

Disability Rights Movement

FROM CHARITY TO CONFRONTATION



Doris Zames Fleischer and Frieda Zames

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Personal Notes

IN THE EARLY 1950s I attended Brooklyn College, located on a campus built in the 1930s in the pseudo-Georgian style of the 1830s. In order to enter the two main buildings, Boylan Hall and Ingersoll Hall—mirror images facing each other across a central quadrangle—I had to go up two steps. On rainy days I was terrified of falling because my crutch tips would slip. Snowy or icy days were worse. Never once at Brooklyn College did I think that those two steps in any way could be changed. I had to make do as best I could. I thought that it was my responsibility to fit in. I felt lucky just going to college since relatively few people with disabilities had such an opportunity at that time. It never occurred to me to ask for anything, certainly not to make demands—not even for a banister.

Why did most people with disabilities of my generation and many that followed—some of whom even gained considerable prominence in the modern disability rights movement—make the same assumption that I did? What caused the leap in consciousness of people with disabilities in the 1970s? How did this new vision give birth to a civil rights movement for people with disabilities? How has this civil rights movement affected people with disabilities as well as the wider society? These are the questions that inform this book.

-Frieda Zames

The most important thing that ever happened to me occurred two years before I was born. My sister (and now my coauthor) contracted polio. Despite her stay in a hospital and convalescent home during my first five years, she was always a presence in my life. In our home, my entire family and our circle of friends celebrated every one of my absent sister's birthdays. My parents even "conned" me into thinking that each of the frequent long train and bus rides that we took to visit her was a treat. Although I was too young to be allowed into the hospital, I loved standing outside and waving to her, for to me she was Rapunzel high up in the tower. When she came home and solved my problems and taught me how to fight back, I imagined myself the hero for rather absurdly holding up my five-year-old fingers to traffic in the middle of the rather empty streets near our house as she slowly crossed using her crutches and braces.

The much publicized Chair in Bioethics at Princeton's Center for Human Values, Peter Singer, wrote in *Practical Ethics*, a book he assigned in his course at the university: "When the death of a disabled infant will lead to the birth of another infant with better prospects

of a happy life, the total amount of happiness will be greater if the disabled infant is killed." If my parents somehow could have known that at two and a half my sister would become disabled, and had they chosen the path that Professor Singer prescribes, would his Benthamesque vision of the greatest good for a greatest number have been achieved? To respond to this question, I think of the many nondisabled people I know who have not lived lives as productive or fulfilling or happy as my sister's. When I consider her social roles as mathematics professor and disability rights activist, her loving personal relationships, and the daily lessons in living I have learned from her, I don't know about that other sibling who might have taken her place. And the point is, neither does Professor Singer. But I do know one thing for certain. I'm not ready to trade her in.

-Doris Zames Fleischer

Preface

IN THE ANATOMY OF PREJUDICE (1996),¹ Elisabeth Young-Bruehl analyzes what she believes to be "the four prejudices that have dominated American life and reflection in the past half-century—anti-Semitism, racism, sexism, and homophobia." No reference is made to disability discrimination. Misrepresented as a health, economic, technical, or safety issue rather than discrimination, prejudice based on disability frequently remains unrecognized.

Although disability bias impacts upon a great many people, often with devastating consequences, Young-Bruehl's omission is not surprising. R. C. Smith, author of *A Case About Amy* (1996)³—an analysis of the 1982 Supreme Court ruling that denied a public school accommodation of a full-time sign-language interpreter for Amy Rowley, an extremely intelligent, profoundly deaf child—observes:

Unkind words against homosexuals, African-Americans, Hispanics, and other minorities at least prompt rebuke from people who, though not members of these stigmatized groups, still recognize the prejudice. But prejudice against individuals with disabilities commonly goes undetected by a general public too unaware of its own feelings to recognize what has been said or written as prejudicial.⁴

Perhaps this oversight stems from a collective fear of disability since everyone is subject to illness, accident, the declining powers of advanced age—all forms of human vulnerability. "Handicapism," also referred to as "ableism," is the only "ism" to which *all* human beings are susceptible.⁵

This denial of the reality of disability results in stereotypes that continue to prevail. Films present people with disabilities either condescendingly as "inspirational," endeavoring to be as "normal" as possible by "overcoming" their limitations, or as disfigured monsters "slashing and hacking their way to box office success." The inspirational figure hearkens back to Tiny Tim from Dickens's A Christmas Carol, a receptacle for the pity of those who did not have poor Tim's misfortune. In fact, "in the nineteenth century notion of charity, afflicted [the term used at the time for the disabled] people might be said to be created in order to provide opportunities for Christian folk to exercise their Christian virtue." In the process, the lucky nondisabled could surreptitiously celebrate their superiority while simultaneously imagining that, by means of their charity, they were imitating the life of Christ.

When the authors of this book began their work over five years ago, the issue of disability rights had not yet entered into the public consciousness. Although President George Bush had signed the Americans with Disabilities Act (ADA) in 1990, which gave people with disabilities many of the same civil rights won by other groups, the struggle of the disability community to secure these rights appeared to lack the drama of the struggles of African Americans or women and indeed did lack the media attention. Even the controversy regarding an appropriate memorial for Franklin Delano Roosevelt, which did attract media attention, pointed to the surprising *invisibility* of disability and to a lack of awareness of the profound separation of images of power (the Presidency) and images of disability (the wheelchair). Disappointing as actor Christopher Reeve's emphasis on spinal cord regeneration, rather than disability rights, has been to many in the disability community, his struggle—after an accident left him quadriplegic—did catch the attention of a public watching a superman who once flew, but now cannot walk, re-create his life.

Until recently, the media did not seem cognizant of the significant number of people with disabilities in the United States (not to mention the rest of the world), nor the degree to which "invisible disabilities" such as psychiatric disorders, heart disease, diabetes, cancer, and learning disabilities predominate over visible ones. According to 1994–1995 data, over 20 percent of Americans—fifty-four million—were disabled, with almost half of them having severe disabilities.⁸ As a consequence of medical and technological progress, the disability and the aging populations will continue to grow. It is not surprising that as people age, the probability increases that they will become disabled, and the likelihood of that impairment being severe also increases. What is surprising is the prevalence of disability for specific age groups: almost one-fourth of people forty-five to fifty-four, over one-third of those fifty-five to sixty-four, almost one-half of those sixty-five to seventy-nine, and almost three quarters of those eighty years and above.

The public's avoidance of acknowledging the ever-threatening possibility—and after a certain age, probability—of disability is not unexpected. Yet, the results of a 1998 study—indicating that even for adults with disabilities, only 54 percent have heard of the ADA9—reveals that despite the social and political gains achieved by disability activists in the past twenty years, the educational challenges ahead are significant. For example, the failure to select a handicapped-accessible site for the December 3, 1997, Presidential Conference on Race in Akron, Ohio, illustrates how often the pervasiveness of disability is unappreciated; officials did not consider that people with disabilities are included among racial minorities.

Almost a decade after passage of the ADA, this landmark legislation fueled by the civil rights movement is being seriously challenged in the courts. In 1999, the U.S. Supreme Court ruled in three separate employment cases that physical impairments that can be controlled by medication or assistive devices did not constitute a "disability" under the Americans with Disabilities Act. More threatening, however, to the viability of the ADA are challenges to the constitutionality of Title II of this law. In the year 2001, the Supreme Court is expected to rule in *Garrett v. University of Alabama* on whether Congress has the authority under the "equal protection" clause of the Fourteenth Amendment to ban discrimination by states against individuals with disabilities. In 2000, the Court, in *Kimel v. Florida Board of Regents*, invoking the doctrine of "sovereign immunity" as embodied in the Eleventh Amendment, held that Congress lacked the power to require states to pay damages for violations of another federal statute—the Age Discrimination in Employment Act. A decision against plaintiff Garrett could eliminate Title II's ban on discrimination

against people with disabilities by state or local governments in any sphere—employment, access to public services, education, health care, or other programs administered by states and localities.¹⁰

Because many people with disabilities require "reasonable accommodation" under the ADA in order to achieve equality, civil rights for this population are in jeopardy. While critics of the ADA overestimate the cost of such accommodation, they also underestimate the cost of discrimination, not only to individuals with disabilities, but also to society in general. The U.S. Senate recognized this frequently untapped potential in people with disabilities when, on June 16, 1999, it passed by a vote of 99 to 0 the long-overdue Work Incentives Improvement Act permitting those who require health care benefits to work without losing such benefits. On that occasion Senator Edward M. Kennedy (D-Mass.) declared, "We must banish the patronizing mind-set that disabled people are unable. In fact, they have enormous talent, and America cannot afford to waste an ounce of it." This book is an effort to document the enormous talent that brought forth the disability rights movement.

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Chronology

1817

	Connecticut.
1829	Louis Braille invents the raised dot system for the blind known as Braille.
1841	Dorothea Dix begins her efforts to improve conditions for people with
	disabilities incarcerated in jails and poorhouses.
1864	The National Deaf-Mute College-known as Gallaudet College in 1954 and later
	Gallaudet University—is established.
1880	The Congress of Milan bans the use of sign language in schools for deaf people.
	The National Association of the Deaf is founded.
1903	Helen Keller publishes her autobiography, The Story of My Life.
1904	Winifred Holt Mather establishes Lighthouse No. 1 for blind people in New York
	City, the first of many throughout the world.
1909	Clifford Beers, author of A Mind That Found Itself, organizes The National
	Committee for Mental Hygiene, later known as The National Mental Health
	Association.
1914	The War Risk Insurance Act becomes law.
1917	The Smith-Hughes Vocational Education Act becomes law.
1918	The Smith-Sears Veterans Rehabilitation Act becomes law.
1920	Disabled American Veterans of the World War is founded—later known as
	Disabled American Veterans.
_	The Smith-Fess Vocational Rehabilitation Act becomes law.
1921	The American Foundation for the Blind is founded.
_	Franklin Delano Roosevelt contracts polio.
	The United States Veterans Bureau is established—later known as the
	Department of Veterans Affairs.
1922	Edward F. Allen establishes the National Easter Seal Society in Elyria, Ohio.
1923	Henry Kessler, a pioneer in rehabilitation medicine, initiates surgical techniques
	that allows muscular control of artificial limbs.
1927	Franklin Delano Roosevelt co-establishes the Warm Springs Foundation.
1929	Dorothy Harrison Eustis and Morris Frank found Seeing Eye, the first guide dog
	training school in the United States.

The first school for deaf students in the United States is established in Hartford,

- National Easter Seal Society establishes Rehabilitation International.
- 1932 Franklin Delano Roosevelt is elected President of the United States.
- 1935 The League of the Physically Handicapped is organized; it disbands in 1938.
- The Social Security Act, providing federal old age benefits and grants to the states for assistance to blind people and children with disabilities, becomes law.
- 1937 The March of Dimes is founded.
- The National Foundation for Infantile Paralysis is founded.
- 1940 Jacobus tenBroek organizes the National Federation of the Blind in Wilkes-Barre, Pennsylvania.
- 1943 The Barden-LaFollette Act dealing with vocational rehabilitation becomes law.
- 1947 Paralyzed Veterans of America is organized.
- Tim Nugent initiates services and a sports program for students with disabilities at the University of Illinois, and the university institutes a paratransit system on its wheelchair accessible campus.
- United Cerebral Palsy Association, uniting all local cerebral palsy organizations in the United States, is founded.
- 1950 Elizabeth Boggs forms a parents' group working for improved services for children with developmental disabilities.
- Gunnnar Dybwad and others organize the Association of Retarded Citizens, which later develops branches throughout the United States and the world.
- 1951 Howard Rusk opens the Institute of Rehabilitation Medicine at the New York University Medical Center in New York City.
- 1955 Jonas Salk develops the first successful polio vaccine.
- A law is enacted enabling people aged fifty or older to qualify for Social Security Disability Insurance.
- The Social Security disability program is amended to allow people under fifty to quality for Social Security Disability Insurance.
- William Stokoe's paper on Sign Language Structure legitimizes American Sign Language and ushers in the movement of Deafness as culture.
- 1961 Former members of the National Foundation for the Blind found a new organization, the American Council of the Blind.
- 1962 Edward Roberts sues to gain admission to the University of California, the same semester that James Meredith requires a lawsuit to become the first black person to attend the University of Mississippi.
- The Civil Rights Act, which will impact significantly on subsequent disability rights legislation, becomes law.
- 1965 The Social Security Act is amended, establishing Medicare and Medicaid.
- 1968 The federal Architectural Barriers Act becomes law.
- Prodded by Harold Willson, the California state legislature guarantees that the Bay Area Rapid Transit system will be the first rapid transit system in the United States to accommodate wheelchair users.
- 1970 Judith E. Heumann organizes Disabled In Action in New York City.
- The Urban Mass Transportation Assistance Act becomes law.
- The Mental Patients Liberation Project is initiated in New York City, and similar projects begun by "psychiatric survivors" emerge throughout the nation.

- Amendments to the Social Security Act allow recipients of disability benefits under the age of sixty-five to qualify for Medicare.
- The appalling conditions at Willowbrook State School in New York City for people with developmental disabilities are exposed as the result of a television broadcast from the facility.
- Demonstrations are held in Washington, D.C., by disability activists protesting President Nixon's veto of what will become the Rehabilitation Act of 1973.
- Guide Dog Users is organized in New York City.
- Passage of amendments to the Social Security Act creates the Supplemental Security Income program.
- Edward Roberts establishes the Center for Independent Living in Berkeley, California—a symbol of the Independent Living Movement emerging throughout the nation and the world.
- U.S. District Court for the District of Columbia decides in *Mills v. Board of Education* that every school-age child is entitled to a free public education regardless of the nature or severity of the individual's disability.
- The Architectural and Transportation Barriers Compliance Board—later known as the Access Board—is established under the Rehabilitation Act of 1973 to enforce the Architectural Barriers Act of 1968.
- The Rehabilitation Act of 1973, including Section 504, becomes law.
- The first convention of People First—the largest U.S. organization of and led by people with developmental or cognitive disabilities—is held in Salem, Oregon.
- 1975 The American Coalition of Citizens with Disabilities is organized in Washington, D.C.
- Wade Blank relocates adults with severe disabilities from a nursing home into apartments, initiating what will become the Denver, Colorado, Atlantis Community.
- The Education for All Handicapped Children Act, later known as the Individuals with Disabilities Education Act, becomes law.
- Edward Roberts becomes director of the California Department of Rehabilitation.
- James Cherry wins lawsuit (*Cherry v. Mathews* in U.S. District Court for the District of Columbia) requiring that the Secretary of Health, Education, and Welfare develop and promulgate Section 504 regulations.
- *Disabled In Action of Pennsylvania v. Coleman* (known as the Transbus lawsuit) is filed in the Eastern District of Pennsylvania.
- 1977 Following nationwide demonstrations by disability activists, HEW Secretary Joseph Califano signs the regulations for Section 504 and the Individuals with Disabilities Education Act.
- *Lloyd v. Regional Transportation Authority* is decided in U.S. Court of Appeals for the Seventh Circuit, establishing a private right of action under Section 504.
- 1979 U.S. Supreme Court decides *Southeastern Community College v. Davis*, a suit impacting on accessible public transportation.
- Disability Rights Education and Defense Fund is founded in Berkeley, California.
- The National Alliance for the Mentally Ill is founded in Madison, Wisconsin.
- 1980 Black Deaf Advocates is founded.

- The year is designated as the International Year of Disabled Persons by the United Nations.
- The U.S. Supreme Court decides in *Hendrick Hudson Central School District v. Rowley* that there is "no Congressional intent to achieve strict equality of opportunity or services" in the Individuals with Disabilities Education Act.
- ADAPT, denoting American Disabled for Accessible Public Transit, is organized.
 Edward Roberts and Judith E. Heumann (together with Joan Leon) organize the World Institute on Disability in Oakland, California.
- 1984 The National Council on Disability becomes an independent federal agency.
- The U.S. Supreme Court decides in the Baby Jane Doe case (*Bowen v. American Hospital Association*) that parents' refusal of needed surgery does not violate Section 504.
- Irving Zola founds the Society for Disability Studies.
- 1988 The Gallaudet University uprising results in its first deaf president, I. King Jordan.
- The Fair Housing Act is amended to include people with disabilities.
- Civil Rights Restoration Act becomes law, in effect overturning the U.S. Supreme Court's 1984 Grove City College v. Bell decision regarding the discrimination on the basis of sex in federally assisted education programs or activities.
- 1989 *ADAPT v. Skinner*—decided by the U.S. Court of Appeals for the Third Circuit—helped pave the way for accessibility of public transportation.
- Ralf Hotchkiss establishes the Wheeled Mobility Center at San Francisco State College, from which his International Wheelchair Program emanates.
- Ronald Mace establishes the Center for Universal Design in Raleigh, North Carolina.
- Daniel R. R. v. State Board of Education (Fifth Circuit) in Texas—the first of four significant inclusion cases (from 1989 to 1994) involving children with developmental disabilities—results in consistent legal decisions that the Individuals with Disabilities Education Act mandated the integration of these children into regular classes with full supports.
- 1990 ADAPT now denotes American Disabled for Attendant Programs Today as the organization focuses on a new primary purpose.
- President George Bush signs the Americans with Disabilities Act into law.
- The American Association of People with Disabilities is established in Washington, D.C.
- Diane Coleman and others organize Not Dead Yet to oppose Jack Kevorkian and supporters of physician-assisted suicide.
- Justin Dart and others organize Justice For All in Washington, D.C.
- Billy Golfus's film, When Billy Broke His Head—a personal view of the disability rights movement—premiers on public television.
- The paradigm shift in scientists' characterization of the development of AIDS begins the process of changing AIDS from a fatal disease into a chronic one.
- Veterans Health Care Eligibility Reform Act (dealing with Vietnam veterans) becomes law.
- The U.S. Supreme Court validates the state prohibition on physician-assisted suicide in *Vacco v. Quill* and *Washington v. Glucksberg*, while deciding that this issue

- is properly within the jurisdiction of the states.
- 1998 Persian Gulf War Veterans Act becomes law.
- The U.S. Supreme Court decides in its first Americans with Disabilities Act case, Bragdon v. Abbott, that the act's definition of disability includes asymptomatic HIV.
- The U.S. Supreme Court decides in *Pennsylvania Department of Corrections v. Yeskey* that the Americans with Disabilities Act covers state prisons.
- The U.S. Supreme Court decides in *Carolyn C. Cleveland v. Policy Management Systems Corp.*, *et al.* that people receiving Social Security disability benefits are protected against discrimination under the Americans with Disabilities Act if and when they are able to return to the work force.
- The U.S. Supreme Court decides in *Olmstead v. L.C. and E.W.* that individuals with disabilities must be offered services in the "most integrated setting."
- The U.S. Supreme Court decides in three employment cases, Sutton et al. v. United Air Lines, Inc., Murphy v. United Parcel Service, Inc., and Albertsons, Inc. v. Kirkingburg that individuals whose conditions do not substantially limit any life activity and/or are easily correctable are not disabled according to the Americans with Disabilities Act.
- The Work Incentives Improvement Act, allowing to work those who require health care benefits, becomes law.

Abbreviations and Acronyms

AAPD American Association of People with Disabilities

AARP American Association of Retired People

ABA Applied Behavioral Analysis **ACB** American Council of the Blind

American Coalition of Citizens with Disabilities ACCD

American Civil Liberties Union **ACLU**

ACRMD Association of Children with Retarded Mental Development

AIDS Coalition To Unleash Power Act-Up **ADA** Americans with Disabilities Act

American Disabled for Accessible Public Transit, later American Disabled for ADAPT

Attendant Programs Today

American Foundation for the Blind AFB AHCA American Health Care Association AHRC

Association for Help of Retarded Children

AIDS autoimmune deficiency syndrome ALS amyotrophic lateral sclerosis American Medical Association AMA

American National Standards Institute ANSI APTA American Public Transit Association

ARC Association of Retarded Citizens (currently known as The Arc)

ASL American Sign Language BART Bay Area Rapid Transit

BCID Brooklyn Center for Independence of the Disabled

Boston Center for Independent Living BCIL

Black Deaf Advocates BDA

CARR Committee Against Right on Red CHIP Child Health Insurance Program CIA Central Intelligence Agency

Center for Independence of the Disabled in New York CIDNY CIL Center for Independent Living (Berkeley, California)

DAV Disabled American Veterans

XXVIII ABBREVIATIONS AND ACRONYMS

DAVWW Disabled American Veterans of the World War

DIA Disabled In Action
DNR do-not-resuscitate (order)

DREDF Disability Rights Education and Defense Fund

DSP Disabled Students Program

EEOC Equal Employment Opportunity Commission EPSDT Early Periodic Screening, Diagnosis and Testing

EPVA Eastern Paralyzed Veterans Association

ERB Emergency Relief Bureau

FAHA Federal Aid Highway Administration FDA Food and Drug Administration

GMHC Gay Men's Health Crisis

HCFA Health Care Financing Administration

HEW U.S. Department of Health, Education, and Welfare

HILC Harlem Independent Living Center HMO health maintenance organization

HPLSU Handicapped Persons Legal Support Unit

HUD U.S. Department of Housing and Urban Development

ICD Institute for the Crippled and Disabled, later International Center for the

Disabled

IDEA Individuals with Disabilities Education Act

IEP individualized educational plan

IL independent living

ILC independent living center

ILRU Independent Living Research Utilization (program)

IYDP International Year of Disabled Persons

JFA Justice For All
JOB Just One Break
LD learning disability
LIU Long Island University
LRE least restrictive environment

MiCasa Medicaid Community Attendant Services Act

MiCassa Medicaid Community Attendant Services and Supports Act

MSA Medical Savings Account

MTA Metropolitan Transportation Authority (New York City)

NAAV National Association of Atomic Veterans

NAD National Association of the Deaf NAMI National Alliance for the Mentally Ill NCD National Council on Disability NFB National Federation of the Blind NIH National Institutes of Health NMHA National Mental Health Association

NOD National Organization on Disability
NYLPI New York Lawyers for the Public Interest

NYSCPD New York State Coalition of People with Disabilities

OVR Office of Vocational Rehabilitation

PARC Pennsylvania Association for Retarded Children

PH physically handicapped

PVA Paralysed Veterans of America
QILC Queens Independent Living Center
SABE Self Advocates Becoming Empowered

SDS Society for Disability Studies

SILC Statewide Independent Living Council

SKIP Sick Kids Need Involved People
SSDI Social Security Disability Insurance
SSI Supplemental Security Income

TAB temporarily ablebodied

TDD telecommunication device for the deaf

TT text telephone TTY teletypewriter

UCP United Cerebral Palsy (local organizations)

UCPA United Cerebral Palsy Association (national organization)

UMTA Urban Mass Transportation Administration

USDOT U.S. Department of Transportation

VA Veterans Administration

VESID Vocational and Educational Services for Individuals with Disabilities

WID World Institute on Disability
WIIA Work Incentives Improvement Act

WIN Wheelchair Independence Now, later Win Independence Now

WPA Works Progress Administration