

Michigan Law Review

Volume 92 | Issue 6

1994

No Pity: People with Disabilities Forging a New Civil Rights Movements

Cheryl A. Leighty
University of Michigan Law School

Follow this and additional works at: <https://repository.law.umich.edu/mlr>



Part of the [Civil Rights and Discrimination Commons](#), and the [Disability Law Commons](#)

Recommended Citation

Cheryl A. Leighty, *No Pity: People with Disabilities Forging a New Civil Rights Movements*, 92 MICH. L. REV. 1953 (1994).

Available at: <https://repository.law.umich.edu/mlr/vol92/iss6/40>

This Review is brought to you for free and open access by the Michigan Law Review at University of Michigan Law School Scholarship Repository. It has been accepted for inclusion in Michigan Law Review by an authorized editor of University of Michigan Law School Scholarship Repository. For more information, please contact mlaw.repository@umich.edu.

NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT. By *Joseph P. Shapiro*. New York: Times Books. 1993. Pp. ix, 372. \$25.

Joseph Shapiro, a writer for *U.S. News & World Report*, starts his book, *No Pity*, with the line “Nondisabled Americans do not understand disabled ones” (p. 3). The sentence indirectly conveys the book’s purpose: to tell the stories of disabled people in order to create a greater understanding of the needs of the disabled. Shapiro skillfully leads the reader to reject views of the disabled as pitiable “poster children” or heroic, inspirational “supercrips”¹ and, instead, to recognize them as “fully accepted participants in everyday life” (p. 332). Shapiro achieves this goal by relating the stories of those he interviewed during the five years he researched the book. In the process of showing that disabled people are entitled to equal rights, Shapiro describes the increase in their self-awareness and political awareness that led, in part, to Congress’s passage of the Americans with Disabilities Act (ADA)² in 1990.

In his book, Shapiro includes information gleaned from his interviews and adds explanatory and historical information. The book tells the stories of people such as Ed Roberts, whom others described as a “sickly ‘vegetable,’” and a “freak in a wheelchair” when he was a teenager (pp. 42-43). His parents told him, based on what doctors, nurses, and counselors had said, that he would never “go to college, marry, or hold a job,” and one doctor told his mother that it would have been “more humane . . . if the high fever of the polio had killed him quickly” (p. 42). Not to be deterred, however, Roberts fought to change the attitudes of others — attitudes that held him back. Roberts and his equally determined mother persuaded the school board to award him his high school diploma, even though the principal had refused to do so because Roberts had not completed the physical education and driver’s education requirements (p. 44). Next, he convinced officials at Berkeley to admit him, over the objection that “[w]e’ve tried cripples before and it didn’t work” (p. 45). Roberts at-

1. P. 16. As an example of the “supercrip,” Shapiro describes “a paraplegic park ranger who won widespread press coverage for climbing granite peaks.” P. 17. Such an image does not “reflect the day-to-day reality of most disabled people,” who struggle with stereotypes — such as the belief that disabled people cannot work — and practical difficulties — such as finding transportation they can use. *Id.* As evidence for his assertions, Shapiro points to survey results showing that 92% of Americans “usually felt admiration when they met people with severe disabilities,” and 74% “felt pity,” while 16% “felt anger ‘because disabled people are an inconvenience.’” P. 328 (citing Louis Harris & Assocs., Inc., Telephone Survey on Public Attitudes Toward People with Disabilities (June 1991), available in LEXIS, News library, Rpoll file).

2. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended at 42 U.S.C. §§ 12101-12213 (Supp. IV 1992)).

tended Berkeley and, in the process, helped establish programs to allow disabled persons to live independently. He "redefined independence as the control a disabled person had over his life" (p. 51). Independence, for Roberts, referred to "the quality of one's life with help" rather than the number of things a disabled person could do without assistance (p. 51).

The Americans with Disabilities Act covers persons with mental as well as physical disabilities;³ Shapiro describes the rebellion of the former against being "treated as eternal children" (p. 185) who live in institutions and are told "what to eat, when to eat it, when to get up, where to live, where to work, when to watch TV, when to sleep" (p. 199). Shapiro focuses on T.J. Monroe, who is active in the self-advocacy movement for people with retardation.⁴ Monroe spent twenty-three years in institutions, but, at the age of thirty-eight, he has his own apartment, a car, and a job as a veterinarian's assistant. President Bush invited him to the White House to witness the signing of the ADA, and many in the self-advocacy movement have called him a "hero" because of his charismatic speeches exhorting listeners to "make thunder" and "speak for their rights" (pp. 184, 192-93). Monroe, however, still feels lonely, and social workers occasionally come to his unkempt apartment to "dig him out" of the mess (pp. 193-94).

Shapiro devotes another chapter to "Jim,"⁵ who escaped an institutional life only by knowing Shapiro.⁶ Jim remained institutionalized at thirty because he had no one to act as his advocate (pp. 292-93). Doctors diagnosed him as "profoundly retarded" when he entered the institution, even though today's tests would likely have described him as having merely a "severe learning disability" (p. 311). Jim had mechanical talents and could have done well living on his own with a job involving mechanical work (pp. 306-07). The institution regulated everything in Jim's life. When he awoke every day, a staff person instructed him to "'get dressed, wash [his] hands and face, [and] shave,'" and when he complied, he received tokens that could be exchanged for privileges (p. 300). His tasks included hanging his clothes neatly and removing all the dust from his wardrobe and shelves; Shapiro wryly notes that he himself "would not fare nearly so well if social workers paraded through my home each week to see that I had dusted precisely" (p. 301). Shapiro spent nineteen months convincing

3. 42 U.S.C. § 12102(2)(A) (Supp. IV 1992).

4. Shapiro relates Monroe's essential message: "[B]ecause 'retarded' is an ugly word that makes us seem childlike and dependent . . . avoid the word whenever you can. Refer to us as people with retardation, if you must. See us as people first." P. 185.

5. Shapiro does not provide Jim's last name.

6. Shapiro tries to show that while most mentally disabled people today live independently, institutionalization still exists. Stories such as Jim's demonstrate that such a practice may be convenient to society but does not serve the needs of the disabled. Pp. 162-65, 306.

Jim's social worker and the institution's staff that he would be successful on his own. Jim left the institution, and staffers then finally treated him with respect (p. 320).

Shapiro effectively utilizes such stories to invoke a feeling of outrage toward unfair treatment of disabled people while avoiding the feelings of pity. The author carefully includes interviews that anger the reader. For example, Shapiro highlights a "well-meaning" woman in a business suit dropping a quarter into a cup held by a disabled woman in a wheelchair, splashing coffee onto the latter's clothes (p. 19), and the foreman of an electricians' union telling a teenager: "We're not hiring any cripples here" (p. 107).

Shapiro also writes about disabled persons whom others cannot consider "helpless cripples." He selects those successful in the traditional sense, such as the woman who created a \$40-million-a-year business making lightweight, brightly colored wheelchairs (pp. 211-14), and autistic workers prized for their dependability and meticulousness, who succeed despite their disability (pp. 145-51). In fact, Shapiro's examples come close to invoking the inspirational, "supercrip" images that he wants to dispel.

For the most part, Shapiro succeeds in showing the need to eliminate stereotypes without appearing to preach to the reader. He accomplishes this, not only through the narratives of the challenges particular individuals have had to face, but also through the subtle reminders throughout the book that disability "is the one minority that anyone can join at any time" (p. 7). Many of his generalizations about what those with disabilities prefer seem to be accurate. For example, Shapiro consistently stresses that assistance in the home should replace institutionalization.⁷

In other parts of the book, however, it seems as if Shapiro imposes his own view of how disabled people feel. After describing one paraplegic woman's painful and futile attempt to walk again and relating that she does not see herself in a wheelchair when she dreams, he suggests that paraplegics who maintain a belief that they will walk again, despite evidence to the contrary, do so as "a way to hide from the stigma of disability" (pp. 218-19). Shapiro fails to consider other explanations, such as the influence of religious or scientific beliefs on some paraplegics' conviction that they will walk again. Suggesting that only those who accept their disabilities are "at peace" fits Shapiro's theme that we should not force the disabled into futile attempts to overcome their disabilities. At the same time, however, it comes dangerously close to creating another stereotype.

7. Cf. Peter S. Canellos, *New housing policy sought for people with disabilities*, BOSTON GLOBE, Feb. 11, 1991, at 24 ("[T]he leaders of advocacy groups for people with disabilities say most of their members prefer living independently, with service providers available to visit regularly or when needed, to residing in group homes or institutions.").

Moreover, when Shapiro addresses issues other than equal treatment, he implies that there is only one way to view issues that others see as creating serious ethical dilemmas. Such issues include whether parents should have children when a chance exists of genetic physical⁸ or mental disabilities,⁹ and when doctors should discontinue medical treatment for children born with severe disabilities or for patients with terminal illnesses.¹⁰

The most disturbing chapter regarding the discontinuation of medical treatment involves the issue of a disabled person's ability to end his own life through refusing unwanted medical treatment.¹¹ Shapiro describes Larry McAfee, a thirty-four-year-old quadriplegic who was required to use a respirator after an accident left his lung muscles paralyzed. McAfee was severely depressed, and when he "just [couldn't] take it anymore," he successfully convinced a court that having his respirator turned off was not suicide but rather the refusal of unwanted medical treatment.¹² Although McAfee eventually changed his mind, Shapiro quotes with approval those disability rights activists who argued that the court placed a lower value on McAfee's disabled life and would not have permitted such a refusal if McAfee had not been disabled.¹³ Shapiro implies, inconsistent with his assertions throughout the book, that the disabled should not independently make their own decisions regarding medical treatment. McAfee himself, according to his lawyers, in response to questions about his wish to end

8. Pp. 277-81. See, e.g., Louis J. Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 836-43 (1990); Albert S. Moraczewski, *Ethical Aspects of Genetic Counseling*, in *PSYCHIATRY AND GENETICS: PSYCHOSOCIAL, ETHICAL, AND LEGAL CONSIDERATIONS* 163 (Michael A. Sperber & Lissy F. Jarvik eds., 1976). Shapiro discusses the issue in the context of a newscaster with ectrodactyly — fused bones in the fingers and toes — whose decision to have a child sparked a national debate. Pp. 38-40. Shapiro's way of describing the child is an example of the way he tries to eliminate stereotypes in a subtle way: "[The child] was born healthy. He, too, inherited ectrodactyly." P. 40.

9. Pp. 278-79. The issue includes sterilizing persons with retardation, especially those vulnerable to sexual assault. Pp. 158, 271-72. For example, in one opinion — which has not been overruled — the Supreme Court permitted involuntary sterilization and noted that "[t]hree generations of imbeciles are enough." *Buck v. Bell*, 274 U.S. 200, 207 (1927); see also Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 BERKELEY WOMEN'S L.J. 122 (1993); Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806.

10. Pp. 272-74, 324-28. The issue will engender heightened debate because at least one recent attempt at health care reform has included rationing. See, e.g., Marilyn Chase, *Rationed Health Care Helps Oregon's Poor but Real Test Is Ahead*, WALL ST. J., Mar. 22, 1994, at A1 (chronicling the debate about rationing under the Oregon health plan).

11. Again, scholars fiercely debate this issue. Compare, e.g., RONALD DWORKIN, *LIFE'S DOMINION* 179-217 (1993) (reviewed in this issue by Professor Alexander Capron — Ed.) (arguing that people should have autonomy to determine quality of life) with Yale Kamisar, *Are Laws Against Assisted Suicide Unconstitutional?*, HASTINGS CENTER REP., May-June 1993, at 32 (opposing assisted suicide).

12. Pp. 258-70; see *State v. McAfee*, 385 S.E.2d 651 (Ga. 1989).

13. As an example of how far Shapiro takes this position, Shapiro compares the court's decision to the murders of the disabled in Nazi Germany. Pp. 270-71.

his life, answered: "I salute [disabled people who find life rewarding], but it's not for me" (p. 270). Regardless of one's views on the "right to die," Shapiro oversimplifies the issue by accepting as legitimate only his own views and those of some disability rights activists.

One group of disabled people largely missing from *No Pity* — perhaps because this group has been reviled and blamed rather than pitied¹⁴ — is people who are HIV-positive or who suffer from Acquired Immune Deficiency Syndrome (AIDS). Although Congress intended to include AIDS as a disability covered by the ADA,¹⁵ Shapiro does not include any stories of persons with AIDS in his narratives.¹⁶ He only briefly mentions that some people with AIDS and other chronic conditions, such as chronic fatigue syndrome, play an active role in the disability rights movement. Obviously, Shapiro could not have covered all disabilities adequately in one book. Nevertheless, a more expanded discussion in this area, including stories describing what people with these conditions need to live independently and whether the ADA has gone far enough in this regard, would make the book more useful for understanding these disabilities.

The ADA, though an important part of Shapiro's book, does not constitute its main focus. Shapiro treats the ADA not as the culmination of the civil rights movement for the disabled but rather as part of a continuing process. Shapiro uses the ADA to demonstrate the power of the disability rights movement and its "hidden army." His unofficial legislative history shows that during the Bush administration the bill passed largely through the efforts of lawmakers who were themselves disabled and of those such as President Bush who had several disabled relatives (pp. 117-19). Shapiro describes how President Bush's attention to disability rights in his campaign gained him large numbers of votes that one otherwise might expect to go to Democratic candidates (p. 125). Ironically, when Congress passed the bill, liberals "narrowed the scope of the accommodations to be made, making the bill more palatable to business and therefore more likely to become law" (p. 114).

14. See Josephine Gittler & Sharon Rennert, *HIV Infection Among Women and Children and Antidiscrimination Laws: An Overview*, 77 IOWA L. REV. 1313, 1319-31 (1992) (discussing the nature and causes of prejudice against those with AIDS).

15. The ADA defines *disability* as "a physical or mental impairment that substantially limits one or more of the major life activities." 42 U.S.C. § 12102(2) (Supp. IV 1992). Legislative history shows that Congress clearly intended AIDS to be included under this definition. S. REP. NO. 116, 101st Cong., 1st Sess. 22 (1989) ("The term includes . . . infection with the Human Immunodeficiency Virus."); H.R. REP. NO. 485, 101st Cong., 2d Sess., pt. 2, at 51 (1990), reprinted in 1990 U.S.C.A.N. 303, 333 (using identical language).

16. For a particularly moving photographic essay that puts a human face on the AIDS epidemic, see Peter Goldman, *The Face of AIDS*, NEWSWEEK, Aug. 10, 1987, at 22 (showing photos of those who have died from AIDS with captions including facts about their lives). This piece serves the same purpose as Shapiro's book — to force people to confront and to care about the way society treats those with AIDS.

The realization that "more than one in seven Americans had a disability that would be covered under the ADA" (p. 117) kept business from opposing the bill too vociferously and gave the bill necessary political support. No business "wanted to look like a bigot fighting a civil rights bill" (p. 116). The Act also set limits on the accommodation required, based on the size of the business.¹⁷ Moreover, many accommodations were simple and inexpensive, such as placing a desk on blocks to accommodate a wheelchair user (pp. 115-16). Accommodation might even require only creative thinking. For instance, an office with more than one secretary could allocate tasks so that a deaf secretary could be responsible for filing and typing while other secretaries covered the phones (pp. 115-16). Finally, "businesses had come to see disabled people as a new source of both labor and customers."¹⁸ As a result, the ADA passed quickly and many businesses eagerly complied with its provisions. Disabled people have become "a minority which now ha[s] rights to challenge its exclusion" (pp. 140-41).

The disability rights movement continues beyond the enactment of the ADA (p. 141). Shapiro's book demonstrates that in order for disabled people to achieve the goal of "common respect and the opportunity to build bonds to their communities as fully accepted participants in everyday life," they must continue to struggle to overcome irrational prejudices and stereotypes (p. 332). Shapiro's book provides important insights necessary to ensure that the movement toward equality for disabled Americans continues.

— Cheryl A. Leighty

17. P. 115. 42 U.S.C. §§ 12111(9)-(10), 12112(b)(5)(A) (Supp. IV 1992).

18. P. 116. Businesses have also provided "the most consistently positive portrayals" of people with disabilities in their advertisements. P. 35. *See, e.g., HUDSON'S, ANNIVERSARY SALE CATALOG*, Mar. 1994, at 8, 13, 64 (copy on file with the *Michigan Law Review*) (picturing two models in wheelchairs and one on crutches).