

# NO PITY

---

## People with Disabilities Forging a New Civil Rights Movement

Joseph P. Shapiro



R A N D O M H O U S E

*For my parents,  
Gertrude and Harold Shapiro,  
and for Suzanne*

Copyright © 1993, 1994 by Joseph P. Shapiro  
All rights reserved under International and Pan-American Copyright Conventions. Published  
in the United States by Times Books, a division of Random House, Inc., New York, and  
simultaneously in Canada by Random House of Canada Limited, Toronto.

*This work was originally published in hardcover and in a slightly different form by Times  
Books, a division of Random House, Inc.*

*Grateful acknowledgment is made to The New York Times for permission to reprint excerpts  
from "Aiding the Disabled: No Pity Please" by Evan Kemp from the September 3, 1981 Op-Ed  
page of The New York Times. Copyright © 1981 by the New York Times Company.  
Reprinted by permission of The New York Times.*

*Library of Congress Cataloging-in-Publication Data*

*Shapiro, Joseph P.*

*No pity : people with disabilities forging a new civil rights movement /  
Joseph P. Shapiro.*

*p. cm.*

*Includes index.*

*ISBN 0-8129-2412-6*

*1. Handicapped—Civil rights—United States. 2. Discrimination  
against the handicapped—United States—History. 3. Handicapped—  
Government policy—United States—History. I. Title.*

*HV1553.S52 1993*

*323.3—dc20*

*92-34751*

*Manufactured in the United States of America*

*9 8 7 6 5 4 3*

## Introduction

*You Just Don't Understand*

Nondisabled Americans do not understand disabled ones.

That was clear at the memorial service for Timothy Cook, when longtime friends got up to pay him heartfelt tribute. "He never seemed disabled to me," said one. "He was the least disabled person I ever met," pronounced another. It was the highest praise these nondisabled friends could think to give a disabled attorney who, at thirty-eight years old, had won landmark disability rights cases, including one to force public transit systems to equip their buses with wheelchair lifts. But more than a few heads in the crowded chapel bowed with an uneasy embarrassment at the supposed compliment. It was as if someone had tried to compliment a black man by saying, "You're the least black person I ever met," as false as telling a Jew, "I never think of you as Jewish," as clumsy as seeking to flatter a woman with "You don't act like a woman."

Here in this memorial chapel was a small clash between the reality of disabled people and the understanding of their lives by

others. It was the type of collision that disabled people experience daily. Yet any discordancy went unnoticed even to the well-meaning friends of a disability rights fighter like Cook. To be fair to the praise givers, their sincere words were among the highest accolade that Americans routinely give those with disabilities. In fairness, too, most disabled people gladly would have accepted the compliment some fifteen years before, the time when the speakers' friendships with Cook had begun. But most people with disabilities now think differently. It is not that disabled people are overly sensitive. But as a result of an ongoing revolution in self-perception, they (often along with their families) no longer see their physical or mental limitations as a source of shame or as something to overcome in order to inspire others. Today they proclaim that it is okay, even good, to be disabled. Cook's childhood polio forced him to wear heavy corrective shoes, and he walked with difficulty. But taking pride in his disability was for Cook a celebration of the differences among people and gave him a respectful understanding that all share the same basic desires to be full participants in society.

Never has the world of disabled people changed so fast. Rapid advances in technology, new civil rights protections, a generation of better-educated disabled students out of "mainstreamed" classrooms, a new group consciousness, and political activism mean more disabled people are seeking jobs and greater daily participation in American life. But prejudice, society's low expectations, and an antiquated welfare and social service system frustrate these burgeoning attempts at independence. As a result, the new aspirations of people with disabilities have gone unnoticed and misunderstood by mainstream America. This book attempts to explain, to nondisabled people as well as to many disabled ones, how the world and self-perceptions of disabled people are changing. It looks at the rise of what is called

the disability rights movement—the new thinking by disabled people that there is no pity or tragedy in disability, and that it is society's myths, fears, and stereotypes that most make being disabled difficult.

There are hundreds of different disabilities. Some are congenital; most come later in life. Some are progressive, like muscular dystrophy, cystic fibrosis, and some forms of vision and hearing loss. Others, like seizure conditions, are episodic. Multiple sclerosis is episodic and progressive. Some conditions are static, like the loss of a limb. Still others, like cancer and occasional paralysis, can even go away. Some disabilities are "hidden," like epilepsy or diabetes. Disability law also applies to people with perceived disabilities such as obesity or stuttering, which are not disabling but create prejudice and discrimination. Each disability comes in differing degrees of severity. Hearing aids can amplify sounds for most deaf and hard-of-hearing people but do nothing for others. Some people with autism spend their lives in institutions; others graduate from Ivy League schools or reach the top of their professions.

Medicine once promised to wipe out disability by finding cures. Instead, doctors only spurred a disability population explosion by keeping people alive longer. In World War I, only four hundred men survived with wounds that paralyzed them from the waist down, and 90 percent of them died before they reached home. But in World War II, two thousand paraplegic soldiers survived, and over 85 percent of them were still alive in the late 1960s. The development of antibiotic drugs and new medical procedures improved the odds. As recently as the 1950s, death remained likely in the very early stages of a spinal cord injury as a result of respiratory, bladder, and other health complications. Now doctors neutralize those problems, and paraplegics and quadriplegics can live long, healthy lives.

Similarly, after World War II, the development of chemotherapy from wartime gas experiments allowed many people to

survive cancer. Insulin allowed others to live with diabetes. And in the 1980s, hospital trauma centers modeled after Vietnam War helicopter evacuation units began saving people with severe head injuries from auto accidents and other traumas. In the mid-1970s, 90 percent of people with severe head injuries died; today 90 percent live. Premature babies born at twenty-three or twenty-four weeks old, instead of the usual forty weeks, live now, too. The world's smallest baby, weighing 9.9 ounces, was saved by doctors in Chicago in 1989. In the early 1980s, it was a rarity for extremely low birth-weight infants to survive. Today, almost 50 percent weighing as little as one pound, two ounces, to one pound, ten ounces, survive, and the majority will have some disabling neurological condition.

The graying of America, too, expands the ranks of the disabled. One-third of disabled Americans are sixty-five or older. Today, 32 million Americans, or about 13 percent of the population, are over age sixty-five; by the year 2020 the older population is expected to hit 51 million people, or 17 percent. This will bring about an increase in potentially disabling chronic conditions such as cardiovascular disease and rheumatoid arthritis, as well as cancer. But older people have avoided affiliation with the disability rights movement. They have grown up with prejudices about a disabled life being a sad and worthless one. Many fear the same stigma will be used to take away their independence. The concerns of disabled and older people overlap—both seek to maximize independence and stay out of institutions—and the two could become forceful allies. But the shame of disability will have to ease first.

There are some 35 million to 43 million disabled Americans, depending on who does the counting and what disabilities are included. In 1991 the Institute of Medicine, using federal health survey data, came up with a total of 35 million—one of every seven Americans—who have a disability that interferes with daily activities like work or keeping a household. "Disability

ranks as the nation's largest public health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large," the report concludes.

During debate on the Americans with Disabilities Act, lawmakers, President Bush, advocates, and members of the media freely used the higher figure of 43 million. That number came from other federal data. But even this figure did not include people with learning disabilities, some mental illness, those with AIDS, or people who are HIV positive and have other conditions covered under the civil rights legislation. A 1994 census report counted 49 million. Researchers cannot agree on the size of the disability population because they have no consensus on what constitutes disability, notes Mitchell LaPlante of the Disability Statistics Program. Most researchers like LaPlante use activity limitation as the definition. Many disability rights advocates, however, include health conditions that may not be limiting but still stigmatize or cause discrimination, like having had cancer. Some even looser estimates that include any disease or chronic health condition count 120 million or more disabled Americans. Some 31 million Americans, for example, have arthritis, but it limits the activities of only 7 million.

There are some 30 million African-Americans. So, even at the lowest estimate, disabled people could be considered the nation's largest minority. Not all disabled people, however, see themselves as part of a minority group. Many even deny they are disabled, to avoid the taint accompanying that label.

Disability, however, is the one minority that anyone can join at any time, as a result of a sudden automobile accident, a fall down a flight of stairs, cancer, or disease. Fewer than 15 percent of disabled Americans were born with their disabilities. "Disability knows no socioeconomic boundaries," notes Patrisha Wright, the Washington lobbyist for the Disability Rights Education and Defense Fund. "You can become disabled from your mother's poor nutrition or from falling off your polo pony."

And since disability catches up with most of us in old age, it is a minority that we all, if we live long enough, join. "It doesn't matter if your name is Kennedy or Rockefeller, or Smith or Jones, your family's been touched," says Wright.

My own look at disability culture began with a simple phone call in 1988, the type that reporters get daily, from a public relations woman. Would I write about a man whom her group, the National Multiple Sclerosis Society, had flown to New York to honor as their Man of the Year? They had put him up in a hotel across the street from the club where he was to be feted. But getting across the street had been bizarrely difficult. There were no curb cuts at the end of the block, making his hotel a remote island in the middle of Manhattan. Taxicabs could not pick up the man's heavy battery-powered wheelchair. Buses lacked wheelchair lifts. So the MS Society had hired a van with a special hydraulic lift simply to transport this man across the street. It was an interesting story, but not something that I could write for my weekly newsmagazine. I was looking, I explained, for something with broad national significance, something important that was happening in the lives of all disabled people throughout the country. The persistent PR woman, Arney Rosenblat, called back. There was something gathering momentum around the country called the disability rights movement, she said. That very week in Washington, members of an obscure government council were meeting to complete their version of the Americans with Disabilities Act, a bill to give disabled people the civil rights protection that had already been extended to blacks, women, and ethnic minorities.

A few days later, I sat in a conference room in a modern marble-and-glass Washington hotel where two dozen men and women had come together to finish writing the bill. In Washington, drafting legislation is an everyday occurrence. And this bill was being written by an utterly anonymous presidentially appointed council. However laudable their goal, the members

were putting together dreamy, pie-in-the-sky legislation. Lobbyists for business groups were already lined up to crush it. Congress and the White House would pay it no more than passing attention.

Yet I was drawn in by the impassioned talk in the room. Disabled people were a vast minority group, it was being argued, oppressed by discrimination. Some of the obvious disabilities were represented on the council: spinal cord injuries, hearing loss, neuromuscular diseases like muscular dystrophy, polio, and visual impairments.

Even more enticing to me was that this civil rights legislation was being drafted by thirteen politically conservative members of an unnoted federal council, all of whom had been appointed by President Ronald Reagan. The Reagan Administration had always seemed hostile to civil rights causes. Now, members of the National Council on the Handicapped, out of step with the president who had chosen them, were drafting a sweeping civil rights bill.

Still, while this was interesting, I was not sure that I saw a story. I left the hotel. The U.S. Capitol rose majestically a few blocks to the south. Outside the hotel lobby, I stood in a line for a taxi. Behind me came a young man in a suit, pushing the wheels of his bright orange wheelchair. There were two cabs at the curb. The doorman signaled for the first cab in line, which drove up the circular drive to pick me up. The second taxi, a station wagon, started moving too. But then the driver jerked the vehicle in an abrupt U-turn and sped off down the avenue toward the Capitol. As I got into my cab, I glanced back at the man in the wheelchair, now waiting to see if another taxi would come along. His face showed no anger, no emotion at all, as if getting passed up by cabdrivers was an everyday occurrence. I was reminded of the MS Society's Man of the Year, unable to cross the street in one of the world's most modern cities, stranded without transportation. The cabdriver had spotted the

man's wheelchair. He did not want to be bothered helping to fold the man's chair and lift it into the back of the station wagon. If not for cabs, how would this man get back to his office or to his home? Few buses in Washington had wheelchair lifts. The subway system was accessible, assuming the elevator at his stop was working. But the subway reached only some parts of the city. Access to transportation, then, would circumscribe where the man lived and where he worked, or if he even worked at all. If people like him were precluded from working, then they would depend on welfare. If a society expected its disabled people not to work and instead need public assistance, would it even try to give them a decent education? Back at my office, I began writing my first story about disability as a rights issue.

My next epiphanic encounter with the disability rights movement would come just a few weeks later, in March of 1988, when students at Gallaudet University, the nation's only four-year liberal arts school for the deaf, demanded the selection of the first deaf president in the school's 124-year history. When the one hearing candidate was chosen instead, outraged students protested, closing down the school. It was hypocritical, students told me, for a school that boasted of readying deaf students for the world to think a deaf educator unfit to lead them. Once again, I was intrigued, this time by the moral certainty of these students rebelling against the paternalistic attitudes of school officials.

From these beginnings, I set out to understand the new point of view of disabled Americans. In the five years since, I have conducted over two thousand interviews with several hundred people. In the course of that work, I took a one-year sabbatical, on a fellowship from the Alicia Patterson Foundation, specifically to study the disability rights movement. As a journalist covering social policy issues for *U.S. News & World Report*, I found that there was a disability angle to any subject I covered, from access to health care to aging, from abortion to prenatal care, from education to work, from welfare to civil rights.

I also discovered a unique movement that had much to teach other social and civil rights movements. The disability movement is a mosaic movement for the 1990s. Diversity is its central characteristic. No one leader or organization can claim to speak for all disabled people. It is accepted, as a matter of course, that members of the disability cause will hold shades of belief and not hew to an overriding orthodoxy. All social crusades are made up of people with complex and varying opinions. But today the black civil rights and feminist movements, in particular, are perceived as struggling with such diversity of thought and weakened by challenges to traditional thinking. The result is to diminish our appreciation of the enormous change each cause has brought about. Without one highly visible leader, the disability movement has gone largely unnoticed by nondisabled people. But by its acceptance of differences, the campaign for disability rights has forged a powerful coalition of millions of people with disabilities, their families, and those that work with them. People with disabilities have been a hidden, misunderstood minority, often routinely deprived of the basic life choices that even the most disadvantaged among us take for granted. In the last twenty to thirty years, little noticed alongside the civil rights struggles of African-Americans, women, gays and lesbians, and other minorities, another movement has slowly taken shape to demand for disabled people the fundamental rights that have already been granted to all other Americans. It has led to the emergence of a group consciousness, even the start of a disability culture, which did not exist nationally even as recently as the late 1970s.

This book is in part a chronicle of the formation of this movement and the issues and identities that define it. At the same time, I hope to help draw attention to the political and social issues that have yet to be resolved. There is potent and widespread support for the movement's accomplishments and goals among disabled people, their families, and friends, and even many of the charity and professional groups that are so often the target of the movement's anger, but the struggle is far from over.

CHAPTER I

## TINY TIMS, SUPERCRIIPS, AND THE END OF PITY

**T**he poster child is a surefire tug at our hearts. The children picked to represent charity fund-raising drives are brave, determined, and inspirational, the most innocent victims of the cruelest whims of life and health. Yet they smile through their “unlucky” fates—a condition that weakens muscles or cuts life expectancy to a brutish handful of years, a birth “defect” or childhood trauma. No other symbol of disability is more beloved by Americans than the cute and courageous poster child—or more loathed by people with disabilities themselves.

“Pity oppresses,” complains Cyndi Jones, who publishes and edits *Mainstream*, a national disability magazine. No other symbols of disability play up pity more, Jones says, than charity telethons and their poster children. Jones should know; she is a former poster child herself.

Jones remembers feeling like Cinderella when, at age five,

she was chosen as the March of Dimes poster girl in St. Louis. It was 1956. A photographer flew in from New York and outfitted her in fine, frilly party dresses. She was kissed by the mayor. Her image—smiling gamely and holding on to her crutches—was painted on a huge billboard in the heart of downtown. She was a television celebrity, too, having appeared on the January telethon. There, she touched hearts—and opened wallets—across St. Louis when she dropped her heavy aluminum crutches at a producer’s instruction and walked a few wobbly and terrifying steps before falling with a clumsy thud to the stage. It was good drama for a telethon, although the young girl had cried at the thought of having to abandon her crutches, knowing she would not get very far.

The Cinderella spell was broken for good a few months later in Jones’s first-grade classroom when her teacher handed out a flyer urging parents to sign up their children for a polio vaccination. PARALYTIC POLIO IS INCREASING AGAIN, declared the headline across the top of the page. VACCINATE YOUR FAMILY NOW AGAINST POLIO. Underneath were two photos. One was of a young brother and sister, holding hands and joyfully skipping through a field. Over their picture was stamped: THIS. Next to them was a picture of Jones, leaning grimly on her braces, hair curled, decked out in one of her new party dresses. The caption over Jones’s picture said: NOT THIS. Jones slid down in her seat, embarrassed, hurt, feeling “invalid,” she recalls, and holding back tears. She hoped none of her classmates would recognize her but knew every one of them would. She now understood with a bitter clarity. It had all been a lie; she was not special—she and her polio were feared.

That Jones and most other disabled people have come to find the poster child an oppressive symbol reflects the fact that a disability rights movement is radically reshaping the world of people with disabilities. The 35 million to 43 million disabled Americans have come to take a growing pride in being identified



as disabled. And, like blacks, women, and gays before them, they are challenging the way America looks at them.

Rejected is society's deeply held thinking of tin cups and Tiny Tim—the idea that disabled people are childlike, dependent, and in need of charity or pity. People with disabilities are demanding rights, not medical cures. To Jones, there is nothing tragic about the childhood polio that resulted in her needing a wheelchair or a three-wheeled, motorized scooter to get around. Disability becomes a tragedy only when she and her husband, Bill Stothers, who also uses a wheelchair, cannot get into a restaurant or are kicked out of a movie theater because the manager decides their scooter and wheelchair make them a “fire hazard,” as happened near their home in San Diego.

But what if a miracle cure were developed overnight? Wouldn't Jones eagerly swallow a magic pill that would wipe away the lingering paralysis of her polio and let her walk again? She answers quickly: No. “It's the same thing as asking a black person would he change the color of his skin,” says Jones. That is not to deny that being disabled is difficult. Some people with disabilities have persistent pain or chronic poor health. Many can count on shortened life expectancies and loss of independence over time. For Jones, as with other polio survivors, there is the fear that her muscles will deteriorate with age and that, in addition to lacking mobility, she will lose the ability to care for herself. Yet, as Jones sees it, “The main thing disabled people need to do is to claim their disability, to feel okay about it. Even if you don't like the way society treats you as a disabled person, it's part of your experience, it's part of how you come to be who you are.”

And that is why the poster child image oppresses. “The poster child says it's not okay to be disabled,” argues Jones. “It plays on fear. It says this could happen to you, your child, or your grandchild. But it says, if you just donate some money, the disabled children will go away.”

The early poster child campaigns of the mid-1940s and

1950s did “evoke images of cure,” says Marilyn Phillips, a Morgan State University professor of folklore who has studied images of poster children. There were never poster adults. Disability was barely tolerable—and only to be pitied—when it struck cute and innocent children. It was unmentionable in adults. The poster child was pictured often on the lap or in the arms of a protective adult, who, the ad copy suggested, could help restore the child's health by donating to the charity. “It was a secular religion. If you sent your money, your dimes, you got miracles. You got cures,” says Phillips, who, like Jones, is another regenerate poster child.

“Then something funny happened: not everybody was cured,” says Phillips. Dr. Jonas Salk invented his polio vaccine, and the fear of polio subsided. But the vaccine did not cure Jones, Phillips, or the other children and adults who already had the virus. “It was promised we'd be fixed and we weren't,” says Phillips. “So something had to be wrong with us,” not with the unrealistic expectation that they would be cured. Disabled children became an affront to the country's postwar faith in “technology and progress—the good old American way,” contends Phillips. Starting in the mid-1950s, she says, there was a new image in the charity poster child campaigns: the valiant “crippled” child on crutches, trying to walk.

Now, says Phillips, disabled children were “damaged goods” who had to “try harder” to prove themselves worthy of charity and society's respect. If science could not cure disabled people, then society would expect them to cure themselves. It would take hard work, determination, and pluck. “It was the Horatio Alger cripple story,” says Phillips. The worthy cripple was expected to overcome his or her disability. “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.”

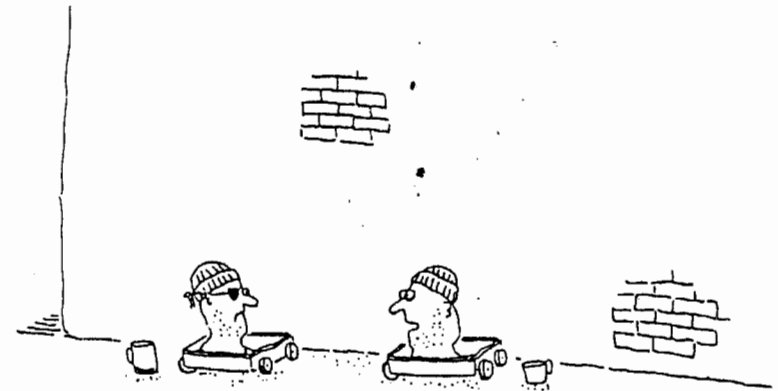
It was not just those with polio but all disabled people who

were expected to overcome in this way. For those with polio, however, this expectation proved to be a bitter irony. The "best" polio patients were those who tried hardest to beat their paralysis by building up other, working muscles. They walked on heavy braces and crutches, although it was exhausting. Those who used a wheelchair because it was easier were reproached as lazy. But in the 1980s, medical specialists began reporting studies of postpolio syndrome, the atrophy of a polio survivor's working muscles as he or she aged. Those who had walked on crutches now had to settle for using wheelchairs. Those who had maneuvered push wheelchairs now traded them in for battery-powered ones. The irony was that the "best" patients, those who had exerted themselves the hardest, later seemed to watch their remaining muscles be eaten away the fastest. Doctors had not advised such early exertion out of any medical certainty that walking was physiologically superior to using a wheelchair, says Phillips. They had done so because sociologically it was expected.

The belief that a disability could be overcome led to the rise of the other ruling image of disability: the inspirational disabled person. It is another model deeply moving to most nondisabled Americans and widely regarded as oppressive by most disabled ones. The disability rights movement discards the notion that people with disabilities should be courageous or heroic superachievers, since most disabled people are trying simply to lead normal lives, not inspire anyone. Many disabled people even use a derisive nickname for such people: "supercrips."

The "supercrip" is the flip side of the pitiable poster child. It is just as hurtful, Jones argues, because it implies that a disabled person is presumed deserving of pity—instead of respect—until he or she proves capable of overcoming a physical or mental limitation through extraordinary feats. Today, these "supercrips" remain among our most glorified disabled role models, lavishly lauded in the press and on television. Such

uncommon achievers have included Mark Wellman, a paraplegic park ranger who won widespread press coverage for climbing granite peaks in Yosemite National Park, and Terry Fox, a cancer survivor whose run across Canada on an artificial leg became television movie fare. (In an arch cartoon by John Callahan, himself a quadriplegic, two heads mounted on skid carts at a street corner beg with tin cups. The first head says to the second, who is identical except that he is wearing an eyepatch, "People like you are a real inspiration to me!") While prodigious achievement is praiseworthy in anyone, disabled or not, it does not reflect the day-to-day reality of most disabled people, who 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.



CALLAHAN  
©1988

"People like you are a real inspiration to me!"

John Callahan cartoon reprinted from *Don't Worry, He Won't Get Far on Foot*, permission of Levin Represents.

Even disabled achievers who do not seek such veneration often have it thrust upon them by an adoring public and press. Baseball pitcher Jim Abbott was cheered sincerely but with a

paternalistic fervor during his rookie season. Because he was born without fingers on his right hand, Abbott has an unconventional way of pitching. He throws with his complete hand, cradling his pitcher's glove on the other. He had taught himself how to move the glove onto his left hand in one swift motion as he completed his pitching delivery. He can catch the ball in his right hand, then whip off the glove, pick out the ball, and throw it with his complete hand. *USA Today* led its sports page with a breathless account of Abbott's first spring training game in March 1989. ABBOTT SHINES IN ARIZONA read the headline atop the story that reported that the pitcher had "flourished," struck out slugger Jose Canseco, and even "made a smooth pivot to nail" a runner at second base. A more restrained accounting from the Associated Press in the same day's *New York Times* carried the headline ABBOTT STRUGGLES IN DEBUT and reported a very different game. The "smooth pivot" was actually a botched play, in which Abbott "allowed a run when he was slow trying to turn a double play." He may have struck out Canseco, but he "struggled" with wildness in the two innings he pitched, during which he gave up a run and walked three batters.

Despite the reverential treatment Abbott got for a mediocre performance, he was not seeking worship. Like most other disabled people, he wanted only to make it in his profession on equal terms with everyone else. Abbott knew that his manager, in search of a pennant, was not going to allow sentimentality to determine his starting pitching rotation. Abbott did make the California Angels that year and went on to prove himself one of the more talented pitchers in professional baseball. Because he made nothing special of his disability, his unorthodox playing style soon became secondary to his earned run average.

While Abbott's acceptance on his own terms may be what disabled people hope for, the poster child and "supercrip" images remain the most significant obstacle to normal interaction between nondisabled and disabled people. Disability rights ac-

tivist Mary Lou Breslin can tell a story of how her own reality clashed with stereotypes and prejudice about disability. Awaiting her flight at the airport, the executive director of the Berkeley-based Disability Rights Education and Defense Fund (DREDF) was sitting in her battery-powered wheelchair, in her dressed-for-success businesswoman's outfit, sipping from a cup of coffee. A woman walked by, also wearing a business suit, and plunked a quarter into the plastic cup Breslin held in her hand. The coin sent the coffee flying, staining Breslin's blouse, and the well-meaning woman, embarrassed, hurried on.

Most disabled people can tell similar stories, like National Public Radio's John Hockenberry. He had been the network's prolific West Coast correspondent. But Hockenberry's bosses and colleagues had never met him until one day, a few years after he had begun filing his reports, he showed up at NPR's Washington headquarters. His appearance was jolting. Hockenberry is a paraplegic. Only a few in the newsroom knew this. How, his fellow correspondents wondered, had a man in a wheelchair managed to cover political races or the exploding Mt. Saint Helens volcano? Then they realized, in a disturbing wave of self-recognition, that had they known of his disability, Hockenberry almost certainly never would have been given such challenging assignments. It would have been assumed that he was not able to cover them.

Our society automatically underestimates the capabilities of people with disabilities, observing what I call the Hockenberry Rule. Or, put differently, a disability, of itself, is never as disabling as it first seems. The only thing that could have kept Hockenberry from being an accomplished reporter would have been the paternalistic assumptions of his colleagues.

According to the thinking of the disability rights movement, it is not so much the disabled individual who needs to change, but society. It may be the automatic assumption that a

man in a wheelchair cannot get around to do his job. Or that a woman in a wheelchair holding a cup of coffee—even if she is a smartly dressed attorney with a briefcase—is a beggar in need of charity. It may be an employer's refusal to hire a cancer survivor or someone with epilepsy, or a larger societal failure to build offices, houses, hotels, and stores accessible to people in wheelchairs. Says disability rights activist Judy Heumann, "Disability only becomes a tragedy for me when society fails to provide the things we need to lead our lives—job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I'm living in a wheelchair."

For the first time, people with disabilities are defining themselves. They are saying their existence is all right. Mary Johnson, the editor of *The Disability Rag*, the irreverent magazine of the disability rights movement, says the best analogy may be with gay rights. Like homosexuals in the early 1970s, many disabled people are rejecting the "stigma" that there is something sad or to be ashamed of in their condition. They are taking pride in their identity as disabled people, parading it instead of closeting it.

This simple but iconoclastic thinking—that a disability, of itself, is not tragic or pitiable—is at the core of the new disability rights movement. Using it, disabled people have quickly begun to attack discrimination wherever they find it, deriving unexpected power by playing off the very stereotypes they seek to destroy. Consider the case of Evan Kemp, Jr., one of the advisers credited with convincing President George Bush to make disability civil rights a priority of his administration.

Kemp, one might say, was the original Jerry's Kid. His parents, along with parents of other children with muscular dystrophy and related conditions, founded the Muscular Dystrophy Association. In 1947, Kemp, then twelve, had come down with an illness that, for years, confounded doctors. It was initially thought to be amyotrophic lateral sclerosis, better known

as Lou Gehrig's disease. A doctor told him to his face that he would die before reaching his fourteenth birthday. When he did not die, doctors decided that he had Duchenne muscular dystrophy and likely would not live beyond his teens. Not until Kemp was twenty-eight was his illness diagnosed properly as Kugelberg-Welander syndrome. The rare muscle-weakening disease related to polio is one of the forty conditions supported by the muscular dystrophy telethon. In 1959, Kemp's mother and other parents put together the first telethon on a television station in Cleveland, where the Kemps lived. Their idea was to use the new medium of television to broadcast a variety show where entertainers and celebrities would ask viewers to donate money for muscular dystrophy medical research. In 1966, Jerry Lewis took over the national telethon, which he would perfect as an extravaganza of Las Vegas glitz and schmaltz. To date, Lewis's Labor Day telethon has raised over \$1 billion, and other charities have begun their own telethons. Without question, Lewis's tireless fund-raising built MDA into an organization that would support important scientific work. But Kemp felt that such telethons fostered the stereotype that muscular dystrophy was a tragedy, its "victims" childlike and perpetually sick, and that these misconceptions hurt disabled people more than the condition itself. Kemp, a quadriplegic who uses a wheelchair, would encounter such attitudes often. In 1991, as chairman of the federal Equal Employment Opportunity Commission, he had flown to Jacksonville, Florida, to make a speech. City officials sent an ambulance, instead of a van, to pick him up. Kemp refused to ride in it, since he was not sick. Instead, he flew back to Washington.

A long history of such slights helped put clout behind Kemp's 1981 attack on the Muscular Dystrophy Association's annual Labor Day telethon. On the opinion page of *The New York Times*, Kemp complained that the telethon encouraged prejudices about disabled people. "By arousing the public's fear

of the handicap itself, the telethon makes viewers more afraid of handicapped people," wrote Kemp. "Playing to pity may raise money, but it also raises walls of fear between the public and us." Further, by focusing on innocent children, the telethon, he said, "seems to proclaim that the only socially acceptable status for disabled people is their early childhood. The handicapped child is appealing and huggable—the adolescent or mature adult is a cripple to be avoided." Kemp objected that the telethon focused on the tragedy of a small number of children who died from muscular dystrophy, when in reality a far greater number of adults, like himself, led normal lives with neuromuscular conditions. Finally, he charged, "the telethon's critical stress on the need to find cures supports the damaging and common prejudice that handicapped people are 'sick.' As sick people, it follows that we should allow others to take care of all our needs until a cure is found." For one of the few times in its history the telethon collected less money than the year before, the result perhaps of both recession and Kemp's complaint. It would take another decade before large numbers of disabled people would echo Kemp's complaint about the telethon's "pity approach." In large part this was because a broad disability rights mind-set would not flower until the passage of the Americans with Disabilities Act in 1990 and its enactment into law in 1992. It vexed MDA officials that the disability movement's anger was cresting at the moment of some of MDA's most spectacular research success. Most stunning was the finding announced in 1992 of the precise DNA location of the gene that caused myotonic dystrophy. Yet, once again, these breakthroughs were not cures so much as prevention measures. And to the new disability rights movement prevention had ominous overtones. Many activists fear that with the growth of such predictive tests, pregnant women will be expected or coerced to abort fetuses when there is an indication of disability. Others worry that if genetic engineering can one day wipe out an illness, a person who already has that

disability will be seen as a freak or devalued as a preventable mistake.

As disabled people asserted their demands for dignity, Jerry Lewis seemed to intensify his mawkish pandering. In a 1990 magazine article, the comedian wrote of imagining himself as one of Jerry's Kids. It would be, he mused, 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." (To a reporter in Chicago, Lewis used the word "mongoloid," a particularly odious and obsolete term for retardation that seemed jolting coming from the mouth of a self-styled champion of disabled people.) Yet in his magazine article, Lewis also spoke of the need for accessible homes, restaurants, planes, and hotels, making his writing a strange stew of the worst pity stereotypes mixed with a dash of disability rights thinking. The telethon is now a similarly odd concoction. It features a handful of tales of successful children in school or adults at work—a nod to the evolving sensitivities of disabled people and their families—but remains fixed on the fear of disease, the misery of disability, and unfortunate Jerry's Kids doomed to early death. That the children on the telethon were picked for their smiling and cheery personalities makes their impending tragedy all the more pitiable.

But pity opens hearts, and that raises a quandary for charities like MDA: Do they listen to the complaints of critics like Kemp and sacrifice what is considered their best money-making pitch? One Los Angeles columnist, impressed by the \$80 million raised in 1991, thought Lewis's critics ungrateful and misguided. He wrote, "Let's ask this last question of the marchers who would like to see Lewis drummed out of the telethon: Just who is going to keep this cash machine going?"

Other charities, however, have junked the pity approach in their telethons. The National Easter Seal Society and United

Cerebral Palsy Associations have turned their shows into vehicles for rights advocacy. The numbers on the tote board climbed steadily, from \$23 million in 1985 for Easter Seals to \$42 million in 1992, disproving old ideas that a telethon had to make hearts bleed. "Our mission is to enhance the independence of people with disabilities," explains Easter Seals president James E. Williams, Jr., "and that can't be done on the backs of the people we serve by using pity." The charity replaced its poster child with a "representative" child and adult. Those chosen are shown as successfully integrated in their schools, jobs, and communities. "One of the biggest problems facing disabled people is stereotypes. If you portray people as objects of pity, in a mass medium like a telethon which has sixty million viewers, then it only reinforces those stereotypes," says Williams.

Many disabled people, like Kemp, point to the Easter Seals and UCP telethons as acceptable models. But for others, like Marilyn Phillips, "There are no good plantations and there are no good telethons." Indeed, other telethons, even when they avoid pity language, still tend to divide the world between the lucky and unlucky, between us and them. Even the best still play maudlin violin music softly underneath the profiles of adults. There is always an implied and frightening threat that all of us are vulnerable to the same misfortune.

### From Image to Action

It is not only those paralyzed by polio and related conditions who have begun to reject our society's image of and expectations for them. Patrisha Wright, president of the Disability Rights Education and Defense Fund, believes that "All disabled people share one common experience—discrimination." Statistics show that disabled people agree. Seventy-four percent of disabled Americans say they share a "common identity" with other disabled people, and 45 percent argue they are "a minority group

in the same sense as are blacks and Hispanics," according to a 1985 poll by Louis Harris and Associates. These numbers, reflecting a militant disabled population, may surprise a society that still assumes disabled people will be grateful for charity and eager to be made whole again. If anything, disabled people are far more likely today to view themselves as part of an oppressed minority. Since 1985, the Gallaudet student protests and passage of the Americans with Disabilities Act have broadened the sense of group identity and a commitment to overcoming prejudice.

Often the discrimination is crude bigotry, such as that of a private New Jersey zoo owner who refused to admit children with retardation to the Monkey House, claiming they scared his chimpanzees. It may be intolerance that permitted a New Jersey restaurant owner to ask a woman with cerebral palsy to leave because her different appearance was disturbing other diners. Resentment may have led an airline employee in New York to throw a sixty-six-year-old double amputee on a baggage dolly—"like a sack of potatoes," his daughter complained—rather than help him into a wheelchair and aid him in boarding a jetliner. Others may feel that disabled people are somewhat less than human and therefore fair game for victimization, as when a gang of New Jersey high school athletes allegedly raped a mildly retarded classmate with a baseball bat in 1989. Because of the girl's retardation, a judge later relaxed the rape shield law that existed to protect the privacy of rape survivors. She became twice victimized as the 1992 trial focused on her sexual behavior—including whether she had once delighted in seeing boys naked in a locker room—as much as on the actions of the boys accused of raping her. In a similar case, three volunteer ambulance rescuers allegedly pummeled to death a homeless man with retardation in the back of their ambulance because he annoyed them, as if, in a prosecutor's words, he were "a punching bag."

In other cases, however, the discrimination at issue is more

subtle because it is based on the paternalistic assumption that disabled people are not entitled to make their own decisions and lead the lives they choose. One such case was that of Tiffany Callo, a woman with cerebral palsy, who in 1988 fought, unsuccessfully, for custody of her two young sons. California welfare officials asserted that she was too physically disabled to care for them. The state was willing to pay the bill for expensive foster care rather than fund several hours a day of in-home child care to support Callo. Basic rights of parenthood were denied that would have been unquestioned for a nondisabled person. Being a successful parent, after all, has less to do with one's ability to move around than with the love and nurturing that Callo's supporters said she brought to her family. "So what if it takes longer to change a diaper?" asks Callo. "That's where disabled parents do their bonding. It's quality time."

Also troubling was the case of Sharon Kowalski, seriously disabled from a head injury in an automobile accident, who was refused her wish to leave a nursing home to live with her former roommate, Karen Thompson. A court questioned whether she had the judgment to make such a decision. The head injury had impaired some of her mental ability, particularly her short-term memory. Yet Kowalski remained capable of making a choice. She still had wishes, emotions, and knowledge. When I visited Kowalski and Thompson, the tenderness between them was clear. They held hands, and Kowalski smiled broadly as Thompson recounted how the two had recently gone fishing from a boat on the Mississippi River. Kowalski, animated and happy, was clear about wanting to leave the suburban Minneapolis nursing home and move into the new home Thompson had built to be wheelchair accessible. Kowalski spoke briefly, slowly typing out her answers on a small computer with a voice synthesizer that Thompson had bought for her. Mainly, she communicated with smiles and sounds.

It was a scene far different from the one painted by St. Louis

County District Judge Robert Campbell. The judge conceded that Kowalski, when asked where she chose to live, "has consistently said, 'St. Cloud with Karen.'" But Campbell decided Kowalski was no longer capable of making choices for herself and ruled that she needed the continued protection of a nursing home. The issues were difficult and compounded by Kowalski's homosexuality. Kowalski's parents denied their daughter could be a lesbian and claimed she was being exploited by Thompson to raise money for lesbian causes. (Actually, Thompson had been a closeted lesbian until Kowalski's accident forced her to go public.) Campbell noted that another woman now lived with Thompson and feared this could hurt Kowalski emotionally, though Kowalski already knew about the other woman from her occasional trips to Thompson's home. Even if Kowalski regretted her decision, she could always choose to return to a nursing home or live elsewhere. No nondisabled woman would be denied her free choice to live with her lesbian lover. The judge's failure to honor Kowalski's clearly stated wishes was part of the "infantilizing of people with disabilities," complained the late disability rights attorney Timothy Cook. "We're treated like eternal children." After seven years of court battles, Thompson finally won guardianship of Kowalski in late 1991.

But the biggest problems of discrimination are more everyday and more entrenched, such as employment bias. Only one-third of disabled people hold jobs. Seventy-nine percent of the rest say they can work and would like to work, according to a 1994 Harris poll, but they are prevented from doing so because, among other reasons, they face discrimination in hiring or lack transportation. They "want to work and can work," instead of being forced to accept welfare, says Sandra Swift Parrino of the National Council on Disability. Although she says a disability may limit the type of work a person can do, more often companies simply do not want to hire or accommodate physically disabled workers. Those who do not work collect federal dis-



ability and welfare checks, costing nearly \$60 billion a year. When other costs, such as medical treatment and rehabilitation and lost productivity, are included, it is estimated that the cost of disability to the nation runs \$170 billion a year. "It doesn't make sense to maintain people in a dependency state when those people want to be productive, tax-paying citizens," argues Jay Rochlin, former director of the President's Committee on Employment of People with Disabilities.

Rarely does a company say outright that it will not hire a disabled person. Paul Steven Miller is a dwarf—he prefers to describe himself as being of "short stature"—who graduated near the top of his Harvard Law School class in 1986. While his classmates quickly snared prestigious jobs, he was rejected by each of the more than forty law firms where he interviewed. Finally, an attorney in a Philadelphia firm explained that, although the partners were impressed by his credentials, they feared their clients might see Miller in the office hallway "and think we're running some sort of circus freak show." Miller later handled disability discrimination cases for the Los Angeles-based Western Law Center for Disability Rights.

Even when disabled people have jobs, they earn far less than their coworkers and are far less likely to be promoted. According to a study by Syracuse University economist William Johnson, this is the result of employers' prejudices and their underestimation of disabled workers—not because of limits on the work that disabled employees can do. Even after Johnson factored in things such as the possibility of a disabled person's lack of experience or lowered productivity, disabled men, he found, still make 15 percent less than nondisabled coworkers. For women, there is a 30 percent difference. A 1989 Census Bureau survey supported Johnson's findings and concluded that the gap between the earnings of disabled workers and their nondisabled coworkers is growing. A disabled worker in 1987 made only 64 percent of what his nondisabled colleagues earned. In 1980, it was 77 percent.

In part, this discrepancy reflects employers' fears about hiring someone with a disability, which remain strongly rooted despite recent prohibitions against discrimination in hiring disabled people. Edward Yelin, a professor of health policy at the University of California, San Francisco, adds that "persons with disabilities, like those from minority races, constitute a contingent labor force." When industries retrench, these contingent workers are the first to lose their jobs. When there is growth, they are the last to be hired.

The workplace is a haywire world for disabled people in other ways as well. For one thing, a job may mean the loss of essential health insurance and Social Security benefits. Historian Paul Longmore is one example. In 1988, he burned a copy of his biography of George Washington outside the Social Security offices in Los Angeles to protest the threat to his benefits. Longmore received a \$575 monthly Social Security check and \$20,000 a year from state Medicaid that paid for his ventilator and the in-home attendant who helped him live on his own instead of in a nursing home. That money allowed him to get his doctorate in American history and eventually write the biography. But the Social Security law was drawn up at a time when it was assumed that people like Longmore would never work but would always need government assistance. For Longmore to make even minimal income—Social Security disability income recipients are not allowed to have resources of more than \$2,000—would be taken as a sign that he was no longer disabled and no longer in need of aid. Since Longmore expected to make about \$10,000 in royalties from the book over several years, he would lose all of his benefits yet still be in need of them. It simply did not pay for him to work and be a taxpayer. Since the mid-1980s, Congress has responded to complaints by Longmore and others and rewritten some of these catch-22 rules. One new program lets disabled people on Medicaid—and denied insurance under company health plans because of their preexisting conditions—pay the Medicaid pre-



miums and hold on to their public health insurance. But work disincentives remain.

### Disabling Images

Like any other emerging minority group, disabled people have become sensitized to depictions of disability in popular culture, religion, and history. There they find constant descriptions of a disabled person's proper role as either an object of pity or a source of inspiration. These images are internalized by disabled and nondisabled people alike and build social stereotypes, create artificial limitations, and contribute to the discrimination and minority status hated by most disabled people.

In the Old Testament, being blind, lame, deaf, crippled, sick, or diseased is a sign of having done something to incur God's disfavor. Disability is brought on by sin. In the New Testament, people with disabilities are cursed or possessed by evil. Today, many of these traditional views remain in the church. There are evangelical preachers who claim the power to heal those with the proper faith, and the more commonplace Sunday school stories cast the disabled as pitiable. Many churches now make an effort to reach out to people with disabilities, such as the United Methodist General Conference, which revised its hymnal to delete "dumb," "lame," and other references offensive to people with disabilities. Other churches and synagogues, notes Ginny Thornburgh of the National Organization on Disability, welcome disabled worshipers by installing wheelchair ramps, buying large-print hymnals, or providing sign-language interpreters.

Portrayals in literature and popular culture, too, shape our images of disability. Often a disabled character is depicted as helpless and childish, like Tiny Tim in Charles Dickens's "A Christmas Carol," and in need of cure or care from a nondisabled person. But it was more common in classical literature (as it

often is today) for an author to exaggerate a disability as an emblem of a character's "sinister, evil or morally flawed" nature, according to Kean College special education professor Arthur Shapiro. William Shakespeare, Shapiro notes, gave Richard III a hunchback, even though the real king had no such disability, to make more ominous and obvious his ability to murder ruthlessly. Shakespeare's king speaks of being "deform'd, unfinished, sent before my time," of dogs barking at him because they were frightened by his looks, and feeling "determined to prove a villain" because of his anger over his disability. Another such villain is Herman Melville's Captain Ahab, who has lost a leg to Moby Dick and his mind in a madly obsessive pursuit of revenge.

These images undergird some of society's deepest fears and prejudices about people with disabilities, says Shapiro in an article co-written with Howard Margolis. "Lenny, the mentally retarded character in Steinbeck's *Of Mice and Men* who killed living things—including a young woman—because he was unaware of his own strength, is an image that may very well be involved in the minds of those who oppose group homes for the developmentally disabled," they write. And journalist Paul Gastris speaks of the blow to his own self-image at finding himself, at fourteen, living in a Shriners Hospital for Crippled Children, being fitted for a prosthetic arm and discovering a mural of the limbless and evil Captain Hook menacing the pretty and good Wendy and Peter Pan.

The modern successor to these diabolical characters is a staple of horror movies. Freddy Krueger, the villain of the *Nightmare on Elm Street* films, was turned into a hateful, sadistic killer because of his disfigurement, caused by a fire that left him more monster than human being. Every movie season has its examples of such fiendish disabled people, from the coldhearted banker in a wheelchair in the 1946 film *It's a Wonderful Life* to Jack Nicholson's demented Joker, disfigured by a fall into a vat of

acid, in 1989's hit *Batman*, and Danny DeVito's embittered Penguin, abandoned by his parents when he was born with flippers instead of arms in the 1992 sequel *Batman Returns*.

The precursor of the modern horror movie was the freak show. Scholars of disability history debate whether the carnival sideshows amounted to a crass exploitation of people with disabilities or their glorification. Between the 1860s and early 1900s, disabled people were seen as marvels of nature, not as frightening freaks, argues Robert Bogdan, a Syracuse University professor of special education. The well-appointed Victorian home would have a photo album filled with pictures not only of family members, statesmen, generals, and authors, but of Henry "Zip the Pinhead" Johnson; General Tom Thumb, "the perfect man in miniature"; Chang and Eng, the Siamese twins; or other sideshow attractions. Bogdan argues that with the professionalization of medicine, scientists, and then the public, stopped celebrating these "human oddities," and the freak shows died out. Doctors in the new twentieth century decreed that these freaks were no longer "benign curiosities" but "pathological" and "diseased," Bogdan argues. They became, he says, "'sick' and to be pitied." Other scholars, including historian David Gerber, claim that the willingness of dwarfs and others to be put on display only shows the extreme extent of their victimization and that other forces, like movies, brought about the end of the freak show. One of the first horror films was the 1932 movie *Freaks*, in which the circus sideshow attractions extract a bitter and bloody revenge on a beautiful aerial artist and her lover, the strongman.

Just as disabled people have begun protesting the power of pictures on a charity telethon, they are objecting, too, to the way they are portrayed in popular culture and the media. Language has been one of the first battlegrounds. Disabled people resent words that suggest they are sick, pitiful, childlike, dependent, or objects of admiration—words that, in effect, convey the imag-

ery of poster children and supercrips. "Invalid" is out, as is "afflicted with" and "patient," unless the person is really in a sickbed, or common adjectives such as "brave" and "courageous," since most disabled people are not seeking to be models of inspiration.

"Disabled" has become the usage of choice, replacing "handicapped" in recent years and becoming the first word to emerge by consensus from within the disability community itself. More acceptable still is "person with a disability" (or "who is deaf," "who has mental retardation," etc.), since it emphasizes the individual before the condition. One of the most common attacks on the disability movement is to mock the politically correct terms often used to describe disability. Yet it is almost always nondisabled people—relying on the stereotype that a disabled person should be an inspiration overcoming some challenge—who use prettifying euphemisms. Virtually no disabled person uses these cute phrases. Concoctions like "the vertically challenged" are silly and scoffed at. The "differently abled," the "handi-capable," or the "physically and mentally challenged" are almost universally dismissed as too gimmicky and too inclusive. "Physically challenged doesn't distinguish me from a woman climbing Mt. Everest, something certainly I'll never do," says Nancy Mairs, an essayist and poet with multiple sclerosis. "It blurs the distinction between our lives." Only by using direct terminology, she argues, will people think about what it means to be disabled and the accommodations she needs, such as wheelchair-accessible buildings or grab bars in bathrooms.

Dianne Piastro, who writes the syndicated column "Living with a Disability," complains that such terms suggest that disability is somehow shameful and needs to be concealed in a vague generality. "It's denying our reality instead of saying that our reality, of being disabled, is okay," says Piastro. Mary Johnson, editor of *The Disability Rag*, complains that such euphemistic terms come from nondisabled "do-gooders" who "wouldn't

understand disability culture if we ran over their toes with a wheelchair." These words have "no soul" and "no power," says Johnson. "They're like vanilla custard."

Is there a word with the requisite soul power? There was a surprise when Johnson's magazine surveyed its readers. Newly in vogue among some physically disabled people is the very word that is the ultimate in offensiveness to others: "cripple." "It's like a raised gnarled fist," says Cheryl Wade, a Berkeley, California, performance artist, who likes "crippled" because it is a blunt and accurate description of her body, which has been twisted by rheumatoid arthritis. "Crips," "gimps," and "blinks" have long been for the exclusive, internal use by people of those disabilities. (Terms for nondisabled people include "walkies" and "a.b.s" for able-bodied and "TABs" for the "temporarily able-bodied," a you'll-get-yours-yet reminder that disability hits most of us in old age if not before.)

"Cripple" will not become safe for general usage right away, but its newfound popularity shows that the stigma of disability is being rejected and replaced with a pride in being identified as disabled. Mairs, another who prefers "cripple," compares the change to the civil rights movement's replacement of "Negro" with "black." In reclaiming "cripple," disabled people are taking the thing in their identity that scares the outside world the most and making it a cause to revel in with militant self-pride. That disabled people are reappropriating words to redefine themselves and thinking about "the power of negative language," says Brandeis University sociology professor Irving Kenneth Zola, is a sign of a new and thriving group identity.

Language is not the only arena in which disabled people have begun to appreciate the power of imagery to make or smash stereotypes. With the disability rights movement's emergence, movies and television in the late 1980s and early 1990s began to adopt more positive and realistic portrayals of disabled characters. Disability, after all, can make for compelling drama. Deaf

actress Marlee Matlin won an Oscar in 1986 for her passionate portrayal—and lyrical use of sign language—of a deaf student who falls in love with her hearing teacher in *Children of a Lesser God*. In 1989, Dustin Hoffman won an Academy Award for his representation of an autistic savant in *Rainman*. Actor Daniel Day Lewis won the same trophy the following year for his characterization of Irish writer and artist Christy Brown, who had cerebral palsy, in *My Left Foot*. In 1991, Robert DeNiro won other film honors as a man in a postencephalitic trance in the movie *Awakenings*, based on the autobiographical account of neurologist Oliver Sacks's experiments in reaching a ward of patients who had become disabled during the "sleeping sickness" epidemic of 1916 through 1927.

Television, which still loves sugary disability tales for its made-for-television movies, has nonetheless developed positive characters, particularly in longer-running series. In 1989 Chris Burke became the first television star with mental retardation. He plays Corky, the mildly retarded son who goes to mainstreamed high school classes in "Life Goes On." Marlee Matlin depicts a deaf attorney in "Reasonable Doubts." And nondisabled actor Larry Drake plays Benny Stulwicz, the office clerk with mental retardation in "L.A. Law." Such is the power of television that a corporate personnel director called a local retardation agency to inquire if it had any "Bennys" for hire.

The most consistently positive portrayals have come, perhaps surprisingly, from advertising. Few depictions have shattered myths of dependency and inability more quickly than the DuPont television commercial featuring Vietnam veteran Bill Demby, with two prosthetic legs, playing a spirited game of basketball on an urban blacktop. Similarly, a Budweiser commercial of a wheelchair marathoner with his fit and stunning blonde lover helped tear down widespread assumptions that to be paralyzed is to be sexually dysfunctional. Kmart, Toyota, McDonald's, Levi's, Xerox, IBM, AT&T, and many others have

included disabled people in print and television ads, mixing them in with nondisabled people, to give the positive image that they are just like anyone else.

That advertising would play such a corrective role bespeaks the power of the disability rights movement: disabled people have emerged as a consumer group. They are mighty in part because of the millions of dollars they spend. As more disabled people move into competitive jobs, they have more money to spend. Another source of strength is simply their large numbers. The Minneapolis-based Target department store chain put its first model with mental retardation, a young girl with Down syndrome, in a Sunday newspaper advertising insert in 1990. "That ad hit doorsteps at six A.M. Sunday and a half hour later my phone was ringing," recalls George Hite, the company's vice-president for marketing. "It was the mother of a girl with Down syndrome thanking me for having a kid with Down syndrome in our ad. 'It's so important to my daughter's self-image,' she said." That ad, one small picture among dozens in the circular, generated over two thousand letters of thanks to stunned Target executives.

There is a new militancy, too, as people with disabilities have come to recognize the strength of their numbers. Their anger is often directed, in protests and economic boycotts, at stereotypical depictions in movies and television. Members of the San Francisco-based National Stuttering Project picketed outside movie theaters showing *A Fish Called Wanda* in 1988, and eventually got a letter from the film's producer explaining that a character who stutters in the film because of his repressed anger was not to be taken as a portrayal of all people who stutter. The National Stuttering Project argued that its members are hurt by widespread assumptions that people stutter because of shyness or some emotional disorder when in fact they are no different psychologically from anyone else, and stuttering may be more related to physiological or genetic conditions.

Among the most stigmatizing media images are portrayals of people with mental illnesses. On television, notes one study, 70 percent of such characters are depicted as violent. Yet only a small number of people with schizophrenia, major depression, manic depression and related disorders are dangerous and those are almost always ones who have not received effective treatment. The National Stigma Clearinghouse, a group of people with such conditions, family members, professionals and researchers, wages letter-writing campaigns and protests that, among other successes, have forced DC Comics to rewrite a plot to have Superman killed by a straitjacketed "lunatic" escaped from an "interplanetary insane asylum" and got the New York State Lottery to withdraw the promotion of its Crazy 8's instant lottery game.

Similarly, in 1991, members of the National Federation of the Blind protested outside of ABC network offices around the country in complaint of a Mr. Magoo-like character in the slapstick sitcom "Good and Evil." The blind character destroys a chemistry laboratory by clumsily wielding his long white cane and then woos a fur coat on a coatrack, mistaking it for a woman. After four major companies pulled their advertisements, the network announced after only five episodes that the show was canceled.

Some might dismiss such objections as a case of disabled people having no sense of humor or being overly sensitive and politically correct. "If we were at a point where blindness was not regarded as a negative and if we had truly achieved equal opportunity, then we could laugh and say this is not a realistic portrayal of a blind person," says federation official James Gashel. But for people with visual handicaps who face discrimination in everyday life and a 70 percent rate of unemployment, contends Gashel, such depictions are dangerous. They confirm, he says, every debilitating myth and stereotype that "people hold to some degree to be true about blind people—that you

won't know what room you're in until somebody tells you; you won't know a man from a woman unless you touch them; you'll break things, you'll stumble over things; you cannot perform in your profession competently; and that you can't measure up in competing with sighted people."

Gashel's unemployment figures for blind people are illustrated by the folly of the State Department in refusing to hire Avraham Rabby, who passed the Foreign Service exam three times with near-perfect scores, spoke four languages, and was impeccably educated. But Foreign Service officials argued that he needed to be able to see another person's "body language" in order to handle negotiations. Most ridiculous, complained the Equal Employment Opportunity Commission in 1987, was that the State Department recruited disabled people like Rabby but then refused to hire them. After four years of fighting, Rabby was accepted into the diplomatic corps in 1991.

Fear, disabled people understand, is the strongest feeling they elicit from nondisabled people. Fear underlies compassion for the poster child and celebration of the supercrip. After a spinal cord tumor left him a paraplegic, anthropologist Robert F. Murphy studied his condition through an ethnographer's eyes. Disabled people "contravene all the values of youth, virility, activity and physical beauty that Americans cherish," he wrote in *The Body Silent*. "We are subverters of the American Ideal, just as the poor are betrayers of the American Dream," argues Murphy. "The disabled serve as constant, visible reminders to the able-bodied that the society they live in is a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility." So society shields itself from this "fearsome possibility" by distancing disabled people and treating them as social inferiors.

When people insist on seeing him as either a supercrip, a poster child, or an affront, says historian Paul Longmore, he knows he represents their worst nightmare. Longmore walks

slowly because his body was bent by childhood polio, and he must use a ventilator at night. A stranger once approached him on the street and said, "If I were you, I'd kill myself." Usually, people express such sentiments indirectly in overblown admiration or pitying sympathy. In this case, the stranger's tone made it clear that the sight of a man with a severe disability was an offense, implying that Longmore ought to take his advice.

The force of fear was evident in 1991 when Los Angeles television news anchor Bree Walker Lampley got pregnant. Call-in radio show host Jane Norris of KFI dedicated two hours to the proposition that Walker Lampley was being morally irresponsible by bringing a disabled child into the world. Walker Lampley has a condition called ectrodactyly, a partial fusing of the bones in the fingers and toes. It is a relatively minor disability. The unconventional appearance of her hands did not impede her professionally. Her condition did not even prevent her from typing out news stories on a computer. Nor did it stop her from being a good mother. Her daughter by a previous marriage also had inherited ectrodactyly.

Whose business, then, was it that her child had a 50 percent chance of inheriting the same condition? "Face facts here, having that sort of deformity is a strike against you in life. People judge you by your appearance," said talk-show host Norris, making clear her own position. "By the shape of your hands, and the shape of your body and the shape of your face. They just do. They make value judgments about you. Whether it's right or whether it's wrong, it just is. And there are so many options available—adoption, surrogate parenting. . . . It would be difficult to bring myself to morally cast my child forever to disfigured hands."

All the prejudices that disabled people say stem from the poster child and inspirational cripple images were on display in Norris's ugly call-in show. There was pity for a life of imagined misery. "It's a horribly cruel thing to have the baby, knowing it's going to be deformed," said one caller, Valerie from Mission

Viejo. "If I were a child and I was going to grow up knowing that my parents had me anyway, I think I would truly hate them all their lives no matter how good they were to me." There was the idea, too, that a disabled person commands respect only to the extent that he or she can be an object of inspiration. "I want to know what her motive is for having this child," demanded Lisa of Costa Mesa. "What's to guarantee that this child will be as successful as the mother in overcoming this . . . ? Actually, I think it's kind of irresponsible." There was the fear of a life not worth living. "I would rather not be alive than have a disease like that," said Claire from Oceanside. "I'm not talking perfection, but this is ridiculous—no hands, no feet." And there was the notion that without cure there was no reason or right to live. "To stop something like that, which is very bad [and] not curable, you have to start with reproduction," added Kathy from Elsinore. "And if you know the possibility exists, don't have them [babies]."

Aaron James Lampley was born healthy. He, too, inherited ectrodactyly. Walker Lampley brought a complaint—filed by Paul Steven Miller, the Harvard Law School graduate who had been refused jobs because of his short stature—against the radio station with the Federal Communications Commission. The suit ultimately failed, but Walker Lampley won the war with a barrage of sympathetic national media coverage. Like most other disabled people of her generation, "I was raised to just take it," she noted. "But I just can't roll over and let this one fall into that category. This is about my children and all children in the future born with an unconventional appearance. This station was spreading hatred. I felt I had to pick up the torch on this one." As the group identity of a younger generation of disabled people grows, people like Walker Lampley are increasingly less tolerant of bigotry. Like her, they are taking a stand for equality, independence, and dignity.

## CHAPTER 2

# FROM CHARITY TO INDEPENDENT LIVING

**I**n the fall of 1962, James Meredith, escorted to class by U.S. marshals, integrated the University of Mississippi. That same school season, a postpolio quadriplegic named Ed Roberts entered the University of California at Berkeley. Just as surely as Meredith ushered in an era of access to higher education for blacks and a new chapter in the civil rights movement, Roberts was more quietly opening a civil rights movement that would remake the world for disabled people. The disability rights movement was born the day Roberts arrived on the Berkeley campus.

While Roberts's activism would be shaped by Berkeley, it was first formed in the experiences of being disabled as a teenager—after growing up with all the promises of a full life that are the birthright of the nondisabled. In 1953, polio swept through the modest frame home of Verne Roberts, a second-generation railroad worker, his wife, Zona, and their four sons.