability rights movements to that of a unified disability rights movement determined to achieve passage of the ADA. Formerly, the disability rights movement had “spanned a splintered universe” of groups representing hundreds of different disabilities, each with their own issues and concerns. The massive and unyielding protest by students for appointment of a deaf president at Gallaudet University, a higher learning institution for the hearing-impaired, was totally unrelated to the advocacy of People First’s developmentally disabled constituency, who wanted both integration into mainstream society and greater control over the structure of their own lives. In addition, individual disability rights groups often clashed with each other. The curb cuts fought for by wheelchair-users were opposed by some vision-impaired people who needed the curbs intact in order to derive a sense of location from their canes. Nevertheless, the campaign for the ADA’s passage “brought this fragmented population together in a fight against discrimination.” As noted at the time by ADA lobbyist Liz Savage, “People with epilepsy now will be advocates for the same piece of legislation as people who are deaf. . . . That has never happened before. And that’s really historic.”

The original ADA bill, as well as the modified version that Congress would ultimately pass, was largely written and promoted by disabled disability rights activists Robert L. Burgdorf, Jr. and Justin Dart, Jr.

---

62 Id. at 126.
65 See Shapiro, supra note 4, at 126.
66 Id.
67 Id. at 126-27.
68 The original ADA bill provided for an entirely accessible or “flat earth” policy within two years of its enactment, as well as for punitive damages. Id. at 114.
Burgdorf and Dart came from very different socioeconomic backgrounds. Burgdorf is the son of an electrician, Dart the son of a wealthy businessman who ran a huge pharmacy chain. Nevertheless, both contracted polio in 1948, reconfirming that "you can become disabled from your mother's poor nutrition or from falling off your polo pony." Together they labored to convince first the members of President Ronald Reagan's National Council on the Handicapped, and then members of Congress, that "to be disabled meant to fight someone else's reality. Other people's attitudes, not one's own disability, were the biggest barrier."

Burgdorf and Dart were joined in their efforts by professional disability rights advocates, most notably Patrisha Wright, a vision-impaired Washington lobbyist for the Berkeley-based Disability Rights Education and Defense Fund. Wright's 1980 Washington arrival marked "the first time disabled people would be represented in Washington by a group they ran themselves." During Wright's first week in Washington, she paid a courtesy call to a key disability group lobbyist. When she informed the established lobbyist that her focus was on civil rights, Wright was told, "We do budget. We don't do civil rights." Wright replied, "You will." It was this resolve that carried her efforts on behalf of the ADA.

Perhaps most instrumental of all the disabled disability rights advocates was future Equal Employment Opportunity Commission (EEOC) Chair Evan Kemp, a muscular dystrophy quadriplegic. The son of two of the founders of the Muscular Dystrophy Association, Kemp was one of the original Jerry's Kids. He gained recognition as a disability rights advocate when he protested the Muscular Dystrophy Association's annual Labor Day telethon in a *New York Times* op-ed piece. Kemp wrote, "By arousing the public's fear of the handicap itself, the telethon makes viewers more afraid of handicapped people. Playing to pity may raise money,

---

69 Id. at 107.
70 Id. at 111.
71 Id. at 109.
72 Id. at 7 (quoting Patrisha Wright, a Washington lobbyist for the Disability Rights Education and Defense Fund).
73 Id. at 112.
74 Id.
75 Id.
76 Id. at 20-21.
77 Id. at 21.
but it also raises walls of fear between the public and us." 78 While working as an attorney in Washington, Kemp developed a close friendship with Bush legal counsel Boyden Gray. 79 This friendship gave the ADA sympathetic support "inside" the White House. 80

While Kemp, Wright, Burgdorf, and Dart lobbied within Washington's corridors of power, the militant disability rights group ADAPT (originally American Disabled for Accessible Public Transit, later re-focused and renamed American Disabled for Attendant Programs Today), staged aggressive and highly publicized civil disobedience. 81 ADAPT was founded by paraplegic Wade Blank in 1983 "to empower disabled people to engage in direct action protest" against inaccessible public transportation. 82 Led by vocal iconoclasts, ADAPT's "direct action protests" used confrontational tactics intended to shock mainstream America into disability-awareness. In early March 1990, during congressional debate on the ADA, more than seven hundred ADAPT members and friends—most of whom used wheelchairs—marched from the White House to the Capitol steps to hold a rally in support of the ADA. 83 One of the more moving events occurred when ADAPT member Mike Auberger spoke to the crowd from his motorized wheelchair:

Twenty years ago, I walked up these steps a wholly equal American citizen. . . . Today I sit here with you as less than second-class citizens who are still legally discriminated against daily. . . . The steps we sit before represent a long history of discrimination and indignities heaped upon disabled Americans. We have faced what these steps have represented. Among us are those who have been forced to live in institutions against our will. There are those among us who have had our children taken away solely because we are disabled. We have been denied housing and jobs. These indignities and injustice must not go on. . . . We will not permit these steps to continue to be a barrier to prevent us from the equality that is rightfully ours.

78 Id. at 21-22; see also Kemp, supra note 4, at A19. In a 1991 magazine piece, Jerry Lewis mused that each of his "Kids" live "the life of 'half a person,' stuck in a wheelchair ('that steel imprisonment') to watch the 'other cripples' play while wishing he could 'play basketball like normal, healthy, vital and energetic people.'" Shapiro, supra note 4, at 23.
79 See Shapiro supra note 4, at 122.
80 Id. at 120-24.
81 Id. at 127-40.
82 Id. at 128-29.
83 Id. at 131-32.
The preamble to the Constitution does not say “We the able-bodied people.” It says, “We the People.”

Before Auberger completed his statement, about three dozen ADAPT demonstrators in wheelchairs threw themselves onto the eighty-three Capitol steps and began to crawl up them. Each “crawl-up” protestor carried a copy of the Declaration of Independence. The next day, ADAPT members staged a sit-in at the Capital rotunda that resulted in their arrest.

Ultimately, much of the strength of the disability rights movement’s efforts to gain ADA passage came from what Congressperson Tony Coehlo of California called a “‘hidden army’ of people who had an instinctive understanding of the stigma of being disabled.” Because nearly one in seven Americans has some form of disability, many of the legislators considering the ADA could relate to someone they knew whose life would be affected by its passage. Coehlo, the House sponsor of the original ADA bill, was a devout Catholic who had epilepsy. During his youth, he had suffered not only community stigma because his illness was considered a “sign of the devil,” but had also been discriminated against in the job market. Maryland Representative Steny Hoyer’s wife is also epileptic. Senator Lowell Weicker of Connecticut, who sponsored the original ADA bill in the Senate, has a son with Down’s syndrome. During floor debate on the ADA’s passage, more members of the “hidden army” came to the fore. For example, during Senate discussion, disabled war veterans Senator Bob Dole of Kansas and Senator Bob Kerry of Nebraska supported passage; Senator Tom Harkin of Iowa signed his speech for his deaf brother who watched on television; Senator Edward Kennedy of Massachusetts talked of his son who had lost a leg to cancer and of his sister with mental retardation; and Senator Orrin Hatch “cried openly on the Senate floor” as he spoke of his brother-in-law with polio who slept at night in an iron lung and had to be carried up the long steps of his Mor-

---

84 Id. at 132-33 (quoting Mike Auberger, ADAPT activist).
85 Id. at 133.
86 Id. at 133-35.
87 Id. at 117.
88 Id.
89 Id. at 118.
90 Id.
Perhaps most importantly, because of the impact that disabling diseases had had upon his own family, President George Bush was a full-fledged member of the “hidden army.” In 1953, his three-year-old daughter Robin died of leukemia. In addition, his son Neil has a severe learning disability, while another son Marvin is a survivor of and a spokesperson for the Crohn’s and Colitis Foundation of America. Finally, Bush’s favorite uncle and a man he greatly admired, surgeon John Walker, became a post-polio quadriplegic. It was perhaps with these people in mind that Bush pledged during his acceptance speech at the Republican National Convention “to do whatever it takes to make sure the disabled are included in the mainstream.”

With the combined support of a unified disability rights coalition, politicians, and the “hidden army,” the ADA passed quickly through Congress. Following a ceremony on the White House South Lawn for three thousand optimistic members of the “hidden army,” it was signed into law by President Bush on July 26, 1991. After putting his pen to the bill, “Bush turned to Evan Kemp, who was sitting next to him on the podium overlooking the Washington Monument, and gave him an affectionate kiss on the head.”

III.

This outstanding book is not without flaw. No Pity has both the benefits and the drawbacks of being a talented journalist’s series of reports. Covering a wide range of people and issues, a major shortcoming of this otherwise exceptional book is that it fails to adequately explore the psyche of its subjects. Most notably, although Shapiro recognizes that “it is society’s myths, fears, and stereotypes that most make being disabled difficult,” he only focuses on the external and physical manifestations of this prejudice, while passing over the impact that this treatment has upon the

---

91 Id. at 118-19.
92 Id. at 119.
93 Id.
94 Id. at 124 (quoting President Bush).
95 Id. at 140.
96 Id. at 5.
internal identity and self-perceptions of the disabled.97 For example, one of the life stories recounted in No Pity is that of Ed Roberts, a post-polio quadriplegic who went on to found first the Center for Independent Living and then the Independent Living Movement.98 In describing how “the disability rights movement was born the day” Roberts enrolled at the University of California at Berkeley,99 Shapiro graphically details the appalling treatment Roberts received at the hands of California public officials and educators. First Shapiro recounts that the California Department of Rehabilitation refused to pay for the same four-year education for Roberts that it did for less severely disabled students, because the expenditure of such sums “would be wasted since it was ‘infeasible’ that he would ever work.”100 Then, when Roberts lobbied Berkeley directly, Shapiro writes that he was informed very matter-of-factly by one dean that they had “tried cripples before and it didn’t work.”101 By contrast, in describing Roberts’ transition from an active and able-bodied teenager to a severely disabled person, Shapiro only briefly states that “Roberts saw himself as a ‘helpless cripple’ overwhelmed by depression, powerlessness, and self-hatred. . . . Shy and ashamed of his crippled body, he had rarely ventured outside his home.”102 Absent from Shapiro’s account is why Roberts now hated himself and what caused the shame that he felt about his body. No explanation is given about what images were presented or statements made that shattered Roberts’ self-esteem.103

97 In a similar vein, Shapiro gently mentions, without any elaboration, the sexual relationships embarked on by several of the people with disabilities he chronicles. This omission, which was probably motivated by Shapiro’s sensitivity toward his subjects, is a loss for No Pity’s readers, because it could have helped dispel the common myth that disabled people are sexless. Although Shapiro himself rebuts this myth by reporting that “most men and women with spinal cord injuries report satisfying, and often more adventurous, sex lives,” see id. at 263, a personal account would have been more compelling. It would have also revealed a great deal about bodily self-perception. An especially noteworthy book on disabled sexuality was coauthored by a disabled husband/non-disabled wife team. See Ken Kroll & Erica Levy Klein, Enabling Romance: A Guide to Love, Sex and Relationships for the Disabled (and the People Who Care About Them) (1992).


99 See Shapiro, supra note 4, at 41.

100 Id. at 44.

101 Id. at 45.

102 Id. at 42-43.

103 Disabled historian Hugh Gallagher brilliantly explores this subject in another context. See Hugh Gregory Gallagher, FDR’s Splendid Deception (1985).
Shapiro’s primary focus is exemplified by the following passage, describing the daily existence of the disabled: “[M]ost disabled people[...] struggle constantly with smaller challenges, such as finding a bus with a wheelchair lift to go downtown or fighting beliefs that people with disabilities cannot work, be educated, or enjoy life as well as anyone else.”104 Although this statement is accurate in and of itself, it does not address how the disabled are effected when they struggle with “smaller challenges” or preconceived beliefs presented by mainstream society. This is a grave omission. If No Pity is to be used to increase able-bodied American society’s sensitivity to the impact of its actions upon their disabled neighbors, then it should also be cognizant of the terrible hurt that it fosters daily due to its actions.

Contrary to popular myth, disability is not something that is accepted, digested, and then “overcome.” The disabled person—even one who is comfortable with herself and fully adjusted to her situation—does not go on with an otherwise “normal” life. Yet Shapiro apparently buys into this myth. In discussing Roberts, Shapiro informs us that “[o]ver time, he had come to accept his disability, which now was central to his identity.”105 After this statement, Roberts’ disability and his adjustment to it are not mentioned.

Instead, being disabled in America—and, one would imagine elsewhere106—involves a daily struggle of either confronting or avoiding people’s misperceptions and mistreatment. It involves not only contending with the adversity of physical barriers, but also dealing with the underlying attitudinal barriers. Disabled people must learn how to cope with being pointed at by a small child who asks his mother, “What’s wrong with that man?,” or being asked over the telephone by someone they’ve met at a party, “Were you the cute one or the one in the wheelchair?”

Disabled people have developed a very negative self-image because of societal perceptions.107 The 1991 Louis Harris and Associates study men-

---

104 See Shapiro, supra note 4, at 17.
105 Id. at 43.
tioned above108 found that seventy-four percent of Americans felt pity to­
ward disabled individuals, forty-seven percent reacted with fear "because
what happened to the disabled person might happen to them," sixteen
percent were angered because "disabled people are an inconvenience," and
nine percent said they felt resentment at "the special privileges disabled
people receive."109 This study shows at the very least that Americans are
uncomfortable when interacting with disabled people. This discomfort
manifests itself in varying degrees from the awkwardness of not knowing
quite how to relate to a person with a disability—and therefore, with the
best of intentions, relating only to the person's disability—to the inexcus­
able act of attempting to remove a woman in a wheelchair from an auc­
tion house because the operators thought that she was "disgusting to look
at."110 The result of having to interact with mainstream society's mis­
perception-driven behavior is not only anger at the subject, but also—like
with other recipients of prejudice—self-directed frustration that results in
a poor self-image.111

Shapiro's emphasis on the exoteric manifestations of ableism is also in­
complete because external forces do not offer the only stimulus to poor
self-imagery. A great deal of frustration ensues when one's body either
cannot do what others can or, even worse, acts in a way that proves em­
arrassing. In a perfectly tolerant society, incontinence is still a humiliat­
ing and painful experience. In a perfectly accessible and sensitized world,
it hurts not to be able to feel a lover's caress.

Indeed, personal accounts of the lives of individuals with disabilities,
such as those written by John Callahan112 and Ron Kovic,113 or por­
trayed in film by Neil Jimenez,114 tell a story very different from the

108 See supra note 43.
109 Id. at 13.
victim of the injustice became one of the founders of the Center for Independent Living and is cur­
cently serving as an Assistant Secretary of Education. See Shapiro, supra note 4, at 55-58.
111 See generally Martha Minow, Surviving Victim Talk, 40 UCLA L. REV. 1411, 1420 (1993)
(discussing the danger of victim talk creating a self-fulfilling prophecy by suggesting that the victims
are themselves powerless).
112 John Callahan, Don't Worry, He Won't Get Far on Foot (1989).
113 Ron Kovic, Born on the Fourth of July (1976).
114 Neil Jimenez's experiences were the subject of his semiautobiographical film The
Waterdance (No Frills Film Production 1992).
disability—is—an-obstacle—that—is—overcome—and—then-serenely-lived—with
myth. Instead, these accounts reveal very personal, lifelong grappling with
notions of self-identity and worth.

This internal struggle often manifests itself in the cartoons of
quadriplegic artist John Callahan whose controversial work portrays peo-
ple with disabilities in ways that border on the macabre. One Callahan
cartoon, which is reproduced in No Pity, demonstrates the disabled com-


doing and self-worth. In the cartoon, two heads mounted on skid carts beg with tin cups at
a street corner. The first head says to the second head, which is identical
except that he wears an eyepatch, “People like you are a real inspiration
to me!” 118

Another cartoon which appears in Callahan’s autobiography is part of a series that he has drawn on “How to relate to handicapped
people.”118 Among the behavioral don’ts are: (a) acting “over friendly;”
(b) being “patronizing;” (c) “directing your questions to the friend of the
handicapped person;” (d) “being over-apologetic;” and (e) “acting like
Leo Buscaglia.”117 That Callahan felt compelled to illustrate a series of
cartoons on relating to disabled people also demonstrates the oversimplic-
ity of the “overcoming disability” myth—it is not possible to overcome a
disability that non-disabled people cannot themselves overcome. Calla-
han’s ongoing personal struggle to cope with his disability is also demon-
strated in his description of his personal hygiene routine:

Once a week, just after my shower, we have to change the urine
apparatus that is patch-glued to the permanent opening at the lower
right-hand corner of my stomach. I slip back onto the bed. The old


glue gets scraped off and a new self-adhesive patch, tube, and bag unit is pressed on. If it’s not done just right, I leak. I’ve been writing
a song about this:

I broke my neck upon a rock
And now I cannot feel my cock;
The doctors filled me up with fibs
And now I piss between my ribs . . .

I can see Neil Diamond singing it.118

118 Shapiro, supra note 4, at 17.
119 Callahan, supra note 112, at 189-99.
117 Id.
118 Id. at 203.
Another notable flaw of No Pity—and one that is at least partially the result of embracing the overcoming disability myth—is that it paints a much too aggressive picture of disabled self-identity. For example, the book frequently asserts that the present generation of disabled people have not only reconciled themselves to their disabilities, but have also "come to take a growing pride in being identified as disabled." To support this point, Shapiro quotes John Limnidis, a deaf athlete who appeared briefly in the film *Children of a Lesser God*, as saying that "[i]f there was a medication that could be given to deaf people to make them hear, I wouldn't take it. Never. Never till I die!" This sentiment is repeated by Cyndi Jones, the former poster child mentioned above, who avers that given the opportunity, she would refuse to swallow a "magic pill" that could wipe away the paralysis that lingers from her childhood bout with polio.

Notwithstanding Limnidis and Jones having such feelings, their view does not necessarily coincide with that of most individuals with disabilities, and should not be perceived as such. Most disabled people would probably agree with Jones that accepting one's disability is "part of [the] experience" of being a disabled person, and that being comfortable with one's own identity is necessary to every person's emotional adjustment and well-being. This position is, however, a far cry from the declaration of the militant disability rights community that "[w]e want more disabled people, not fewer."

One example of how Shapiro misses the mark in his assessment of disabled people's self-valuation arises in his chronicle of Marilyn Hamilton. After becoming a paraplegic as the result of a hang gliding accident, Hamilton's frustration with heavyweight hospital-issue wheelchairs inspired her creation of lightweight sport(y) wheelchairs. Those wheelchairs were not only less cumbersome than what had otherwise been available, but they also boosted the spirits of their users through their

---

119 Shapiro, supra note 4, at 13-14.
120 Id. at 85.
121 See supra notes 29-31 and accompanying text.
122 Shapiro, supra note 4, at 14.
123 Id.
124 Id. at 282.
125 Id. at 211-19.
resplendent neon colors. After reporting Hamilton's reconciliation with her new status as a disabled person—"I knew I was the same as always. . . . I just got around by a different means of transportation"—Shapiro notes, "Even today, when she dreams, she is not in a wheelchair." Shapiro then concludes that a belief by a paraplegic that she will walk again despite contrary evidence "is a way to hide from the stigma of disability."

Shapiro's assertion echoes Cyndi Jones's flawed analogy that asking a disabled person if he would like to be to able-bodied is "the same thing as asking a black person would he change the color of his skin." A more accurate analogy would ask a person of color who has magically been turned Caucasian if she would like once more to be African-American or, if she were not always disabled, to ask if she would like to participate in activities that were previously within her physical capabilities. Although the answers to these questions might vary, it is incorrect and naive to assume that affirmative responses are driven by shame. Just as there is nothing innately wrong with being disabled, there is also nothing shameful about a disabled person wanting to be able-bodied. As Tevye the Milkman said in another context: "I realize, of course, that it's no shame to be poor, but it's no great honor either."

One explanation for Shapiro's skewed perception may be that, with the exception of Marilyn Hamilton, he has largely profiled individuals who were born with their respective disabilities and for whom these factors are the only "norm" they have experienced. Individuals with congenital conditions, however, account for only a portion of individuals who are disabled. The remainder of the population are individuals who have crossed the barrier from "able-bodied" or "normal" to what society depicts and treats as out of the ordinary and deserving pity. Therefore, the perception of disability by people who have lived their entire lives with their disabilities is probably very different from that of individuals who

---

126 Id. at 212.
127 Id.
128 Id. at 218.
129 Id.
130 Id. at 14.
132 See ICD Survey, supra note 15, at 13 (reporting that only 20% of all people with disabilities became disabled before adolescence).
have become disabled later in life. For example, paralyzed Vietnam War veteran and disability rights advocate Ron Kovic writes in his memoirs, which later became the basis for a film, that he would “give anything” to be able to once again participate in able-bodied activities.\textsuperscript{133} So would I.

IV.

\textit{No Pity} ends by raising a very daunting question. Unlike the civil rights statutes that empowered people of color and women, the ADA’s enactment was not preceded by dramatic and highly publicized consciousness-raising activities such as the “I Have a Dream” speech that stirred national passion, nor does the disability rights movement have a singular familiar figurehead.\textsuperscript{134} Therefore, asks Shapiro, “What happens when Congress grants a new group minority rights, but society has little understanding that those rights have been awarded or why they are needed?”\textsuperscript{135}

One uncomfortable possibility Shapiro raises is that a backlash similar to that against other newly empowered minority groups\textsuperscript{136} will occur against people with disabilities. Such an occurrence would not be unprecedented. Following passage of the Rehabilitation Act twenty years ago, a backlash against people with disabilities occurred after reports were published that grossly overestimated the costs involved in implementing the new regulations.\textsuperscript{137} Therefore, a similar backlash might be in the making.

When Oregon’s statewide health plan was rejected by the Bush Administration as being contrary to the mandates of the ADA, a \textit{Wall Street Journal} editorial complained, “[W]e have the architects of the Americans with Disabilities Act deciding that Oregon’s plan, the product of an arduous political consensus within that state, simply doesn’t fit the grand design of their legislated benevolence,” while a \textit{New York Times} editorial gratuitously declared that the ADA “is beginning to have the look of Big Brother.”\textsuperscript{138} These statements were made even though the Oregon plan rationed medical treatment on the basis of a priority list that undervalued

\begin{itemize}
\item \textsuperscript{133} Kovic, \textit{supra} note 113, at 97.
\item \textsuperscript{134} Shapiro, \textit{supra} note 4, at 324.
\item \textsuperscript{135} Id. at 323.
\item \textsuperscript{136} See, e.g., Susan Faludi, \textit{Backlash: The Undeclared War Against American Women} (1991).
\item \textsuperscript{137} Shapiro, \textit{supra} note 4, at 70-73.
\item \textsuperscript{138} Id. at 327-28.
\end{itemize}
the treatment of conditions effecting many people with disabilities and would therefore toll their death knell.\footnote{139}{Id. at 324-27. But see Note, The Oregon Health Care Proposal and the Americans with Disabilities Act, 106 Harv. L. Rev. 1296 (1993) (concluding that the Oregon Health Care Proposal withstands scrutiny under the ADA).}

In addition to the threat of backlash, there are other questions, beyond the scope of \textit{No Pity}, that need to be raised about the ADA’s future impact on the lives of Americans with disabilities. The most pressing of these questions parallels concerns that have been raised by many prominent legal scholars of color. These critics—most notably Professor Derrick Bell—have characterized as ineffectual the civil rights statutes relating to their status. Specifically, these scholars assert that civil rights legislation has to date been impotent because it has not given people of color the tangible economic equality that should have flowed from legal equality.\footnote{140}{See generally Derrick Bell, \textit{Faces at the Bottom of the Well: The Permanence of Racism} (1992); Derrick Bell, Foreword: The Civil Rights Chronicles, 99 Harv. L. Rev. 4 (1985).}

Some have even argued that, because of inherent racism, such equality is more than evasive: it is also impossible to acquire.\footnote{141}{See, e.g., Kimberlé Williams Crenshaw, \textit{Race, Reform, and Retrenchment: Transformation and Legitimation in Antidiscrimination Law}, 101 Harv. L. Rev. 1331 (1988); Neal Devins, \textit{The Rhetoric of Equality}, 44 Vand. L. Rev. 15 (1991); Charles R. Lawrence, III, \textit{The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism}, 39 Stan. L. Rev. 317, 322-23 (1987).}

A viable question for those concerned with the status and circumstances of the disabled would therefore seem to be: Will the same phenomena happen to people with disabilities? As a “second-generation civil rights statute,”\footnote{142}{The term was coined by Professor Burgdor. See generally Burgdor, supra note 2.} will integration of people with disabilities under the ADA be different from the desegregation of people of color under the Civil Rights Act of 1964 or the economic empowerment and equalization of women under Title VII? Moreover, will the disabled community be able to counteract challenges to its empowerment by fielding the same type of pan-disability rights coalition that it did in support of the ADA’s enactment, especially if a feeling persists among individuals with disabilities that disabled people should be neither seen nor heard?\footnote{143}{See generally parts I, II.}

At least one post-ADA example seems to indicate that even when physical barriers are eliminated, attitudinal barriers remain.\footnote{144}{See generally Michael Ashley Stein, \textit{When Justice Is Blind: Appointing Vision-Impaired}}
1992, more than two years after the ADA's enactment, President George Bush nominated Richard C. Casey for a judgeship on the United States District Court for the Southern District of New York. As a former federal prosecutor who had later also gained a reputation as an accomplished trial attorney in private practice, Casey's designation would ordinarily have raised few eyebrows. Casey's nomination, however, garnered a great deal of attention and for only one reason: Casey is blind.

Most of the attention surrounding the nomination focused exclusively on Casey's disability, and often portrayed Casey's physical differences in a negative light. The most egregious example was an editorial that appeared in the New York Times, shortly after Casey's appointment was sponsored by Senator Alfonse D'Amato. The Times editorial began by stating that the nomination of a vision-impaired individual to the federal trial bench "pushes the outer boundaries of what the judicial system can accommodate." The editorial further explained that:

Presiding at a Federal civil or criminal trial calls for supervising a courtroom of lawyers, witnesses, spectators and the contesting parties. Federal judges do most of the questioning of prospective jurors and routinely weigh the credibility of witnesses in non-jury cases. The ability to make eye contact has almost universally been assumed indispensable for the task of trial judging.

Without eyesight, a judge can't personally observe every lawyer's or spectator's illicit attempt at improperly influencing a jury, such as hand signals or silent demonstrations. And he cannot see for himself what impact a trial exhibit, say an inflammatory poster, might have on a viewer.

The editorial then concluded that, to the burden of proving adequate judicial ability "must be added the burden of proving [Casey] is so experienced and able that he can beat a large handicap."

Putting aside the factual inaccuracies of these comments—federal judges rarely question jurors and eye contact is hardly the watermark of a fine


146 Id.
147 Id.
judge—and ignoring the colloquial mythology invoked—that during the
course of a trial, both witnesses and jurors are shocked by Perry Mason-
like dramatics—the editorial’s audacious tone is striking. Surely, the edi-
tors wouldn’t suggest that women are emotionally incapable of sitting as
trial judges or that members of racial minority groups should not be dis-
trict court judges because they cannot fairly adjudicate issues involving
law enforcement officers who have historically discriminated against
them? Even so, analogous questions were raised within the context of
Casey’s nomination.

Perhaps even more striking than the ignorance of the assumptions un-
derlying the editorial were the prejudices and misconceptions regarding
the vision-impaired that the piece reveals. Casey’s lack of sight is equated
with want of insight: because he cannot see, he cannot fully comprehend
the actions that surround him. His disability is compared with a privation
of wisdom: being vision-impaired will allow unethical lawyers to ensnare
him in a twisted game of judicial “blind man’s bluff.” The editorial also
asserts that Casey must prove that the very qualities that separate him
from the majority of individuals who are nominated to the bench will not
interfere with his judicial abilities. This is a burden that is not placed on
other minority nominees and should not have been unilaterally set upon
Casey’s shoulders by the New York Times.

Casey’s nomination was of crucial importance to the disabled legal com-
munity for a number of reasons. First, although a number of federal
judges—most notably Supreme Court Justice John Marshall Harlan—
have become blind after their judicial appointments, Casey was the first
vision-impaired individual to be nominated to the federal bench. Second, if
the Senate had decided that vision-impaired individuals were per se un-
qualified to sit as district court judges, then Casey’s nomination to the
federal trial bench might very well have been the last nomination of a
vision-impaired individual. Third, the manner in which the Senate han-
dled the issue of Casey’s disability would have been very revealing in dis-
closing many common perceptions (and possibly quite a few mispercep-
tions) about the disabled. Perhaps most telling about the criticism of
Casey’s nomination was that, even after the ADA’s enactment, a person
with a disability who was fully capable of performing a specific function
was still discriminated against solely because of certain preconceived no-
tions regarding his disability.
Shapiro has written an incisive, well-researched, and exceptional book about the disability rights movement and the personal struggles of many of its leaders. Although *No Pity* falls a bit short in fully exploring the psyches of its characters, Shapiro must be thanked for producing a work which can help better educate American society about the people who comprise one-seventh of its members.

The future holds a great deal of promise for Americans with disabilities now that a federal statute has empowered them with civil rights, but it is also a future that is filled with perilous challenges and obstacles to real and meaningful empowerment. In short, a great story has begun to unfold. Shapiro would do a great service to both disabled and mainstream society by continuing to direct his enormous talents to the telling of that tale.