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NUMBER 1

TOWARD INCLUSION



*Meeting the
Needs of Persons
with
Disabilities
in the
United States*



— JANUARY 1999 —

FROM THE EDITORS

A United States senator conducts pressing affairs of state for his constituents and for the nation from a wheelchair. A professional baseball pitcher thrills sports fans with his strikeout prowess, despite the fact that he has only one fully-developed arm. A young man with Down syndrome becomes a pivotal character in a popular U.S. television series. A child born without arms and legs becomes, with the help of prostheses and gritty inner strength, a leading attorney and social activist.

Year after year, people across the United States are becoming attuned to the presence and potential of individuals with disabilities of varying types — both physical and psychological. Celebrities such as those mentioned above are only a small — if highly visible — part of the story. The fact is that millions of people with disabilities are engaging in productive, gratifying endeavors as never before.

To a large extent, the spark was ignited by people with disabilities themselves, who fought for, and won, legislation that — during the past generation — has helped change the face of U.S. society. So, too, have scientific and technological achievements benefitting people with disabilities, and inclusive policies across the spectrum of education. Legislation and new tools, however, can accomplish only so much. Equally challenging, and just as vital, has

been the struggle to change perceptions and attitudes. Within the disability rights community, there is widespread agreement that the overall struggle is beginning to bear fruit.

The issue of how to meet the needs of people with disabilities — by executive fiat, legislation, societal evolution and the like — is being confronted beyond the borders of the United States as well. Concerned citizens in many countries are starting to interact with professionals and activists in the United States on this topic, and with each other as well.

The purpose of this Journal is to inform audiences worldwide as to current developments in the United States on the subject at hand. Ideally, it may also assist the networking process. It describes how awareness and concern have been fostered in the United States by the disability rights movement itself, by the thousands of men and women whose mandate is to assist those with disabilities, by the scientific and technological sectors, and by other individuals — both those with and without disabilities. We hope that these articles and reference sources will enable interested parties to become more informed, and to continue interacting so that the global society will progress in this effort on behalf of many millions of the world's citizens. ■



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CORRECTION: The opening quote in the article "Volunteerism and Corporate America," in *USIA's September 1998 Electronic Journal, THE UNITED STATES: A NATION OF VOLUNTEERS* (Vol. 3, No. 2, U.S. Society and Values), was erroneously attributed to Peter Drucker. It should be attributed to Frances Hesselbein, President and CEO of the Drucker Foundation.

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THE 21st CENTURY WORKPLACE: A RIGHTFUL PLACE FOR ALL

BY PRESIDENT BILL CLINTON

On January 13, 1999, President Clinton announced a budget initiative to improve economic opportunities for U.S. citizens with disabilities. The following text is drawn from the President's remarks on that occasion.

 Any years ago, after I lost an election, a wise old country lawyer wrote me a letter, telling me that it takes a little bit of strength to sustain a terrible setback, but the real courage in life is living through the grind of day-to-day existence with dignity and nobility and charity.

How much more true is that for people with disabilities, for whom daily existence can be a greater grind, for whom charity is harder to muster, because so many of the rest of us have been so blindly insensitive to things which would enable all of us to get through that daily life better.

A lot of good things have happened in recent years — the passage of the Americans with Disabilities Act, the renewal of the Individuals with Disabilities Education Act. But 75 percent of

Americans with disabilities are still unemployed. Millions are forced to make the impossible choice between going to work and keeping their health insurance. Millions more lack the tools and services that could make the difference between dependence and independence.

We all know working is a fundamental part of the American Dream. Maya Angelou once said that work is “something made greater by ourselves, and in turn, that makes us greater.” Every single one of us wants to be fully engaged in life. And we ought to have the chance to do so.

With the largest surplus in our history, the longest peacetime expansion, perhaps the strongest economy we've ever had, now is the time to address the following issue.

Today, I am pleased to announce that the balanced budget I will present to Congress fully funds a vitally important three-part disability initiative.

First, it fully funds the proposed Work Incentives Improvement Act, which improves access to health care, modernizes the employment services system and creates a work incentive grant program. Our

citizens will never have to choose between the dignity of work and the health care they need.

Second, we must make it easier for people with disabilities to get to work. As anyone with a disability can tell you, it takes more than a job to enter the work force. Often, it takes successful transportation, specialized technology or personal assistance. And the cost can be prohibitively high. I am pleased to announce today a new \$1,000 tax credit so hundreds of thousands of people with disabilities will be helped to meet these critically important expenses.

Finally, we have to give people with disabilities the tools they need to succeed. These can range from a portable computer kiosk that helps people with disabilities vote or find a job to the latest voice recognition software that lets you use a computer without touching a keyboard. It includes a new generation of mobile telephones that connect directly to hearing aids and a device to immediately translate music into Braille. This kind of “assistive technology,” as it is called, will empower people as never before. I am pleased to announce that my budget will double our investment in this sort of

technology, to make it more available to people with disabilities.

We will also help states to expand low-income loan programs to help more people afford these promising products. The federal government will become a model user of assistive technology; we will increase our commitment to research and development to continue our progress.

Increased access to health care, more assistance at home and in the workplace, remarkable new technologies made more available — this is how we can make sure that all Americans can take their rightful place in our 21st-century workplace.

People with disabilities are increasingly a powerful presence in the United States, from our schools to our businesses to the halls of government — but maybe equally important, increasingly a welcome, comfortable, normal presence. President Franklin D. Roosevelt said, “No country, no matter how rich, can afford to waste its human resources.” This is really all about living up to that objective. ■

THE AMERICANS WITH DISABILITIES ACT (ADA)

FROM *Access and Opportunities: A Guide to Disability Awareness*

In the “Findings and Purposes” of the Americans with Disabilities Act of 1990 (ADA), the U.S. Congress noted that people with disabilities are a “discrete and insulate minority who have been subjected to a history of purposeful, unequal treatment and relegated to an inferior status in our society.” Congress further described the persistent discrimination experienced by people with disabilities in employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting and access to public services.

Congress reported that the discrimination experienced by Americans with disabilities had taken many forms, including overprotective rules and policies, segregation or relegation to lesser services or programs, exclusionary standards, outright intentional exclusion and a variety of physical barriers. The ADA was passed to address and eliminate the major forms of discrimination.

The population of people with disabilities — nearly 54 million in number — is the largest and most diverse minority group in the United States, surpassing the elderly and African Americans. As a group, people with disabilities are older, poorer, less educated and less employed than people without disabilities. Disability itself does not discriminate; it affects every racial and economic segment of society.

In order to receive the protections afforded by the ADA, a person must satisfy at least one of three conditions:

❑ must have a physical or mental impairment that substantially limits one or more major life activities, such as hearing, seeing, walking, breathing or speaking.

❑ must have a record of a substantially limiting impairment to a major life activity, such as a person who has recovered from cancer or an individual previously categorized as having a learning disability.

❑ be misperceived as having a substantially limiting impairment, which in reality is not substantial, such as controlled high blood pressure; or does not cause any substantial limitations, such as a facial scar or physical disfigurement.

This definition is broad in design. Congress specifically chose not to create a laundry list of qualifying disabilities under the ADA.

EMPLOYMENT

The employment provisions of the ADA prohibit discrimination in all job-related practices and activities. They are rooted in the legislative history of the 1973 Rehabilitation Act, but are much more far-reaching. The ADA requires that all employment decisions be made without reference to the existence or consequence of disability. This prohibition applies not only to hiring, but to all aspects of the employment process, including: testing, assignment of duties, evaluation, disciplinary action, training, promotion, termination, compensation and leave and benefits administration.

Employers are required to provide reasonable accommodations for workers with disabilities when such accommodations would not impose any undue hardship, such as significant difficulty or expense to the overall business operation. The term “reasonable accommodation” may include making the workspace physically accessible; acquiring or modifying equipment or devices; restructuring the job or

modifying the work schedule; adjusting or modifying training materials or policies; and providing qualified readers or interpreters.

Employers need not lower quality or quantity standards as an accommodation. Nor are they required to accommodate disabilities of which they are not aware. If an individual does not request an accommodation, an employer is not obligated to provide one.

The employment provisions of the ADA went into effect in July 1992, but employment rates of people with disabilities have remained consistently low since then. In 1995, only 28 percent of working-age, non-institutionalized people with disabilities were employed, as compared to 75 percent of working-age Americans without disabilities.

ARCHITECTURAL AND COMMUNICATION BARRIERS

The ADA recognizes that one significant barrier to inclusion is access to and within places where services are provided. Inaccessibility affects the entire community — not only people with disabilities, but also others, such as pregnant women and the elderly. One provision of the ADA specifies that discrimination includes a failure to remove architectural or communication barriers in existing facilities if such removal is readily achievable — that is, without much difficulty or expense. Examples include adding “grab bars” in restrooms, lowering public telephones or adding Braille markings on elevator control buttons.

If the removal of a barrier is not readily achievable, then one must attempt to provide alternate methods for services or programs — such as arranging assistance to retrieve items in an inaccessible location. The ADA mandates a much higher standard of accessibility for new construction and major alterations of facilities because it costs far less to design accessibility into a new construction project.

DISCRIMINATION AND OTHER BARRIERS

Drafters of the ADA certainly recognized that some of the most serious impediments to access for people with disabilities are not problems which can be solved solely by architects. There also are problems of attitude. An attitudinal barrier is defined as a way of thinking or feeling that results in behavior which limits the potential of people with disabilities to function independently.

Extensive research shows that a small percentage of people have openly negative attitudes toward people with disabilities that are associated with prejudice, fear, ignorance, intolerance, insensitivity, discrimination, dislike or condescension. They subscribe to most of the myths surrounding disabilities, even in the face of documented evidence to the contrary. The vast majority of the U.S. public is neither positive nor negative toward people with disabilities. Their general reaction is indifference. They prefer not to think about it.

In order to overcome these attitudinal barriers, it is important that people educate themselves about the facts of disability, and participate in community programs that include people of all abilities.

ACCOMPLISHMENTS OF THE ADA

The ADA’s signing augured the promise of greater access to public venues, more and better employment opportunities, and the chance to participate more fully in the mainstream of community life. The legislation’s advocates envisioned a world where performing arts centers, museums, public parks and recreation centers would be designed or adapted to accommodate everyone, a world in which wheelchair users could move freely and where technology would bring the sights and sounds of the community within the reach of every resident.

Changes in the Washington, D.C., arts community typify what has happened across the United States during the 1990s. At The John F. Kennedy Center for the Performing Arts, the availability of technology to assist patrons with specific visual and auditory needs has increased attendance of persons with disabilities by as much as 400 percent. Every Kennedy Center publication includes a schedule of

signed performances. Enhanced listening devices, accessible seating, audio description services and better directional signs make the Center a more welcoming facility. Arena Stage, one of the largest theaters in the nation's capital, was accessible to people with disabilities long before enactment of the ADA. It and other arts facilities continue to find ways to assist patrons with disabilities so that accommodation is the norm, not the exception.

Thanks to the ADA, the U.S. physical landscape now is marked by curb cuts, enhanced sound and lighting systems, wider doorways, more spacious public restrooms and larger printing sizes. In spite of fears about cost and inconvenience, which delayed enactment of the legislation for quite a while, a 1994 Harris Poll confirms that 70 percent of Americans see no reason to retreat on any of the act's provisions. ■

THE DISABILITY RIGHTS MOVEMENT: A BRIEF HISTORY

From Access and Opportunities: A Guide to Disability Awareness

As our parents, children, friends and neighbors, people with disabilities are — and always have been — everywhere. The history of the disability rights movement, however, is relatively new. While people with disabilities have always been members of most communities, it is only within recent memory that they have begun to recognize themselves as a cohesive social group.

There are nearly 54 million people with disabilities in the United States. As the largest single minority in this country, they represent a potentially formidable voting bloc. Yet many people with disabilities claim that they are still an unrecognized minority. The disability rights movement intends to change all that, and to bring the needs, concerns and rights of people with disabilities to national attention.

Historically, the condition of having a disability — in any society — has been viewed as tragic. In pre-industrial times, when people with disabilities often were unable to support themselves or their families, they were seen as social dependents, objects of pity or recipients of charity. In the early years of the United States, society assumed a paternalistic approach towards people with disabilities — often institutionalizing them in special homes or hospitals. People with disabilities were looked upon as patients or clients who needed curing. In those institutions, medical professionals and social workers were considered the primary decision-makers, rather than the people with disabilities themselves.

As a result, these people found themselves excluded from the larger society. While the assumption was that people with disabilities needed to be rehabilitated from their “problems,” great numbers had conditions for which there was no known cure at the time. And so society provided no room for integration, thereby perpetuating myths of

inequality.

In the first half of the 20th century, however, the United States’ involvement in two world wars had a profound effect on the way people with disabilities were viewed and treated by the culture at large. As thousands of disabled soldiers returned home, society made provisions for them to re-enter the work force. The first vocational rehabilitation acts were passed by the U.S. Congress in the 1920s to provide services to World War I veterans with disabilities.

The biggest changes, though, came in the throes of the civil rights movements of the 1960s. As African Americans, women and other social minorities gained political influence, so, too, did people with disabilities.

A pivotal moment in the history of the disability rights movement may have been the admission of Ed Roberts to the University of California at Berkeley in 1962. Paralyzed from the neck down due to a childhood bout with polio, Roberts overcame opposition to gain admission, where he was housed in the campus hospital. A headline in a local newspaper proclaimed, “Helpless Cripple Attends UC Classes.”

Within a short period of time, several other men and women with disabilities joined him on campus. Dubbing themselves the “rolling quads,” they banded together to fight for better services and for permission to live independently, rather than at the hospital. With a grant from the U.S. Office of Education, they created the Physically Disabled Students Program, the first of its kind on a college campus. It was, in effect, the beginning of the independent living movement.

This movement rests on the concepts of consumer control, self-reliance and economic rights. It rejects

the supremacy of medical professionals in decision-making and advocates the right to self-determination by people with disabilities. The first center for independent living opened in Berkeley in 1971, with an eye towards providing peer support, referral services, advocacy training and general information. Today, there are more than 200 such centers across the nation.

With the success of the independent living movement, people with disabilities began to band together on behalf of their civil rights. In the early 1970s, they lobbied Congress to add civil rights language for people with disabilities to pending legislation. In 1973, the legislature passed the revised Rehabilitation Act. Its most important aspect was Section 504, a one-sentence paragraph prohibiting any program or activity receiving U.S. Government financial assistance from discriminating against qualified individuals with disabilities.

On a parallel track to the disability rights movement was a campaign to provide access to educational services for children and youth with disabilities. The Education for All Handicapped Children Act, passed in 1975, ensured equal access to public education for such students. Renamed the Individuals with Disabilities Education Act (IDEA) in 1990, it called for a free and appropriate public education for every child with a disability, to be delivered in the least restrictive environment. IDEA promotes the concept of inclusion, requiring that students with disabilities be educated in general education settings, alongside students without disabilities, to the greatest extent appropriate.

Despite these pieces of legislation, people with disabilities did not gain broad civil rights until the enactment of the Americans with Disabilities Act (ADA) in 1990. Modeled after the Civil Rights Act of 1964, this landmark U.S. Government anti-discrimination law ensures equal access to employment opportunities and public accommodations for people with disabilities. The ADA guarantees that no person with a disability can be excluded, segregated or otherwise treated differently than individuals without disabilities. With this act, Congress identified the full participation, inclusion and integration of people with disabilities into society as a national goal.

With increased access to employment opportunities and public services, though, discrimination does persist — with obstacles to full participation in housing, transportation, education and access to public accommodations. Many of these obstacles are the result of ongoing ignorance and lack of public awareness. This has led to the disability culture movement.

The legislative changes represented the first phase in the quest for disability rights. The second is what disability expert Dr. Paul Longmore calls “a quest for collective identity,” an exploration of what it means to have a disability in today’s society.

Disability culture is aimed at fostering pride in one’s disabilities, creating positive self-images, and building a society which not only accepts, but also celebrates, diversity. It calls for the collection of disability history, the establishment of disability studies in academia, and the support of artistic expressions of the disability experience through poetry, art, music and dance.

“Gradually, people with disabilities are finding their history and cultural legacy,” says Carol Gill, a psychologist who has studied disability culture at length. “They are seeking support and validation in the community — the family — of other disabled people.” ■

MOVING PEOPLE FORWARD

A Conversation with Tony Coelho

During the latter phase of his tenure as a United States Congressman from California, Tony Coelho introduced a piece of legislation that was the first version of what became the Americans with Disabilities Act (ADA). Coelho, who served in Congress from 1978 to 1989, and who has held other posts in the private and public sectors, is chairman of the President's Committee on Employment of People with Disabilities [<http://www50.pcep.gov/pcep>]. As such, he is at the center of one of the most challenging issues facing those involved with disability rights. He knows the field well, from personal experience: he has suffered from epilepsy since the age of 16.

Recently, in a conversation with Michael J. Bandler, Coelho reflected on his mandate — his accomplishments and challenges — as he perceives it today.

Q: To begin with, what are the contours of the landscape for people with disabilities in the United States today?

A: Well, the thing that's important is that when the ADA was adopted nine years ago, in effect, it only changed the legal landscape. It did not change what is most important — attitudes. But it also empowered people with disabilities to bring our abilities onto the radar scope, to do our thing, to demand our rights. Now what's happening is that the business community, because of low unemployment in the United States these days, is looking for a ready workforce. Employers don't care about race, gender, handicaps — only whether someone is ready to go to work. The good news is that a lot of people with disabilities want to work, can work, and are ready. We've gotten the U.S. Chamber of Commerce to join us as a partner for the

first time. Tom Donohue [president and chief executive officer of the U.S. Chamber of Commerce] is chairing the Business Leadership Network [BLN] [<http://www50.pcep.gov/pcep/projects/business.htm>], which is under the President's Committee on Employment of People with Disabilities. Businesses that currently employ people with disabilities become advocates in the community to get other firms to do likewise, by relating their experiences. The BLN has chapters now in several states, and we're aggressively trying to increase their number over the next year to produce a national base.

The President's Committee sponsors a project called High School/High Tech [<http://www50.pcep.gov/pcep/projects/high.htm>]. We take kids with disabilities who might have an interest in technology, and place them in after-school and summer programs with government or private employers — to get them motivated enough in technology to possibly pursue it as a career. Another of our projects, Workforce Recruitment Program [<http://www50.pcep.gov/pcep/projects/workforc.htm>], is aimed at college students with disabilities. Some participants find summer work while they're in school and others seek full-time employment after graduation. We're trying to find national sponsors for all these different programs. So it isn't just government aid that's being provided; we have private firms joining us as co-sponsors to get that done.

Q: What is the specific mandate of your office?

A: I am involved in two efforts for the U.S. Government — as chairman of the President’s Committee, and as vice-chairman of the task force that President Clinton set up in March 1998 to make the U.S. Government a model employer. It’s a four-year mandate to change attitudes. It isn’t a Department of Labor problem, or a Department of Agriculture problem. It’s really a government-wide problem. President Clinton accepts the fact that the federal government has had a horrible record. We’re now trying to confront it structurally. And it’s going to work.

Q: The federal government’s record, though, is probably no worse than that of the private sector.

A: Oh, you’re absolutely right. But the federal government has been a testing ground in many areas. It’s broken a lot of barriers on issues of race and gender. The President’s new budget for fiscal 2000 is going to have a program dealing with accommodation that will affect every agency and department.

Q: Elaborate, for a moment, on what you mean by “accommodation.”

A: Well, for instance, if you’re [relegated to] a wheelchair, it means making the desk able to accommodate you. A private employer might put two-by-fours [strips of wood] under each of the legs of a desk to raise it so a chair can fit underneath.

Q: There’s been considerable discussion about ostensible increased costs of accommodation. But isn’t it true that businesses don’t necessarily have to reconfigure their whole establishment or configuration to comply with the ADA? For example, if a cleaning establishment is located on the top of a flight of stairs, with no other access, all the proprietor has to do is bring the clothing downstairs to the person with a disability. That will satisfy the law, won’t it?

A: I was the author of the ADA. We put in some language that became controversial, namely, “economically feasible.” We did not define what that meant — on purpose. If you’re a small business, it’s different from being a major corporation.

Q: You can find ways of accommodating, as a small business.

A: That’s my whole point. If you’re a small establishment, you can use the two-by-fours. If you’re a major corporation, that may not be reasonable accommodation. The type of accommodation you have to provide for an employee is based on your economic capability. But we do not want to run any company out of business in order to provide accommodations. That does not serve our purpose.

Q: You mentioned a moment ago that some of the language incorporated in the ADA was left undefined. The fact that the Supreme Court has just chosen [in January 1999] to review not one but three cases from the appellate courts dealing with correctable impairments strongly indicates that the process of defining continues.

A: It’s obvious that what’s going on is that this is a whole new area of law. We knew that the way we had the legislation written, the courts and the administrative procedures would have to put the meat on the bones. And that’s what’s happening now. It’s been going through the court system for a few years. The Supreme Court has already addressed one issue: it said that AIDS and epilepsy and other conditions were covered. Now there are these three new cases. The interesting thing here is that through this process, a group becomes part of established law. The disability community was very upset when we introduced the bill, and said it had to go through a process, about which they were fearful. But I think that if we had written the law in a way that mandated certain things, it would have been repealed. By doing it the right way — which is letting the system work — the system is working.

Q: That’s what’s been happening for more than 200 years.

A: Yes, sir.

Q: While we're on the subject of new developments in this fluid field of U.S. society, there also have been several new initiatives by the Clinton Administration aimed at improving economic opportunities for individuals with disabilities. They're linked to your work on the task force.

A: This is the culmination of a major effort. Adopting the ADA, permitting it to go through the process, the administrative and legal procedures are fine. But then you've got to go after the attitudes. And basically, what President Clinton, in effect, said January 13 was that we understand, and we're going to make the federal government a model employer. And here's what we're going to do: If you are receiving benefits from the federal government, and you still want to work, we're going to help you. We're going to help you with assistive technology, and with regard to accommodations for working. The situation is that all the recommendations by the task force to the President [http://www.dol.gov/dol/_sec/public/programs/ptfead/rechart/index.htm] were approved. What is significant is that now that he has put these in his budget, disabilities will probably be addressed in his next budgets, and as such, the next administration will include disabilities because it would be hard not to. So we have come of age. We're part of the fabric, and we'll start to see some real progress. It's exciting.

Q: Let's telescope in on attitudes, which we've mentioned in passing. What are some of the misperceptions employers have with regard to people with disabilities?

A: First, fear — fear of the unknown. What do I do? How do I handle somebody with a disability? Is he going to have a seizure at the workplace? Is he

going to frighten clients away, or scare other employees? What do I do with somebody in a wheelchair? Do I push the chair or not? What about somebody with prosthetic arms? Do I shake his hand or don't I? That fear of the unknown has to be broken down. And the only way to do so is through actual contact. That's why we're pushing hard for internships and placing people with disabilities at different sites, so that someone working next to them can say, "gee, these guys are great!"

Q: Tell me about the Job Accommodation Network.

A: JAN [<http://www.jan.wvu.edu/english/homeus.htm>] is under the President's Committee. We bid it out every five years. West Virginia University has the contract now. Basically, the network is reached through a toll-free number. An employer or employee can call for confidential information. If you're an employer, you're told what accommodations you have to provide or not, and how to arrange it.

Q: Let's take a hypothetical situation. The owner of a restaurant is a good fellow, needs some new hires, and wants to employ some people with disabilities. What can JAN do for him?

A: They'll tell him how to go about the hiring, what to be fearful of or not. What if he hires somebody who then acquires a disability? Over 50 percent of the adult population with disabilities acquired them after reaching adulthood.

Q: Isn't it also true that 85 percent of Americans with disabilities weren't even born with them?

A: That's right. So you call JAN and tell the consultant that Joe Smith or Sally Brown was just injured. The consultant will tell you what you can or cannot do. You cannot fire them for these reasons — but you can fire them if they can't perform this job. In other words, you'll get all the information you need without having to hire an expensive law firm and fight it in the courts.

Q: By the way, there's also a misperception afoot that there have been lawsuits flying everywhere in the aftermath of the ADA's passage.

A: Right. And there are not.

Q: Let's take another scenario. I'm Phil Smith, and I'm a paraplegic, and I want a job, but I can't find one. Can I call JAN?

A: For now, JAN is primarily for assistance in creating job accommodations for potential and current employees with disabilities. As an employer, what must I do for my employee with a disability? As an employee with a disability, what can I require from my employer? It's not an employment agency. But we are pursuing a new venture with JAN. You are Joe Smith, you have a disability, and you want to start a business. Where do you go? Through JAN we are offering the Small Business Self-Employment Service to help guide people with disabilities who want to start their own businesses. The President's Committee also has a web page called Job Links [<http://www.50.pcep.d.gov/pcep.d/joblinks.htm>]. Many businesses have posted their lists of job openings in an effort to invite qualified job seekers with disabilities to apply.

Q: I happened to notice in *New Mobility* magazine how many small businesses there are — one or two-person operations — that obviously were created by people with disabilities to meet the need they'd come across themselves for a particular product.

A: That's right. You know, when motorbus owners fought us on the legislation with regard to lifts and so forth, my point to them was, okay, it is expensive today — that was ten years ago — but once it is a requirement of law, you're going to have people who are going to spend money, perfect the lift and bring down the cost of it because it makes sense. That, of course, is what happened. It's true with everything in technology. Developers of hardware and software are now taking into account the needs of people with

disabilities by anticipating those needs. That's spectacular. A revolution has taken place. It's happening.

Q: Everything we've discussed sounds quite promising. But employment figures for people with disabilities, nonetheless, are quite low. Something like only 25 percent of severely disabled people are employed. Are there any indications that these numbers may be on the rise?

A: Well, you have to remember that until recently the U.S. Bureau of the Census didn't take official readings of people with disabilities. We have no base to go by — but it'll happen with the next census in 2000. From the best information we have available, though, from 1994 numbers, there was an increase that year of more than a million new jobs among people with disabilities. We presume that the 1995-96 figures coming out soon will be that much better. The thing to keep in mind is that more and more people with disabilities are "coming out." What happened in the past is that we were shoved aside, and that people were benevolent to us, saying, in effect, "we'll take care of you." Now what's happening is that people with disabilities are saying, "I want to participate. I want to get a job. I want to be independent." It's staggering to think that we have basically put out the helping hand, but we've also handicapped a lot of these people into becoming dependent on the handout. And they don't want it any more.

Q: So you're saying that the percentages may stay the same because so many more people are becoming disabled, and more so, identifying themselves as such.

A: That's right. And as the population ages, the number of people with disabilities will grow further. So if you only look at percentages, you're making a mistake.

Q: I realize you're doing a great deal to change attitudes, through internships, through networking and the like. What do you do in the case of an employer who simply balks at the notion of employing someone with a disability?

A: In instances where there's a pattern of abuse by a major employer or an industry, the U.S. Department of Justice and the Equal Employment Opportunities Commission have filed actions against them. We've had significant breakthroughs in those cases. But I am kind when I say that the fear factor is a problem. It's also the 1950s mentality of being benevolent, of taking care of those in need. Getting over that is a major problem. Many loved ones don't want their kids or other relatives to be exposed to hurts in the marketplace. My mother desperately did not want me to be exposed and rejected in the marketplace. Her attitude happened to be the worst thing for me. You have to get out there and suffer discrimination like everybody else.

Q: And if you had come along 30 years later, as a teenager with epilepsy, the picture would have been totally different.

A: Absolutely right.

Q: So what do you think are the greatest challenges right now? What haven't you been able to counter?

A: I have to say it again. It's still attitude, attitude, attitude — of employers, of loved ones, of benefactors, of the community — and the need to make the system work. It's pervasive throughout the public and private sector.

Q: It's also a global issue. Is anything happening on the international scene?

A: We had a conference last October [1998] in Madrid of the European Union and the United States. We discussed the progress they've made, and that we've made, and looked to how we can help each other. High School/HighTech and some other programs were used as examples. We're trying to get other countries to adopt some variation of the ADA. The EU is considering it as an overall policy for their union, which would be fabulous. And several countries are considering it on an individual basis. That's great. But the only way we're really going to turn that around, internationally, is by making a positive example in this country so that people with disabilities throughout the world will make similar demands. It's happening.

Q: Any final thoughts?

A: I feel very strongly that we're only going to make progress if we work at it. Look at what's happened on the race issue. The laws were adopted in the 1960s, and there are still problems. The same with gender issues. But you've got to keep at it. ■

A CHANGING LANDSCAPE IN EDUCATION BEYOND

A Dialogue with Judith E. Heumann

As Assistant Secretary of the U.S. Department of Education since 1993, Judith Heumann has had, as her responsibility, special education and rehabilitative services. She and her staff manage the Department's Office of Special Education Programs, the Rehabilitation Services Administration and the National Institute on Disability and Rehabilitation Research. The combined budget for the task is more than \$5.5 billion, with a general impact on the nation's 54 million disabled citizens, and, specifically, upon nearly six million children, youth and adults with disabilities across the United States. Heumann, a cofounder of the World Institute on Disability (WID) — the first research center devoted to disability issues — developed polio at the age of 18 months. Her parents fought for, and eventually won, the right for their daughter to be educated in the New York City public school system. Later, she was the first person with a disability to be allowed to teach in that same educational system, but only after she sued for that right.

In the following dialogue with Michael J. Bandler, Heumann reflects on her responsibilities, on the evolution of the Department's role regarding people with disabilities, and on her personal history.

Q: The fact that the Department of Education has a sector devoted to your areas of responsibility says something about the degree to which U.S. society has embraced this issue. Detail the scope of that mandate.

A: Our office was created in the late 1970s. Our three program areas — special education, rehabilitative services, and disability and rehabilitation research — really have responsibility over issues affecting children through senior citizens. In education for young children, we have responsibility over the Individuals with Disabilities Education Act (IDEA) [<http://www.ed.gov/offices/OSERS/IDEA/index.html>]. This is a federal-state partnership — meaning that states who agree to accept federal [U.S. Government] dollars also agree to comply with the statute.

I would boil down the major provisions of IDEA as follows: It assures that kids with disabilities are getting into school, are receiving appropriate placements, are being taught by qualified people, are being taught the standard curricula with accommodations where appropriate, and are staying in school. It also assures that they are being given high expectations, and advised that their job is to study and complete school and move into higher education or into the world of work. IDEA is a unique law. Not only does it assure that children have a right to a free appropriate education, but it also provides parents with protections that I think are pretty uncommon in the world. So if a parent believes that his or her child is not receiving appropriate services, there are very specific requirements as to the states' obligations to assure the parents as to avenues to pursue.

Q: You have spoken about “shared responsibility” with regard to education. That’s what you’re referring to here, I presume.

A: Well, I think it’s important for all children — whether they have disabilities or not — to know that the teacher’s job is to make sure they’re getting quality instruction, and the students’ job is to make sure they’re doing everything they can to study hard and to learn. Beyond that, you’re right. Parents of children with disabilities, for many years, have seen it as a shared responsibility. They’re a part of determining whether the child will be evaluated. And if the child is found to need special education and related services, then the parents are equal partners at the table — looking at what kinds of services the child should get, where the child should receive those services, and what the goals and expectations for the child should be.

Q: I gather that this legislation, like most, evolves over time, and continues to be refined.

A: Yes. The basic thrust of the law is the same. But we continue to fine-tune it. The reauthorization in 1997 emphasized the issues of teaching, learning and results. This means making sure the child’s parents receive report cards to the same degree that parents of non-disabled children receive them, that the kids are participating in state or local assessments with appropriate accommodations, and that they’re being taught the same curricula with accommodations. Also, there’s a much stronger emphasis on professional development both for general as well as special education teachers, because there’s a higher probability these days that disabled children will be in regular classrooms for all or part of the school day.

Q: Since you cite that probability, I was struck by the existence of the Individualized Educational Plan (IEP) within IDEA, which would seem to conflict somewhat with the likelihood that kids of all types will be together for most of the school day. What is the thrust of the plan?

A: The IEP is a document intended to help assure that every relevant person — the parent, the regular education teacher, maybe a speech therapist, a physical therapist, an occupational therapist, a rehabilitation counselor — clearly understands what the goals and expectations are for the individual child, that you’re developing a plan to make sure that the child and his or her teachers are going to be able to achieve those goals. It’s the time when you sit down and say, ‘This is the way that Johnny’s disability has an impact on his learning. Let’s look at the fact that he’s going to take algebra next year. What kinds of accommodation is he going to need for that?’ You put that into the IEP. If a student has a learning disability and needs extended test time, or needs material in large print, or needs to be situated in a certain part of the classroom, each of these would be in the IEP. The reality is that the IEP shouldn’t be something special for disabled kids — it’s the type of document that good schools are developing for all their children. The documents being developed for non-disabled children in some of the schools may not be as formal as the IEP process, but better schools are recognizing that it’s important to have discussions with families, and to

look six months or a year down the road at what the expectations are, and what role everybody has to play in helping that happen.

Q: Let's go back briefly to your other areas of responsibility.

A: We are responsible, too, for rehabilitation services, through another federal-state partnership. Here Washington provides about 78 percent of the funds. Under IDEA, we provide only nine percent of the funds. Under the Rehabilitation Act, we give money to states enabling them to provide services to working-age individuals. The purpose is to serve people who have more significant disabilities and needs, yet who are interested in going to work. We help them look at the marketplace, determine what their interests are, identify the areas of study or training they may need. Then we assist them in entering the job market by teaching them, for instance, how to write a resume or to conduct themselves when being interviewed. In many cases, rehabilitation counselors will also contact employers to make them aware of the pool of people with disabilities who are interested in working, and the kinds of qualifications these individuals have.

Q: One of the things that comes along with regulations is the question of monitoring and enforcement. How is that accountability incorporated?

A: That's been a part of both the special education law and the Rehabilitation Act for at least the last 30 years. What it basically means is that we provide, in both areas, funding for states to do things like professional development. We expect states to develop plans that look at their competencies — what are they doing right, what are they expected to do, where are they falling short and how they can improve. We will then monitor the states. In the case of special education, if a state is having a lot of problems, we enter into corrective action plans,

provide technical assistance, and revisit the jurisdiction every year. Where states are still not doing what they need to do, other actions can be taken against them. Some states are doing a good job, and others have significant problems that haven't improved over the years. These are the ones we're focusing more of our attention on, while giving recognition to those states that are doing a good job. In the area of rehabilitation services, money goes to the states, which have offices in different locations. Our office monitors those offices and talks to individuals who have been served. Monitoring is very important, not because we're interested in being punitive, but because our customers — children with disabilities and their families — should know that when we're giving out billions of dollars, accountability counts.

Q: You've served in various *de facto* roles in other countries, representing the United States. You've also interacted with people overseas through the World Institute on Disability (WID) [<http://www.wid.org/>]. What are your impressions of the global interest in, and involvement with, people with disabilities?

A: In this office, we've focused a lot on the international picture. One of our goals in this Administration has been to get disability integrated more effectively into the agendas of the United States Government foreign affairs establishment — the U.S. Information Agency, the Agency for International Development, and the Department of State. My experience working with WID — where a major focus was working with individuals with disabilities in other countries on issues such as civil rights, housing, transportation, independent living, education — was that we excelled in the United States in certain areas. Civil rights protection was an example. But we fell far short in certain other areas, like health care. Comparing us to Western countries, subsidizing disabled individuals who have lower incomes in the area of housing, personal assistance services — where someone will be able to assist families with a significantly disabled child or adult in duties like bathing and cooking and shopping and cleaning and driving — we are far

behind many in that area. So WID was looking at a number of areas, personal assistance services being one of them. That was very beneficial. Now, in this job, I am helping to arouse the United States Government to see that, for example, if we're working in other countries on education issues, the education with which we're helping them models more of what we have. For example, they need to ensure that disabled children are going to school and being included or integrated more often than not, and that there's an expansion in special developed training for teachers. We've had a relationship with Mexico, for instance, that has development government-to-government because of the bilateral agreement between the U.S. Department of Education and the Mexican Department of Education. We sent down a group of our grantees and staff who are knowledgeable on inclusion issues; they sent principals, teachers, and parents from a number of different schools here to discuss issues and concerns involving integrating children with disabilities in schools, and the training that needs to occur in order to facilitate that integration.

Q: Would you consider some of these initiatives tests for what might evolve bilaterally or multilaterally with other countries?

A: Yes. There's an interest on the part of many countries — particularly people with disabilities and concerned staffs and professionals — to do more with the United States in a more formal way. In mid-1997, the United States sponsored its first international women's conference on disabilities, with 632 women from 82 countries. Twenty-two U.S. Government agencies supported it. It followed the platform of action developed as a result of the 1995 United Nations Beijing Conference on Women. Over the next two years, there will be four follow-up conferences in the United States and four in other regions — in Mexico, Africa, Asia and Eastern Europe.

Q: I realize that much of this stems from the Beijing Conference. Still, I have to ask you the obvious — whether actions and progress involving girls and women apply equally to boys and men.

A: It's a very important point. If the U.S. policy on education focuses on education for all, our goal is just that. We would want assurances, when we give money to other countries, that they will serve disabled boys and girls, men and women.

Q: So you're using the framework of these conferences...

A: ...to help advance an agenda across the board.

Q: Let me close with a reflection on your personal history. Your mother, who passed away recently, was one of the early fighters in the struggle for civil rights for people with disabilities. Your parents couldn't even get you into a regular public school until the fourth grade. So your work today all emerges from that heritage, that legacy. Compare, if you will, the landscape of today with the world in which you grew up.

A: I think, basically, that we have many pieces of legislation which have been changing the landscape literally. And while you can't change people's attitudes legislatively, I think the changing of the landscape has really helped begin to change people's views of those of us with disabilities. We've moved from being seen as something inanimate to being people out in the community, with whom citizens with no disabilities engage directly or indirectly more than they ever did before. So I think that is slowly helping to dispel myths that existed about who we were as disabled people. I also think we have a much more articulate group of disabled individuals who have decided for themselves that they are not going to accept a life of second-class citizenship in this country. That's resulted in these pieces of legislation which are helping move the society forward. The society didn't create what it needed to on its own; it needed that strong legislative push.

My parents were not really typical; they were and are the parents of today, who basically make a

decision that they're living at home with their kid with a disability. They didn't expect the child to have a disability. They've had to be dealing with what their expectations were and trying to hold on to having similar expectations. And the system around them then, and still today, too often continues to put out messages which say, 'you need to lower your expectations of what you believe your child can do.' And so, I think, we've seen more organization of parents, just like we've seen more organization of adults with disabilities. And that, in and of itself, has been helpful. Also, younger parents of non-disabled children are being more exposed both to people with disabilities that they knew when they were growing up, and to kids with disabilities in their own children's classrooms, as well as in the workplace.

It's really like questions of race and gender: the more you're willing to interact on a person-to-person level, the more you recognize that we're all individuals, and the labels — whether religious, or racial, or gender-based, or dealing with disabilities — are really no more than labels. You need to figure out who we are individually.

Q: It would have been easier for your parents today, obviously.

A: Well, my parents were trailblazers in many respects. They had a belief. Nobody around them necessarily agreed with it, but they just went forward. ■

REVIEWING POSSIBILITIES

A Discussion with John D. Kemp

In any exploration of the field of disability rights, the name of John D. Kemp invariably surfaces. An attorney and an activist for more than a quarter-century on behalf of people with disabilities, Kemp is president and chief executive officer of Very Special Arts (VSA), which describes itself as “promoting the creative power in people with disabilities.” VSA, which celebrates its 25th anniversary in May 1999, and which will change its name to VSA Arts Connection at that time, is a global network involving chapters in 43 states and 83 countries. Kemp is familiar with the plight of people with disabilities: He was born without arms below the elbows and legs below the knees, and wears prosthetics to maximize mobility.

Recently, in a discussion with Michael J. Bandler, he provided insights into disability awareness today.

Q: Theoretically, what would you say propels a society forward vis-a-vis the needs of its citizens?

A: I think it’s a consciousness and a morality about how it wishes all people to be treated, including those who are the least fortunate — sort of drawing a minimum level below which we think it’s inhumane. This is a constantly evolving standard, hopefully upward, a continuously improving style or direction.

Q: Historically, where would you place the beginnings of consciousness-raising regarding people with disabilities?

A: If I were to pick out a point in time, generally speaking, I could possibly say — from what little I

know about this — is that people in the Jewish faith historically have responded much more warmly and kindly to people with disabilities than any other groups of people I can categorize. And that goes back 2,000 years. I think this fairness is something inherent in their religious beliefs and in their doctrines and value statements. More recently, you can go back to the early 1800s in this country, when Sidney Howe started the first school for people with mental retardation, a residential school. He was blazing a trail. But soon he became very suspicious that it was going to be a dumping ground for people, and he had serious reservations about what he started. The movement towards segregating people with disabilities took off then, and ran for a hundred years.

Q: That was the forerunner of the debate over mainstreaming and inclusion?

A: Right. And we’ve been disengaging from the institutionalization period which he started, and trying to get into an inclusive model. Frankly, there are some of us who think that inclusion in every sector and every aspect of life isn’t always in the best interests of people with disabilities.

Q: How so?

A: There are people who feel that we’re in a 20-to-30-year transition. By immediately going to a total inclusion, people who are teachers or involved in other ways may not be prepared to properly assimilate and serve people with disabilities in the integrated setting that they’re entering. To create an

equal opportunity, according to this point of view, people with disabilities may need some additional separate supports to make the opportunity an equal one. It's a question of fact in each and every instance how well people are being served. Let's take a regular school system. If it really isn't ready — if there hasn't been enough training, hasn't created the right climate, doesn't have the proper natural and technological supports for kids with disabilities to come into the regular classroom, it's going to be a disaster, frankly, for some kids to be placed in that totally mainstreamed, integrated system. It's not the kids' fault — it's the system's fault for not being prepared. Until that system is really ready — and it takes time, knowledge and effort — there will be times when a separate system may enhance an individual's performance.

Q: In other words, you need the groundwork first.

A: Right. To just automatically switch from one day to the next to an inclusive community sounds great. But there's going to be some harm done to some people. I would say that for the most part, most young people with disabilities would do well in an integrated, inclusive setting. But there may be 10, 20, 30 percent who do need some additional, unique supports which aren't ready for delivery by the system.

Q: But eventually, you get to the point where it'll all work out.

A: Absolutely. I think we're going to look back at all of this in 20 or 30 years and say, with some astonishment, 'we segregated kids with disabilities in special schools?' Because it's going to be *de rigueur*. It's going to be obvious, automatic, to integrate them. But we're not there yet.

Q: To return to the historical perspective, specifically to the postwar period, what were the first trigger points for activism?

A: The civil rights era raised the consciousness for all people, especially when you started segmenting those groups who had been treated unfairly. Race came first, then gender. We came along third. The

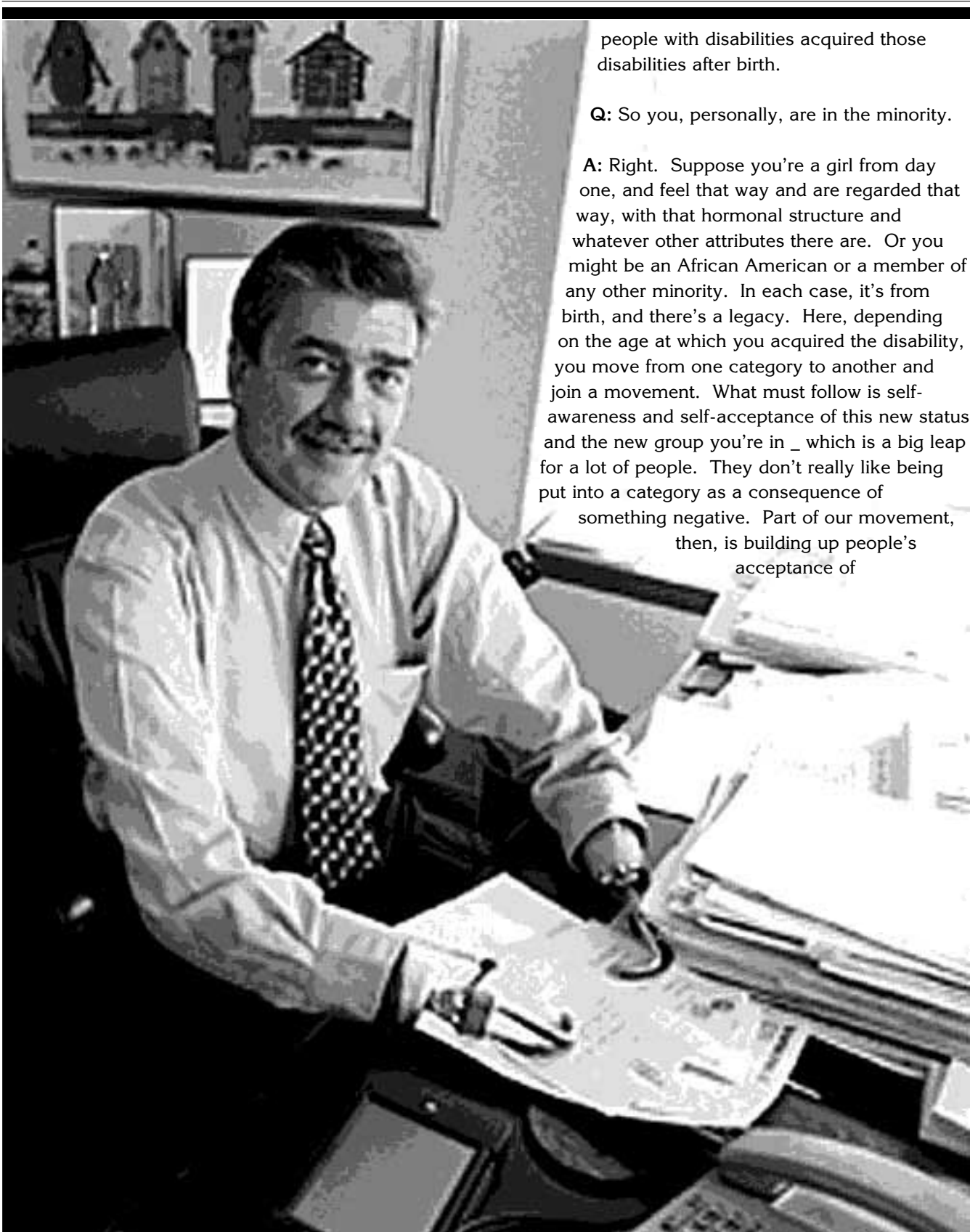
sequence of events is as follows: There were two court cases in 1969 and 1970, both involving education. The plaintiff in each case claimed that because property taxpayers were supporting the educational system, any citizen — especially with a mental disability — had a right to a free, appropriate public education. It was then that the first round of state court decisions recognized the constitutional right to that. Shortly thereafter came the 1973 Rehabilitation Act, which included nondiscrimination in U.S. Government programs and affirmative action in federal contracting. Although that was pretty narrow, there was a sequence of other legislative initiatives. There was also a pretty devastating case in 1970 involving a deaf woman who sought to do her practicum as a nurse. A local community college refused to accommodate her disability in the practicum as she was learning her craft. The school won a 9-0 decision in the U.S. Supreme Court on the basis of Section 504 [of the Rehabilitation Act, which states that any entity that receives federal financial assistance must not discriminate]. We were so unprepared, and unsophisticated in our legal maneuvering that we lost it. That was probably the lowest point. Thus has sprung up some really fine disability rights advocacy groups that focus on creating the proper legal arguments and picking the right cases to take to the circuit courts and higher.

Q: So that, in a sense, was the impetus for the disability rights movement.

A: Right. At the same time that you had the 1970 decision and then the 1973 legislation, you had the Vietnam war. A lot of people came back injured. And whether it was guilt or a heightened sensitivity, something happened to pique the social consciousness.

Q: Forward movement would appear to be two-sided. Society should respond to those with disabilities, but people with disabilities need to have pride in what they can and should accomplish.

A: You're really talking about the fact that in order to be a better citizen, or family member, or student, or employee, you need to take pride in yourself. What is such a challenge to us is that 85 percent of



people with disabilities acquired those disabilities after birth.

Q: So you, personally, are in the minority.

A: Right. Suppose you're a girl from day one, and feel that way and are regarded that way, with that hormonal structure and whatever other attributes there are. Or you might be an African American or a member of any other minority. In each case, it's from birth, and there's a legacy. Here, depending on the age at which you acquired the disability, you move from one category to another and join a movement. What must follow is self-awareness and self-acceptance of this new status and the new group you're in _ which is a big leap for a lot of people. They don't really like being put into a category as a consequence of something negative. Part of our movement, then, is building up people's acceptance of

their condition and their membership in a social minority movement, which is quite a challenge unto itself. In fact, I'd say that at least half the people who have acquired a disability in their lives, or have a disability, probably don't necessarily regard themselves as part of a social minority movement. They've overcome their disability. They've tucked it away. It's one thing to throw numbers around when we lobby, to say that we represent 54 million Americans. But many of them would think there's something negative associated with being part of a defined group.

Q: There's also a different kind of awareness that enters the picture if you're someone like [actor] Christopher Reeve, who falls off a horse when he's in his 40s, or if you're an eight-year-old kid who suddenly is stricken with deafness or blindness.

A: That's true. And a lot of what a child picks up — optimism or pessimism — is what the parents feel, especially with young kids. But you know, I have read the research about personality traits before and after disability. You have the same fundamental drive and perspective on life afterwards as before. So if you have a victim personality before you acquire a disability, it's going to get worse. And if you see, optimistically, something wonderful out there every day, you still will.

Q: Talk for a minute about the definition of what constitutes disability. It would seem to me that that definition is evolving.

A: I don't think it's any broader than the way it was defined in 1973. The law passed that September had a three-part definition and framework. It covered any person who has a physical or mental impairment which substantially limits a major life activity; any person who has a record of an impairment; and any person who is regarded as having an impairment. It was found to include AIDS, alcoholism, contagious diseases and the like. As with any civil rights law, there are always definitional

questions that are answered early on in lawsuits. You're defining the boundary of the scope of the law.

Q: Well, has the boundary expanded through court cases?

A: I think it's been more carefully defined through court cases, but it was always intended to protect people who have a physical or mental condition which substantially limits a major life activity.

Q: That third segment — any person who is regarded as having an impairment. Does that mean how the person is perceived by others?

A: Yes. And listen to this: There are several parts of the 1990 Americans with Disabilities Act [ADA] that essentially say that non-disabled people can have protection from discrimination if they are wrongly regarded as having a disability and treated or discriminated against on the basis of that wrongful perception.

Q: Such as?

A: You pull a muscle, and walk into an interview limping. The interviewer notes, 'unable to stand for long periods of time...' The person is wrongfully regarded as having a disability, and treated as if he or she does, and discriminated against. Another part of the law deals with retaliation. If you are not disabled, but you go into your supervisor and tell him you don't like the way the company is treating one of your colleagues who has a disability, you're immediately protected. So is it an expanding protection? I don't think it's any broader than it was originally intended. But we're getting better at identifying conditions.

Q: One of the basics we should explore, particularly while we're speaking of definitions, is the question of sensitizing the general population to the needs of people with disabilities, even in terms of word usage.

A: I've done probably a thousand disability awareness training programs in my early days, for about a seven-to-ten-year period. I included the

intellectual approach to this — what the law says and so on. Then I added some experiential stuff, with about an hour-and-a-half or two hours of people simulating disability. The point is not to teach people what it's like to live with a disability — it's to teach people what it's like to be regarded by others as having a disability. There's no way you'll ever know, if you're not an amputee, what that's like — or blind if you're not blind. The purpose of disability awareness training for human resource personnel, using an experiential process, is to teach people what it's like to be regarded as having a disability, and how different it is from how they are regarded because they don't have a disability. You're treated much less kindly [in the first instance].

Q: What about language — the terms to use, the ones to avoid? It seems that the best rule of thumb is to speak of people who happen to have a particular disability, such as “John Smith, who is blind.”

A: If it's relevant. You are not your disability — that's the underlying approach. You should put the disability into the proper context.

Q: Someone told me that the only impediments to progress for people with disabilities are the unasked questions or the unstated requests. Is that a fair premise — that you can't have an advancement if no one knows that there's a problem?

A: That's true. But the other part of that is that something might be available, but it's too expensive or impractical to get to one human being to use. I do think that we in the United States do have this incredible ability to solve problems. We're starting to use our technologies to solve human problems in a better way. It's an incredibly exciting time. And yet, the solutions are sometimes just too expensive. Having said that, though, one wonderful characteristic about Americans is our creativity. Twenty or 25 years ago, we didn't have computers on our desks. Just think of the human applications of these things! It's mind-boggling what we can

create. And for people with disabilities, computers have been a huge equalizer. Also, we used to think of entrepreneurship resulting from discrimination. It was a consequence of disability. You started a wheelchair repair shop in your garage because you couldn't get a job. Now the cottage industries and home-based businesses are absolutely the way to go.

Q: Give me your personal perspective on the changing times in the public and private sector.

A: Life is so much better for many of us, and I think it's because, in part, we started with the physical environment in our minds, and the mental test was, would a person in a wheelchair be able to get in here. It was something we could touch and change, and people could understand it pretty easily. It was a good starting point — as it should have been — because it created the pluralistic approach to accessibility, to broaden out the uses of existing structures to include more people. That is a very important principle, and it applies in other areas, too. But where it breaks down is when you have policies and procedures that still exclude people with disabilities. Health care is a pretty direct example of that. It's not the accessibility any more; it used to be that the environment was a barrier. Today, the biggest barriers are policy questions, including health care, that keep people with disabilities isolated. It's always the balancing of resources against people's rights. How much does it cost to create access?

Q: In other words, accommodation versus undue hardship.

A: Exactly. But when we get down to it from an advocacy standpoint, we say, what price civil rights? There's always a price. But what frustrates us is that we have such little power to demand full access — the right to basic health care, for example. We're not organized enough.

Q: We talked a moment ago about sensitivity awareness training. How, on a more matter-of-fact level, is negativity countered?

A: The essence of VSA [<http://www.vsarts.org>] is that we are able to demonstrate that you can be a

legitimate artist with a disability, playing just about any role. Art is about breaking down stereotypes and barriers and creating wonderful opportunities. Our avenue to a better quality life is through art and culture; another organization's might be through employment and housing.

Q: Would you say that U.S. society today, as a whole, is more aware, more giving, more considerate...

A: More accepting? Yes. I would say we have done wonderfully for people with physical disabilities, but we have a long way to go for people with cognitive disabilities. It is one of our real challenges. We have developed a sensitivity for people who physically can't get around as well, and we try to accommodate them as best we can in our society. But that's not true for anyone who has a psychological or mental disability, or who has problems associating with speech or communication. People will make terrible assumptions based on someone's limitations of speech.

Q: Tell me about the myths surrounding persons with disabilities — or disabilities themselves.

A: I've already mentioned the most significant one — that if the disability is associated with communication, immediately it's assumed to be linked to one's intelligence quotient. Then there's the assumption that if you're blind you can't hear. When I speak, I tend to use the myths as a point of humor.

Q: On another subject, it isn't true that ADA lawsuits are flooding the courts, is it? There is general compliance with the law.

A: That's right. Most people want to do good. They don't want to intentionally try to violate the law or disregard people with disabilities. I do think that most disability discrimination is unintentional. It's just that people don't know how to handle the situations. A human resources person will try to balance the interests of the company with trying to

accommodate, in a *de minimus* way, the needs of an individual. At some point, you're going to be tested whether the cost is too great. And policy decisions are made by precedent. So human resource people and supervisors do have a real challenge to make careful and fair decisions on an individual basis.

Q: Another myth is that people with disabilities prefer to be separated, alone, with separate programs and services.

A: Right. I don't want to live in a segregated environment. And yet, some people with disabilities may have grown up and worked in sheltered workshops. The thought of inclusion frightens them. If they choose to stay in a segregated environment, they should have that choice.

Q: Meeting the goals of people with disabilities has manifested itself in many ways — from greeting cards and signs in museums in Braille, signed performances for people with hearing loss, incorporation of people with disabilities in the arts and athletics. Can you point to some others — like indentations in the curb at every street corner to accommodate people in wheelchairs?

A: Well, you've mentioned quite a few. Berkeley, California, and Washington, D.C., are nirvana with respect to handicapped access. The business community is starting to realize that there's a significant market of people with disabilities who haven't been talked to as a group, and they're starting to advertise using people with disabilities. That's starting to draw us to their companies. The first ones to do it, and do it well, and in good taste, are the ones who are going to get our business. In the area of memberships in organizations, it's been found that it's part of membership development to

advertise signed plays or audio descriptions. It'll bring a new group of people to the organization.

Q: How did you come to devote your attention to VSA?

A: I was asked to consider working there. I didn't know a lot about it, but the more I explored it, the more I realized that I could learn an awful lot from my experience here. That, to me, was really attractive; it was an area of my life that I hadn't developed. I've learned a great deal from my work in the arts. I think there's added advantage for people with disabilities to participate in the arts, because it's such an effective way to communicate. Many were excluded from their high school and college arts programs because people didn't know how to include them. The arts are a powerful tool for developing self-esteem and self-confidence and self-expression. It gives people with disabilities the chance to be players in the world today.

Q: With scores of VSA chapters around the world, it would seem that there is an awareness, around the world, of how arts can benefit people with disabilities.

A: Exactly. I really think the arts are a universal language, reaching across cultures and generations, connecting mind and spirit, something we practice here a lot.

Q: What have you learned, in your contacts with other countries, about the status of people with disabilities around the globe?

A: There are amazing things happening. I see the written annual reports from the affiliates, and am absolutely blown away by what I read. But I really get excited when I see videos or photos, or actually visit affiliates around the world. In Ireland, there's a powerful playwriting program for people with disabilities. In fact, it's so good that a troupe of actors and award-winning playwrights will be coming to our international festival in Los Angeles the end of May. In Saudi Arabia, there's a fantastic school

servicing thousands of children with severe disabilities, a state-of-the-arts school staffed by teachers who use the arts as the cornerstone of the curriculum. In Japan, there's a workshop in which people with very severe disabilities weave commercially viable products that are marketed worldwide. Those are a few examples. So we have a lot to learn from our international partners and friends.

Q: To sum up, then, are you sanguine about where we're headed as a society with respect to people with disabilities?

A: I'm going to steal a phrase from a friend of mine: "An advocate is never satisfied with the status quo." ■

THE AMERICANS WITH DISABILITIES ACT: ON THE RIGHT TRACK?

BY PAULA N. RUBIN

In describing the plight of people with developmental disabilities, Justice Thurgood Marshall, in 1985, called it “a lengthy and tragic history...of segregation and discrimination that can only be called grotesque.” When the Civil Rights Act of 1964 became law, missing from the list of individuals entitled to protection against discrimination were people with disabilities. It was not until nine years later, when the Rehabilitation Act of 1973 was enacted, that the “handicapped” were afforded any protection at all. Even then, only those entities receiving federal [U.S. Government] funds had to comply with this law.

Congress ultimately realized that people with disabilities faced pervasive discrimination. Besides outright intentional exclusion, examples included the discriminatory effects of architectural, transportation and communication barriers; overprotective rules and policies; failure to make modifications to existing facilities and practices; exclusionary qualifications standards and criteria; and segregation and relegation to lesser services, programs, activities, benefits, jobs or other opportunities. Congress also acknowledged what people with disabilities had known for a long time: that these individuals “occupy an inferior status in our society and are severely disadvantaged socially, vocationally, economically, and educationally” and that unlike the other protected classes of race, religion, national origin, age and

sex, people with disabilities had “no legal recourse to redress such discrimination.”

On July 26, 1990, the Americans with Disabilities Act (ADA) was signed into law as the most sweeping civil rights legislation passed since the 1964 Civil Rights Act. At its core, the goal of the ADA is to integrate people with disabilities into mainstream society. Two years after this law was signed, compliance began to be phased in. By July 26, 1994, the ADA was in full force and effect.

With the fifth anniversary of full impact approaching, is the ADA working? Have the lives of people with disabilities improved? Do they now have access to jobs and benefits of employment? Can they participate in government programs, services or activities? Are people with disabilities able to enjoy meals at the same restaurants, shop at the same malls, see a movie at the same theaters as people without disabilities?

As for those entities covered by this law, what has been the impact on their lives? Is this another “unfunded mandate” costing private business and government entities millions? Have employers been required to lower their standards? Do they now need to hire the “handicapped” even if they can’t do the job?

It seems appropriate at this juncture to see if this law is making the grade.



Readin'

Any assessment of the ADA requires at least a basic overview of the act and the vocabulary needed to understand it.

AN ADA PRIMER

In general, the ADA makes it illegal to discriminate on the basis of disability. The goal is to provide the estimated 54 million people with disabilities access to employment, to governmental programs, services and activities, and to public accommodations. To eliminate the barriers people with disabilities traditionally face in these arenas, the law contains five sections. Title I prohibits discrimination in employment; Title II provides that state and local governments must make their facilities, programs, services and activities accessible; Title III makes discrimination in public accommodations illegal; Title IV bans discrimination in telecommunications; and Title V addresses miscellaneous provisions concerning the ADA's relationship to other laws and the issue of health insurance.

Perhaps the most important question that arises under the ADA is whether, for purposes of the act, a person has a disability. Under the ADA, a person with a disability is someone who: (1) has a mental or physical impairment that substantially limits a major life activity; (2) has a record of such an impairment; or (3) is perceived or regarded as having such an impairment. There are several significant phrases in this definition: "impairment," "substantially limits," and "major life activity." Understanding these concepts is critical to understanding who meets the ADA's definition of disability.

An "impairment" is a physical disorder affecting one or more of the body systems or a mental or psychological disorder. "Substantial limitation" means, when compared to the average person: (1) an inability to perform a major life activity; (2) a significant restriction on how or how long the activity can be performed; or (3) a significant restriction on the ability to perform a class or broad range of jobs. "Major life activities" are those basic activities that the average person in the general population can perform

with little or no difficulty. These activities include walking, seeing, hearing, speaking, breathing, bending, learning and working.

It is important to understand that a diagnosis does not a disability make. For example, according to the Technical Assistance Manual of the Equal Employment Opportunities Commission (EEOC), an individual with mild cerebral palsy that only slightly interferes with his or her ability to speak but has no significant impact on other major life activities "is not an individual with a disability under this part of the definition."

EMPLOYMENT ISSUES. Even if an individual meets the definition of disability, he or she may still not be entitled to the protection. For the ADA does not cover all people with disabilities, but rather encompasses only qualified individuals with disabilities. In the context of employment it means that the individual is qualified for the job because he or she has the requisite education and experience and can perform the essential functions of the job.

If an individual with a disability is otherwise qualified, he or she may be entitled to a reasonable accommodation. Reasonable accommodations include making existing facilities readily accessible and useable, job restructuring, modified work schedules, acquisition or modification to equipment, or adjustments to policies. The accommodation should be effective, that is, one that allows the person to perform the essential functions of the job.

There are times when providing an accommodation will not be required. Obviously it is not required when it would not enable the individual to perform the essential functions of the job. Likewise, no reasonable accommodation is required if it would impose an "undue hardship" on the employer or pose a "direct threat" to the health and safety of the individual with the disability or to others.

An "undue hardship" is a significant difficulty or expense relative to the size and overall financial resources of the employer. Accommodations may constitute an undue hardship, according to the

EEOC, if they are unduly costly, extensive, substantial, disruptive, or would fundamentally alter the nature or operation of the job.



“Direct threat” is a significant risk of substantial harm based on objective evidence and not mere speculation. It cannot be predicated on some remote possibility in the future but must be a present risk. Employers are required to reduce or eliminate the risk with an accommodation. When this is not possible, then a refusal to hire an applicant or firing an employee with a disability may be appropriate.

GOVERNMENT SERVICES AND PUBLIC ACCOMMODATIONS.

With a few variations, the definitions and concepts under Title I also apply to Titles II and III. Under these sections, a qualified individual is someone who meets the “essential eligibility” requirements of the program, service or activity. Entities must also provide reasonable accommodation. Such accommodation may come in the form of reasonable modification to policies and procedures that screen out people with disabilities, to barriers in architecture or communications. No reasonable modification is required, however, if it “fundamentally alters” the nature of the program, service, or activity. A “fundamental alteration” is one which changes the nature of the program, service or activity such that it is no longer the same. Finally, like undue hardship under Title I, entities covered by Titles II and III will not have to provide accommodations that pose an undue burden or pose a direct threat to the health and safety of others (but not the individual with the disability as in Title I).

A common question is whether entities are expected to rebuild or renovate their facilities. The answer is a qualified “no.” While new construction or renovations to existing buildings must comply with ADA standards, entities are not expected to retrofit their existing buildings. Nor are they expected to alter historical landmarks. A rule of thumb is to look at the program, not the building. Is it possible to change the way the program is delivered rather than the building? Is it possible to move the program, service or activity to an accessible part of the building? If so, then remodeling the delivery of the

service rather than the building may suffice.

APPLIED LEARNING

From the day it was signed into law, critics and supporters of the ADA have been locked in a war of words over the potential impact of the law. Early on there were dire predictions about what the ADA would cost those required to comply with it. There were also complaints about the vagueness of the language and cries from employers that the quality of their output would necessarily decline if they were required to hire less qualified individuals with disabilities.

ADA supporters had their own cache of concerns. Would the ADA make a real difference in the lives of people with severe disabilities? How do they protect the integrity of the law from the notion in some quarters that it attracts people solely interested in monetary advancement? Would the change from a Democratic to a Republican majority in Congress result in the law being amended, as the Republicans have vowed on more than one occasion to do.

Furthermore, did the ADA ratchet up the cost of employing people with disabilities? According to a 1995 Harris survey of businesses, 80 percent of those employers polled stated that it had not. Eighty-two percent, in fact, indicated that the ADA was worth the cost of implementation. In fact, a study commissioned by Sears, Roebuck and Company, a leading U.S. merchandiser, found that 97 percent of accommodations provided by employers cost less than \$1000. The average cost of an accommodation was about \$200. These costs seem insignificant especially when compared to the cost of firing and replacing employees (which, for Sears, is roughly \$2,000 per individual). And they pale in comparison to the average cost of an ADA litigation, which is \$12,000.

Yet, despite these statistics, criticism has continued in the media and elsewhere. In fact, supporters of the ADA seem to be losing the public relations battle. But is the criticism justified? Does the ADA’s reality — its existence, policies and results —

support this type of rhetoric? A look at what has taken place in the U.S. legal system may offer answers.



Writin'

According to an article by Paul Steven Miller in the *Syracuse Law Review*, critics of the law claim "that the definition [of disability] is too vague, enabling nearly everyone to be disabled and thus protected by the law." Likewise, there are claims that the ADA has allowed people without disabilities to play games with the system, and bring frivolous lawsuits. However, the reality does not support this rhetoric.

A study released by the American Bar Association (ABA) in 1998 suggests that, on average, in 92.1 percent of ADA cases in which a decision was made in favor of one side or the other, employers have prevailed. One way in which employers have been so successful is by challenging whether or not the plaintiff meets the ADA's definition of disability. The results have been staggering. One hundred and four of the 110 decisions issued by courts in the latter part of 1995 and 1996 under Title I of the ADA found that the plaintiff did not meet the ADA's definition of disability and ruled in favor of the employer.

When the drafters of the ADA defined disability, they borrowed the definition contained in the Rehabilitation Act of 1973. They never expected this definition to be used as a sword against the very group that it was intended to protect. For over the course of the two decades that the Rehabilitation Act had been in effect, it had not been subjected to the kind of attack from the defense bar that the ADA has endured since 1992.

Under the Civil Rights Act of 1964, African Americans do not first have to prove that they are African Americans. Nor must a woman prove she really is a woman. Yet under the ADA, a person must first overcome the threshold issue of whether he or she has a disability.

As the *Daily Labor Report* noted in a 1998 article on the ABA survey, "employees are treated unfairly under the Act due to the myriad legal technicalities that more often than not prevent the issue of employment discrimination from ever being considered on the merits by an administrative or judicial tribunal."

Some of the impairments found not to be disabilities by the courts in late 1995 and 1996 included cancer, depression, diabetes, hemophilia and multiple sclerosis. A woman with breast cancer who could work while undergoing radiation therapy was found not to meet the ADA's definition of disability because she was not substantially limited in the major activity of working.

Surprisingly, it has been the Supreme Court of the United States, and not state and lower federal courts, where people with disabilities have been vindicated. The nation's highest court has reviewed and ruled on two cases involving the ADA and is currently set to hear arguments in five more.

In a 5-4 decision, the Court ruled in *Bragdon v. Abbott* that HIV infection that had not progressed to the so-called symptomatic phase is a "disability" under the ADA. The case involved the refusal by Bragdon, a dentist, to treat Abbott, a patient, who had the HIV virus. The dentist insisted that treatment occur in a hospital (at additional cost to the patient), arguing that this was necessary to minimize Bragdon's risk of exposure.

In reaching its decision, the Court held that lower court decisions that asymptomatic HIV infection does not rise to the level of an "impairment," much less a "disability," are wrong. The Court ruled that in light of the immediacy with which the virus begins to damage the infected person's white blood cells and the severity of the disease, "we hold it is an impairment from the moment of infection."

In addition, the high court found that the ability to reproduce and bear children is a "major life activity" under the ADA, noting that "reproduction and the sexual dynamics surrounding it are central to the life process itself." Such a conclusion may have consequences reaching beyond HIV and AIDS, to the struggle with infertility.

The Supreme Court has also looked at the ADA and its impact on state and local government under Title II, ruling unanimously in *Pennsylvania Dept. Of Corrections v. Yeskey* that state prisons are covered by that provision of the ADA. This case arose when an inmate with a history of hypertension was

denied access to a prison's motivational training camp program. Had the inmate been permitted to participate in this program, he would have been eligible



for release from prison in six months, instead of 18 to 36 months. In ruling that the ADA applies to state prisoners, the Supreme Court found that state prisons fall squarely within the ADA Title II definition of “public entity.”

By mid-1999, the Court will decide whether applying for social security disability benefits prevents an individual from making a claim under the ADA. At issue is whether someone can claim they are sufficiently disabled to be eligible for SSDI, yet nevertheless be a “qualified individual with a disability” under Title I of the ADA. The Court will also review the issue of whether the ADA integration mandate applies to individuals in facilities, thereby requiring states to seek to move people with disabilities from institutions into community-based living situations.

In addition to these issues, the Court, by July 1999, will address the question of mitigating factors — that is, whether the person meets the definition of disability if he or she uses correctable measures. Examples might be an individual with epilepsy who has been seizure-free through medication, or someone with high blood pressure that is kept under control by drugs. The EEOC, and the legislative history, agree that a person’s disability is determined without regard to mitigating circumstances. Lower courts, however, have not always followed legislative intent or EEOC guidelines. By accepting not one but three cases of this type, the Supreme Court clearly has indicated its interest in resolving this matter.

The effectiveness of the ADA cannot and should not be evaluated, however, solely on the results of judicial opinions or other employment statistics. To truly assess the ADA, one must look at what statistics can’t measure — the people with disabilities who have been served by this civil rights law without going to court, who have not filed a claim with the EEOC, and who do not fit into a category being surveyed or polled.

Rithmetic

No one keeps national statistics on the people with disabilities who, because of the ADA, have been able to obtain a successful resolution of an issue without the fanfare of a lawsuit. These stories far outnumber the judicial opinions.

The Protection and Advocacy System (P&A) [<http://www.protectionandadvocacy.com>] is a federally-mandated, federally-funded national network of agencies in every U.S. state and territory. Its mandate is to advocate for the rights of people with disabilities. P&A advocates work with literally tens of thousands of individuals with disabilities, their families and representatives annually. P&As provide information and referrals, supervised inquiries, counseling, negotiation and mediation. Only a few cases ever end up as full administrative hearings and even less result in a lawsuit. And the handful that do go to court more often than not wind up being settled.

The real story is made up of the cases that don’t sell newspapers. The general public never hears about them because they represent problems solved, lawsuits avoided.

P&A STORIES.

□ One P&A enlisted consumers to gather employment applications with disability-related questions. As a result of writing letters and talking to employers, 29 company heads have changed their applications to remove objectionable questions in the two-and-a-half years since the project began. Illegal questions dealt with disability, medical releases and treatment information. No one was sued and the employers were grateful that a solution was found.

□ A symphony orchestra organization refused to allow a musician in a wheelchair with multiple sclerosis to bring her service animal onstage, even though she needed the dog’s services to pick up her bow or sheet music if dropped, and to assist her in maintaining her posture if she began to slump over.

She was in danger of losing her job.

Through negotiations with the symphony, the client received the accommodations she needed and the



symphony personnel received training on disability and the use of service animals.

❑ A vocational rehabilitation counselor with severe rheumatoid arthritis had been denied a one-day-per-week telecommuting request as a reasonable accommodation, despite the employer's own policy encouraging telecommuting for environmental reasons. After the P&A became involved in negotiations, the counselor was immediately granted the accommodation.

❑ A blind individual was starting to receive poor evaluations from her computer service company employer because of its failure to provide her with appropriate assistive technology. The P&A negotiated to provide a Braille printer and a two-way headset to enable the client to perform her job satisfactorily.

❑ A food preparation employee for a major fast food chain called in sick because of his mental illness. When he tried to return to work, he was not placed on the work roster. Although the client found another job in the meantime, with P&A intervention, he received his back wages, and a favorable reference. Furthermore, the company agreed to hold trainings for employees on mental illness and the ADA.

❑ A janitor with a severe learning disability was fired after his probationary period for failure to follow instructions. The P&A intervened and convinced the employer that with a reasonable accommodation — providing instructions on audiotape instead of in writing — the janitor could satisfactorily do the job. This client is still employed and succeeding, thanks to the accommodation.

❑ A hospital employed two deaf individuals. One was employed for seven years, the other for 12. Neither employee was offered the opportunity for advancement. Instead, they were relegated to the Records Room. They were not provided with sign language interpretation at staff meetings or for training. Both employees consistently received good performance evaluations. The

P&A intervened on their behalf. Since then, sign language interpreters have been available as needed. Both employees have now been promoted twice.

These stories exemplify the fact that quietly, behind the scenes, people with disabilities have been helped to find a successful resolution to issues of employment that arise.

Making the Grade?

After more than four years in full effect, the ADA may not have fulfilled the greatest fears of its critics, or the greatest hopes of its supporters. However, it is far too soon to be able to fairly assess the impact or effectiveness of this law. Consider, for instance, if the 1964 Civil Rights Act had been formally assessed after four years — that is, in 1968, a contentious year of political and racial unrest. Nearly 35 years later, we can truly see the difference that that law has made.

As for the ADA, we do know that the number of people with disabilities hired increased between 1991 and 1994 (even before the law was in full effect). According to official statistics, 800,000 more people with severe disabilities were employed in 1994 than in 1991. Even though the ADA may not have been the “magic bullet” — the immediate and complete resolution — the disability community had hoped for, it certainly can be credited with raising awareness. This heightened awareness, in turn, has helped to encourage employers and businesses to make changes in the way they operate that are more inclusive of people with disabilities.

After the test of time, down the road, we will be able to better determine if the ADA deserves a passing grade. ■

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EDUCATION OF CHILDREN WITH DISABILITIES: AN EVOLVING 'IDEA'

BY LESLIE SEID MARGOLIS

Over the last 25 years, the face of U.S. society has changed as previously invisible members — persons with disabilities — began to emerge from behind the closed doors of institutions, hospitals and their homes. They sought access to the rights and privileges enjoyed by other members of society, such as the ability to attend school, obtain employment, enjoy friendships and live in the community.

Much of this change is the result of federal (U.S. Government) legislation, such as Section 504 of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA) of 1990. Each of these statutes has been instrumental in beginning to break down the physical and psychological barriers that have isolated and segregated children and adults with disabilities. This article will focus on the changes in education wrought by the initial passage, and subsequent reauthorization, of the IDEA [http://www.ed.gov/offices/OSERS/IDEA/the_law.html].

In the early 1970s, parents of children with disabilities in a number of states began to file lawsuits to compel school systems to educate their children. Two of the most influential cases, *PARC v. Pennsylvania* (1971) and *Mills v. District of Columbia Board of Education* (1972), led to the enactment of the Education of All Handicapped Children Act (EAHCA), IDEA's predecessor statute. At the time of the EAHCA's passage into law in 1976, the U.S. Congress found that there were more than eight million children with disabilities in the United States. More than half were not receiving appropriate educational services. One million out of the eight million were completely excluded from school. Moreover, many children in regular education were not successful in their studies because they had disabilities that went undetected.

The EAHCA mandated that states choosing to participate in this federally assisted program provide a "free appropriate public education" in the "least restrictive environment" for every child up to the age of 21 whose disability adversely affects his or her ability to benefit from education, and who needs special education and related services to make educational progress. The statute set out a number of procedural requirements for states and local school systems to implement, plus safeguards to protect student and parent rights. In enacting the

statute, Congress made individualization of services the foundation of an appropriate education by requiring the development of an individualized education plan (IEP) for each child receiving special education. The IEP was to contain annual goals and short-term objectives that would serve as the blueprint for the child's education, based on his or her individual needs. Additionally, while states were to ensure the availability of a continuum of program options so that all children with disabilities could be served appropriately, the EAHCA stated a preference for placement in the least restrictive environment in which the IEP could be implemented, and required that a child not be removed from the regular classroom unless he or she could not be educated satisfactorily, even with the use of supplementary aids and services. The statute did not define supplementary aids and services; however, examples include classroom or one-to-one aides, physical classroom modifications, technology devices or equipment and curriculum modification.

The EAHCA was extremely important in opening the schoolhouse doors to children with disabilities and putting into place a variety of procedural protections to govern the special education provided to them. However, as the United States Supreme Court held in its first review of the EAHCA, the statute was not intended to guarantee any particular results once children entered the schoolhouse. While previously unserved and underserved children with disabilities began to receive special education and related services, such as occupational and physical therapy, health services, speech therapy and psychological counseling, among others, they did not necessarily leave school at the age of 18 or 21 able to lead independent or productive lives. In fact, many children with disabilities, particularly those with serious emotional disturbance or learning disabilities, did not complete school successfully.

The EAHCA has been reauthorized several times, with a variety of amendments governing issues such as early intervention services for infants and toddlers, attorney's fees for families who successfully challenge their children's special education

programs, the addition of certain services (such as transition plans for older students and assistive technology), the addition of certain disabilities that could qualify children for special education (such as traumatic brain injury and autism), and changes in nomenclature to recognize society's newfound use of the word "disability" in place of "handicap." In the 1990 reauthorization, the name of the statute was changed from EAHCA to IDEA.

The most significant and far-reaching amendments came in 1997, after two years of intense and sometimes bitter controversy. While the 1997 amendments unquestionably constitute a compromise piece of legislation, Congress' findings in reenacting the IDEA offer insight into how far U.S. society has moved in terms of its expectations for persons with disabilities, and its recognition that special education is simply one piece of the nation's education system, not a separate system of its own.

Congress found, in part, that the education of children with disabilities can be made more effective by:

- having high expectations for them and ensuring their access to the general curriculum to the maximum extent appropriate.
- strengthening the role of parents and ensuring that families have meaningful opportunities to participate in the education of their children at school and at home.
- coordinating the IDEA with other local, state and federal school improvement efforts to ensure that students with disabilities benefit from such efforts, so that special education can become "a service for children rather than a place where they are sent."
- providing appropriate special education and related services and aids and supports in the regular classroom whenever appropriate.
- supporting high-quality professional development.
- improving recruitment efforts to bring more minority teachers into special education.

These congressional findings are particularly significant because they recognize that low expectations for students with disabilities and inadequate professional training can hinder or prevent meaningful educational progress, and because they recognize that the context in which children receive special education is the larger education system as a whole. Therefore, it is critical that special education be considered and included in any education reform efforts. Additionally, the congressional findings are important because they reflect what families, professionals and society at large have learned over the past number of years about the benefits to everybody when students with disabilities receive their special education services in general education classrooms with nondisabled peers.

The 1997 amendments instituted a number of changes designed to strengthen the IEP as the centerpiece of the child's education. For instance, the multidisciplinary team responsible for developing a child's IEP must look at a number of factors regarding the student, such as: communication needs if he or she is deaf; the need for positive behavior supports and strategies if his or her behavior impedes the ability to learn or the ability of other students to learn; the need for assistive technology devices and services; and communication needs if he or she is not proficient in English. Additionally, the IDEA now presumes that students who are blind or visually impaired will be taught Braille unless the team can justify a decision otherwise.

The refinements of IDEA in 1997 also specified, for the first time, that the IEP must include the programmatic supports and services necessary for school personnel so that the child can be educated in the general classroom, rather than simply the services and supports that must be provided to the individual child. This is a particularly noteworthy addition to the IDEA. Often, with training, support, access to resources or even a modification such as a smaller class size, children with disabilities can be successfully educated in general education classrooms. These services and supports have not always been readily available to the school staff, however. In making consideration of such programmatic supports and services part of the IEP

process, staff should be able to more easily obtain what is needed to serve children appropriately, without segregating them in separate, isolated special education classrooms.

In an effort to ensure better outcomes for students with disabilities, the 1997 IDEA mandates the participation of students with disabilities in statewide and local assessments. States must develop alternative testing programs for those students who are unable to participate, even with accommodations, in the regular testing program. Moreover, transition planning must begin at an earlier age, to increase the likelihood that the student will spend the high school years engaged productively in the process of moving from school to post-school endeavors.

The 1997 reauthorization addressed, for the first time, the issue of discipline of students with disabilities. This, unquestionably, was the area of greatest controversy during the reauthorization process. While school systems now have considerably greater latitude in removing children with disabilities from school, the IDEA sets forth a number of procedural safeguards and requirements that must be met in an effort to ensure that children do not face discrimination based upon their abilities. Children who have been removed from their school programs still retain the right to a free appropriate public education. However, such education can be provided in an alternative setting — one which must be able to offer the child access to the general curriculum, implement his or her IEP, and address the child's behavior so as to minimize or eliminate the likelihood that the child will again engage in the behavior that necessitated removal from school.

The IDEA, like many other pieces of U.S. legislation, has sparked a great deal of commentary, controversy and litigation in its 23-year history. The legal process is often used to define the boundaries of statutory requirements. The complexities of trying to individualize educational services for children with disabilities, deal with smaller budgets, and address the concerns of families attempting to enforce their children's legal entitlement to a free appropriate public education have made special education

especially susceptible to this boundary definition process.

For example, the United States Supreme Court is expected to render a decision in early to mid-1999 as to the point at which IDEA-required school health services end, and medical services not required by the IDEA begin. Litigation is likely regarding the new discipline requirements of the IDEA; also, families and school systems will continue to disagree about what constitutes an appropriate education for particular children. Enforcement of the IDEA's requirements at the local, state and federal levels will also continue to be a major topic of discussion, because without meaningful enforcement of the law, its benefits cannot be fully realized. It is axiomatic that many statutes, particularly those dealing with civil rights, are not self-enforcing, but require active effort by their beneficiaries — in this case, students with disabilities and their parents — to make the guarantees real. However, children and parents must be able to anticipate that the agencies responsible for

implementing the IDEA will do their jobs effectively. Monitoring and enforcing implementation of the statute is a key part of this effort.

Despite the controversy surrounding special education, it is clear that the IDEA has made it possible for millions of children with disabilities to be educated in school alongside their nondisabled peers. Ultimately, special education is truly "special" only because it offers children with disabilities the opportunity to do what their friends, neighbors, cousins, brothers and sisters do — attend school, learn and play, becoming, in time, educated citizens and valued members of society. ■

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ASSISTIVE TECHNOLOGY EXPANDS TO MEET GROWING NEEDS

BY BERYL LIEFF BENDERLY

Because she lives in a congested U.S. East Coast city, Katie C. doesn't "believe in gasoline-powered vehicles for short trips." So for errands of a couple of miles she often uses her bike, a mode of transport she finds "much more suitable" for such trips than her wheelchair.

Yes, her wheelchair. Four years ago Katie, who lacks the use of her legs, bought a HandBike, a two-wheeler designed for wheelchair users. Developed by the late designer Chris Schwandt and manufactured by Mobility Engineering of Pasco, Washington [<http://www.televar.com/~pcr/pcr1.htm>], this specialized cycle is one of the burgeoning array of devices now used by people with physical, communicative, sensory and other disabilities to pursue their interests and participate in society more fully and actively than ever before.

Just as her bike represents a radical departure from an older image of physical disability, Katie is one of the growing number of people facing physical and cognitive challenges who want their abilities and ingenuity, rather than bodily limitations, to determine what they can accomplish, learn and enjoy. Whether they face issues involving mobility, muscular control, hearing, speech, sight or other capabilities, many

individuals whom society formerly might have consigned to limited opportunities, social segregation or even dependency are now turning to the many engineers, designers and entrepreneurs now designing and marketing technologies, generally referred to as "assistive technologies," that help people live more actively, independently, productively and enjoyably.

Old standbys like wheelchairs, motorized scooters, white canes, hearing aids and hand-controlled cars, of course, have been around for decades. But with physical fitness and easy mobility now in fashion for everyone and the computer ubiquitous in homes, offices and even Internet cafes, people with disabilities are demanding — and receiving — a whole new level of technological assistance. Across the United States, at research facilities in university laboratories and in home basement workshops, and at companies ranging from large corporations to one-person enterprises, inventors ranging from Ph.D. engineers to amateur tinkerers are working on devices to solve everyday problems of access, inclusion and productivity presented by a variety of disabilities. Whether the problem is manipulating a screwdriver or putting on shoes, playing with toys or

using a computer, climbing stairs or chatting with friends, specialized devices are broadening opportunities as never before.

What's more, Americans' enthusiasm for assistive technology (AT) spreads far beyond individuals or families who are dealing with particular disabilities. For over a decade, creating more and better assistive devices has been official U.S. Government policy. So has the need to bring assistive technology — defined as “any item, piece of equipment, or product system...that is used to increase, maintain, or improve functional capacities of persons with disabilities” — to all those who can benefit from them. In 1988, the U.S. Congress passed the Technology-Related Assistance for Individuals with Disabilities Act, known as the “Tech Act,” which recognizes disability as “a natural part of the human experience” that “in no way diminishes” anyone's right to “independence, self-determination, meaningful careers or full participation” in the “economic, political, social, cultural and educational mainstream” of American life. The Individuals with Disabilities Education Act (IDEA), furthermore, asserts every school child's right to the assistive devices he or she needs to obtain an education.

To turn these rights into realities, the Tech Act authorized funding for the states to establish programs and projects aimed at informing their citizens about available devices and helping individuals choose and obtain the ones right for them. Each of the 50 states, as well as the District of Columbia and the territories, now has an AT service or program. The National Institute for Disability and Rehabilitation Research, part of the U.S. Department of Education, provides grants to the states and encourages research into better devices. The U.S. Department of Veterans Affairs also actively supports research and development of assistive and rehabilitative technologies. To provide access to the wealth of available inventions, the Education Department maintains ABLEDATA [<http://www.abledata.com>], a computerized service listing more than 24,000 commercially produced assistive and rehabilitative products.

AT pays off in independence and satisfaction, research shows. A 1993 study by the National Council on Disability found that nearly 75 percent of surveyed children could stay in regular classes, and 45 percent used fewer school-related services, thanks to assistive devices. Sixty-five percent of working-age adults surveyed depended less on family members, 58 percent used less paid help, and 37 percent increased their earnings for the same reason. Eighty percent of the surveyed older adults depended less on others, half needed less paid help, and half stayed out of nursing homes because of AT. But even so, many people agree with Katie's complaint that “assistive technologies are prohibitively expensive.” In light of their obvious benefits, “the issue becomes not how we can afford effective AT, but what costs are involved if it is not provided,” according to the California Assistive Technology Service, the Golden State's AT program.

The drive for better and more available assistive technologies is also well on its way to becoming a pair of professional fields. Two national organizations of people who develop and manufacture assistive products, the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) [<http://www.resna.org>], and the Assistive Technology Industry Association (ATIA) [<http://www.atia.org>], seek to advance the interests of individuals and companies, respectively. More than 55 firms supplying a wide range of devices belong to ATIA, founded in 1998 as the world's first trade organization in the AT field. The group's inaugural world conference, scheduled for October, 1999, in Orlando, Florida, will showcase members' products and, organizers hope, will attract AT professionals and other interested persons from the U.S. and abroad.

As both the numbers and sophistication of available devices soar, understanding and explaining them to potential users — and helping people make the best choices — have also become vastly more technical and complicated processes. Universities are responding to the need with programs aimed at training specialists in this growing field. California State University at Northridge, for example, offers a certificate program in assistive technology. The University of Illinois at Chicago has announced what it calls “the nation's first Ph.D. program in disability

studies,” coordinated, in part, by its new department of disability and human development, which will also offer a master’s degree.

The scores of U.S. companies now marketing assistive technologies offer everything from the most up-to-date hardware and software to well-cut fashions designed for wearers with disabilities.

AT devices fall into 10 major categories. Aids for daily living help with such routine tasks as cooking, eating, washing, dressing and doing housework. Augmentative and alternative communication allows people who have limited or no speech abilities to communicate both expressively and receptively. Computer access devices meet the needs of those unable to use conventional keyboards, mice and screens. Environmental control systems afford the ability to regulate appliances, security systems and the like. Home and worksite modifications, such as ramps, lifts, bathroom alterations, or other adaptations to structures, decrease or do away with various barriers. Prosthetics and orthotics replace, augment or substitute for body parts that are missing or defective or improve cognitive functioning by serving as reminders or prompts. Seating and positioning devices improve the stability, support, and other characteristics of wheelchair and other seating systems. Aids for the vision-impaired both improve and substitute for the ability to see objects. Aids for the hearing-impaired both improve and substitute for the ability to hear in a wide variety of situations. Mobility aids increase people’s capacities to get around. And vehicle modifications increase people’s abilities to use motor vehicles. Whatever the specific device, however, all have the same goal: to allow people with all kinds of disabilities to live more successful, productive, satisfying lives.

The HandBike’s clever arrangement of levers, handles, wheels and gears epitomizes the new approach. Like all good assistive technology, it builds on the abilities that people like Katie already possess — in this case, the use of their arms and hands. In place of leg power, the rider operates a recumbent two-wheeler by hand-cranking a chain

drive that runs the front wheel. Two small side wheels act as kick-stands and “landing gear,” Katie explains. She taught herself to ride in a couple of hours and, thanks to the side wheels, finds it safe enough to use even on icy streets. Besides biking to work, she joins more conventionally mounted fellow cyclists at environmental events such as an annual Earth Day Bike-In in the spring, when groups of ecologically-minded commuters raise public awareness by pedaling to their jobs *en masse*.

The bounty that inventors’ ingenuity has created is limitless. Should a wheelchair user prefer beach-combing or surf bathing to bicycling, the Beachmaster Aquatic Wheelchair by Beach Wheels, Inc. [<http://www.naples-fl.com/wheels>], may be just the ticket. And though their invention is not yet perfected and commercially available, a team at the University of Pennsylvania’s General Robotics and Active Sensory Perception (GRASP) is working on a wheelchair that can climb over curbs and someday perhaps even up stairs. Using a pair of spider-like front legs, it has successfully mounted platforms as high as twelve inches; the legs also can prove useful for tasks like holding doors open. The team hopes that online videos of the chair mounting a curb [<http://www.cis.upenn.edu/~venkat/wheel.html>] will entice some entrepreneur into producing it for sale.

Electronic travel also presents exciting opportunities and serious obstacles to people with various disabilities. The Internet has proven a boon to many with impaired hearing and other communicative difficulties, who can now communicate online as the equals of all other citizens of cyberspace, something impossible to do on the telephone. The inability to use regular speech, for example, did not prevent Maryland entrepreneur Jamie Clark from establishing a successful internet server, Clarknet. An employee of Clark’s who can hear recently recounted to *The Washington Post* how he applied for, interviewed for and accepted his job at Clarknet completely by e-mail. Only when he reported for his first day of work did he learn that his employer and many of his co-workers are deaf, and that he would need to learn sign language to keep up on office chats.

Still, formidable barriers keep people with many other disabilities out of cyberspace, even though the

ability to log on is now essential at many jobs and schools. Standard input devices require very specific physical abilities: manual control and dexterity to manipulate the keyboard and mouse, and the vision to see clearly screens full of buttons, fields, instructions and labels, and to place the cursor accurately. What's more, the standard output devices, the monitor and printer, only work for those who can see the screen or paper clearly. Fortunately, though, scores of companies offer software and hardware that welcome into cyberspace people with many kinds of disabilities.

A number of options aid those who can't manipulate the ordinary keyboard or mouse. Touch screen software allows people to select material, move icons and objects on the screen, bring down menus, draw images, and perform many other functions on the screen simply by pointing. On-screen keyboard software enables users to type either by touching the screen or using a mouse to move the cursor from letter to letter. Voice programs let people run a wide program, including word processors and spread sheets, using oral commands. Word prediction programs ease the task of entering large amounts of text by having the computer anticipate which word the user intends to write, reducing the number of individual letters that must be keyed in.

Innovative hardware also makes computing more accessible. Specially designed keyboards organize functions for persons with particular cognitive challenges and also meet other needs, such as allowing those who cannot push two keys at once to achieve the same effects by pushing the keys in succession. They can also make it possible for someone who can't roll the mouse to move the cursor by pressing buttons. Special switches can substitute for mouse keys, permitting people to use other hand motions in place of the single finger pushes required by an ordinary mouse. Special handles that fit into the user's mouth operate joysticks that substitute for a regular mouse and produce all the same on-screen effects. Precision-designed sensors allow computer users to control

the cursor by slight movements of their heads, allowing all the usual cursor functions in addition to typing on an on-screen keyboard and even making drawings. Devices enabling users to control the cursor through puffs of breath produce similar results. And specialized data output options include devices that magnify the monitor's image and transform it into speech or Braille. Many of these programs also allow persons with communicative disabilities to use the computer as a speaking machine, which translates typed material into spoken language.

Inability to use other equipment far less complex than a computer can also severely limit occupational and recreational options. Simple hand tools such as screwdrivers, wrenches and graters permit people to repair cars or prepare meals. Losing a hand, therefore, can deprive a person of the independence of doing personal chores. Interchangeable tool systems, used to attach specially designed hand tools to prostheses, can restore a cook's ability to grate cheese or a handyman's ability to turn bolts, as well as the self-reliance that accompanies doing things for oneself.

Conditions that interfere with operating other ordinary household equipment and appliances, such as the television remote control device or a mechanical toy, also vastly increase dependence. But a wide range of specially designed switches lets people turn appliances on and off, change channels, raise the volume, or lower temperatures, all at the touch of the user's cheek, the blink of an eye, or the smallest movement of a head or finger.

And beyond the power to control equipment and tools, the ability to manage one's own appearance vastly increases self-assuredness and enhances social ease. Men and women who use wheelchairs, for example, often find clothing made for people who stand and walk neither flattering nor comfortable in a seated position. But such touches as strategic alteration of the length of shirt tails and skirts, trousers cut wider in the hips or longer in the fly, and side vents and longer backs in tunics and blouses add up to neater, more stylish looks and far more comfortable fits for the seated wearer. A number of companies offer lines of wheelchair wear appropriate for every occasion, from business meetings and

formal receptions to trips to the supermarket.

The last decade's explosion of interest and inventiveness regarding assistive technology shows no signs of abating. As the U.S. population ages and the number of people undergoing the "natural" experience of disability continues to climb, so will the demand for ever more ingenious and obtainable devices useful in living life to the fullest. For now,

though, fortunately, boundless and often surprising opportunities already exist. ■

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GLOBE-TROTTING TV NEWSMAN JOHN HOCKENBERRY: A 'CRIP' WITH ATTITUDE

BY CURT SCHLEIER

Oh, the places John Hockenberry has gone and the things he's done!

The onetime NBC television news correspondent, who now is hosting his own program on MSNBC (a cable network), rode a mule among Kurdish refugees in the mountains of Iraq, came under fire with U.S. troops in Somalia, and covered the funeral of the Ayatollah Khomeini amid millions of Iranian mourners shouting, "Death to America!" He violated an Israeli curfew in Gaza, worked pressroom phones in Jerusalem while Iraqi Scud missiles flew overhead, and reported on the eruption of Mount Saint Helens.

Hockenberry, 42, already has had a remarkable career. But what makes his achievements all the more noteworthy, to everyone but the correspondent himself, is that he's done it all and seen it all from the seat of his wheelchair.

An automobile accident at age 19 left him a paraplegic — or as he calls himself, a "crip." But he's not just a crip, he's a crip with an attitude. Frequently, it's a bad attitude.

Ask him about Christopher Reeve's well-publicized goal to walk again, and he'll tell you it's objectionable. It implies that life as a paraplegic is somehow lacking. "If there's a message that's gotten through in my work," Hockenberry maintains, "it's that I don't go along with that idea. It's an insult to people who have actually been living with their disability, exploring the interesting facets of life with their different physical configuration, and [discovering] the lessons that can be learned and the interesting aspects of culture that come out of

disability. I think that to obsess about a cure is to say that life [in a wheelchair] is diminished somehow, and I won't say that."

His words come out quickly, a series of giant run-on sentences, his voice tinged with a combination of frustration and resignation. No matter how many times he repeats it, few seem to get it. He's fine, thank you. He doesn't want your sympathy. He's not a man with something missing. He's a whole person, just different. "You either think that you're just fine or you're not, and you can't think that you're just fine and be thinking about the cure," he says.

Hockenberry has the broad shoulders and thick arms of an athlete. No surprise there, since he eschews electric wheelchairs and has pushed himself — literally and figuratively — around some of the most inhospitable places in the world. Times are good for him. He has his own television program after having been a correspondent for one of the highest-rated television newsmagazines. His memoir, *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* (Hyperion, \$14.95), was both a critical and commercial success. He's working on a second book, a novel. And his wife recently delivered twins. What could be better?

Well, for one thing, people could stop reading motives into his actions. He is not angry. Never was. Never will be. What about the time he insisted on buying a manual-shift truck even though stick shifts are not made for paraplegics? "Well," he concedes, "that was stupid."

Or the time during the summer of 1977 when, as Hockenberry was leaving a fair, a state trooper asked him to move his wheelchair from its special rack mounted on the side of his truck? When his explanation — he couldn't reach the wheelchair unless it was positioned exactly where it was — failed to sway the policeman, Hockenberry attempted to drive off. The officer held on; other officers pulled out their guns and surrounded his vehicle. "That was anger, but that was a very long time ago."

But what about the time he attacked a cab when the driver refused to put his wheelchair in the trunk? Hockenberry broke the taxi's headlights and jammed the door open, nearly severing his own thumb in the process. "I know that it sounds like I'm protesting too much, but the tone of that story [in the book] is what an idiot I am."

Certainly if anyone is entitled to be angry with the fates, it's Hockenberry. Born in Dayton, Ohio, in 1957, he lived an average, uneventful life until February 1976. His father worked for IBM, and the family lived at various corporate outposts around the United States, from Syracuse, New York, to Grand Rapids, Michigan. Hockenberry was a sophomore majoring in math at the University of Chicago when he and his best friend, Rick, decided to hitchhike to Massachusetts to visit Rick's girlfriend between semesters.

It was a miserable trip. There were missed rides and drivers that left them in obscure, deserted locations where it was difficult to find another ride. It rained, and when they finally flagged down a recreational vehicle that promised to take them nearly to their destination in comfort, the RV broke down. Salvation came in the form of two college students, also on break from school and also in a rush. They'd been on the road 18 hours when they picked up John and Rick, and it wasn't long before they all fell asleep, the driver included.

The car swerved off the road. The driver was killed. Her friend and Rick escaped relatively unscathed. Hockenberry had a fractured skull, a broken shoulder and collarbone, and three crushed vertebrae.

Sitting in his office now, more than two decades later, Hockenberry's legs are strapped together by an elastic bungee cord with hooks at the end — the type used to hold down cargo on the roof of station

wagons. But from the beginning, Hockenberry never felt strapped down spiritually.

There was never any sense of denial or bargaining with God or any of the other stages people who've suffered trauma often experience. "You can't deny that you can't feel your legs," he says. "It's a fact. I know I'm not going to walk tomorrow. The idea that people normally deny [their disability] and then normally get angry and then normally accept it is psychological malarkey.

"I don't think there's anything normal about denial. Psychologists present this to you as if it's the script for how to be a paraplegic. You're in an accident where the driver dies and you're bleeding and can't feel anything when you touch your knees. You don't need a whole lot of psychological mumbo jumbo to recognize the fact that you're not going to walk again."

There is a been-there, done-that sense of resignation to his tone. It's a subject he's discussed before, frequently with total strangers. One of the downsides of life in a wheelchair is that people he's never met before feel free to approach and ask personal questions — about how long he's been in the chair, about his sex life, and his personal favorite, whether or not he has considered suicide. Suicide? Out of the question!

"The human race constantly goes through acts of coping and dealing with adversity. The sun moves a tiny little bit, and we're all dead. The idea that I break my back and boom, we're all over with, I think goes against the general human experience...

"I think it's abnormal to contemplate suicide. I don't understand why that's amazing to people. I think it's more amazing to sit around and look at television all the time. I would say, 'You are so courageous to watch TV every day.' Committing suicide for that makes more sense to me."

Reinforcing this conviction is Hockenberry's recollection of photographs he'd seen of an uncle. He'd never met the man — the picture was actually of a child — and assumed he was dead. In truth, the uncle, who suffered from a rare genetic disorder, had been put in a home. No one was going to put John Hockenberry away. He was determined to take on life — and do it on his own terms.

Temporarily, he went back to school, but the University of Chicago had virtually no facilities for

wheelchairs. The frustrations of coming to terms with his new body, and dealing with employment counselors and other bureaucrats who had little understanding of what it means to be disabled, convinced Hockenberry to drop out, pick up stakes, and start anew.

He chose the Pacific Northwest — Eugene, Oregon, to be exact. He landed a job as a trainer at a home for developmentally disabled adults. Here he met Alice, a nurse and the woman who became his first wife. He also returned to school at the University of Oregon, where he majored in music. His rationale was simple. He'd almost died. Studying something "useful," something helpful in terms of a future career, was no longer a priority. "I loved music and I wanted to do what I wanted."

Interestingly, he chose the piano as his principal instrument. Yes, he'd taken piano lessons as a child. Yes, he loved the piano. But it is an instrument that requires the use of foot pedals. "I didn't take the piano to prove a point," he maintains. Still, it seems an odd choice.

He approached the instrument with his characteristic zeal, developing a device that enabled him to operate the pedals by depressing a bulb in his mouth. And the moment he had proved he could do it, he moved on. "I realized I could either be an event the stunt people talk about, or a pianist, but I couldn't be both."

He came to journalism accidentally. One of his odd jobs during college at Oregon was delivering *The Oregonian* (the local newspaper) early each morning. He'd drive and Alice would fling the paper onto porches and lawns while they listened to National Public Radio (NPR). The local NPR outlet, KLCC, was an enclave of hippies and activists, and when Hockenberry called to complain about a story, he received an unexpected reaction:

"Someone said" — and here he breaks into an imitation of a California surfer dude — "Well, why don't you come down and volunteer? We'd like that.' I had...no answer for [that]. So, sure enough, I said I would go."

Hockenberry signed up as an unpaid intern. At first he performed grunt work, but soon his responsibilities increased. When Mount Saint Helens erupted, NPR network news looked to KLCC, the only station with a news department anywhere near

the mountain, for reports. Many of these came from Hockenberry. Even after the volcano calmed down, the NPR news desk was impressed enough to continue using the station, and Hockenberry, for reports about the Pacific Northwest.

"I loved it from the beginning, but I was always mystified about why I loved it," he says of reporting. In retrospect, the answer seems obvious: He'd found his calling. Though he had never considered journalism as a career, Hockenberry had worked on his high school newspaper and been a member of his debating team. Current events had always intrigued him; he had strong opinions about many issues, and, as he puts it, "I could think on my feet."

Steve Franklin, a *Chicago Tribune* reporter who was posted in the Middle East with Hockenberry in the late 1980s, became a big fan. "One of the most incredible things was how quickly John made friends. He was excellent at making contacts. Other journalists were astonished at how fast that happened," says Franklin. "He had the absolutely brilliant ability to talk to a high-level government minister and then go out and talk to someone at an amusement park in Amman. He also had a great imagination."

He was good. His reports were seamless. As Tim Gorin, a national producer for NBC who covered Princess Diana's funeral with Hockenberry, put it: "He has an extraordinary ability to home in on what the story is. Sure, there were times when we needed to get into buildings and couldn't, but there was no situation we couldn't navigate together, and it became a much richer experience."

After he and Alice divorced in 1984, Hockenberry moved from Eugene to Washington, D.C., as a news reader on "All Things Considered," a popular daily newsmagazine program on NPR. Then he went to the Middle East as a correspondent from 1988 to 1991, and after that, back to NPR in the United States. (During this period he was even named a finalist in NASA's Journalist in Space program, which was later abandoned, following the Challenger disaster.) He joined ABC in the early 1990s, where he met and married his second wife, Alison, an ABC producer, before being hired by NBC in 1996. Whatever he did, wherever he was, he worked harder than everyone else.

The Tribune's Franklin recalls how Hockenberry "threw himself into fighting the perception that someone with his disability couldn't do the job. He had more energy and more vigor than anyone I know. He went to places others never did."

When he couldn't find someone to help him negotiate difficult terrain, he'd literally crawl up flights of stairs to get to a source or, as he did in 1991, ride a mule in northern Iraq — a painful experience — to reach Kurdish refugees.

A far greater problem than navigating the pothole-filled streets and alleyways of the Middle East was convincing others — and, more important, himself — that his efforts were not a stunt. "I kept asking myself whether I was there to prove a point or to tell [the Kurds'] story, and I think I came to realize there wasn't a simple answer. Ultimately, I think the decision to get on that mule had less to do with me being a hardass and everything to do with solving the problem of getting to them.

"I could have walked — rolled — away and done a story. But there was no point to it unless you got to the people."

His friend Steve Franklin believes that "John isn't as driven as he once was. I believe he burned off a lot of that tension when he needed to prove himself." To a degree, Hockenberry agrees. His success, the realization of just how good he is, has calmed him down somewhat.

And so has Ushuaia.

Shortly after joining NBC, Hockenberry interviewed Nicolas Hulot, host of the French television series "Ushuaia: The Ultimate Adventure." In each episode, Hulot, a sort of daredevil-environmentalist, performs death-defying acts in exotic locales.

Hulot uses the term Ushuaia (the name of the southernmost town in the world, in South America, and pronounced oo-'SWAH-yah) to describe his adventures — "the place where reality ends and dreams begin, the outermost bounds of the human spirit," according to the show's producers.

After Hockenberry completed the interview and switched the tape off, Hulot turned to him and said, "So, that wheelchair is your Ushuaia."

"I just said, 'Yes, yes,'" Hockenberry recalls. "I

know the truth of Ushuaia because I lived it." To the indefatigable correspondent, life in his wheelchair is an ongoing adventure, whether it involves conquering the obstacles of piano foot pedals or traversing the mountains of Iraq.

One more Hockenberry epic:

In the early 1990s, he decided, at the last minute, to purchase tickets to a popular Broadway show that two of his friends were planning to see. When he got to the box office the day before the performance, the only seats available were in the balcony. There were no special facilities for disabled patrons, but he was assured this would present no problem if he contacted the manager when he arrived the next day.

On the day of the performance, when Hockenberry left his friends to find his seat a few minutes before the curtain was to rise, the manager refused assistance. Instead, he told Hockenberry the only way to reach the balcony was by the stairs. Worse, he said Hockenberry would have to be accompanied despite the fact that he had been sold a single ticket, and the theater's staff was not allowed to touch him. The best the manager could do was refund his money.

"I just wanted to see the show," Hockenberry says. "I didn't want to get locked in mortal combat... So I said, 'I'll get out of the chair. I'll hop up the stairs. Can you just carry the chair? It will take you no time at all. I've done this all over the world. And there's no particular reason why I shouldn't be able to do it in New York.

"They basically just threw me out of the theater. I was so angry, I would have come back and burned that theater down," he says. Instead, he wrote an op-ed piece for *The New York Times* that attracted the attention of a human-rights lawyer who filed suit on Hockenberry's behalf.

The judge took one look at the case and ordered the theater to install facilities for the disabled. ■

Curt Schleier is a frequent contributor to Biography. This article was published originally in Biography. Copyright 1998 by A&E Television Networks. All rights reserved.

VOICES ACROSS AMERICA

Changes in the law, in attitudes, in self-awareness and in society in general across the United States have had an impact on individuals from all sectors of the populace. A selection of "voices" reflects those developments:

My new set of worries ranged from how Bekah would be aware of a fire alarm to how she would have access to popular culture.... So the passage of the Americans With Disabilities Act in 1990...brought us much-needed relief. The ADA's major emphasis was on accessibility and safety issues, and for us this meant that flashing lights were finally installed in her classroom and in the school bathrooms so the deaf children could know when the fire alarm rang. It meant that Bekah was able to attend a summer science program when she was 10 because the museum, funded by the state, was required to provide a sign language interpreter. It also meant that printed words began showing up on our television screen just about the same time that Bekah was becoming a skilled reader. More programs started offering closed-captioned dialogue, and, under the ADA, after 1993, all televisions were built so the viewer could turn on the captioning without having to buy an external device.

* *Wendy Lichtman, mother of a deaf child. From The Washington Post Magazine, November 22, 1998.*

The Inn on the Park is doing everything it can to make its services as accessible to guests with disabilities as to everyone else. The first time a group came to the hotel and needed equipment for the hearing impaired, the Inn rented the equipment from another hotel. Then we purchased our own equipment, with the input of some consumers with hearing impairments. Today the Inn on the Park is equipped with TDDs [typewriter-like machines through which telephone conversations are transmitted and received as text instead of sound], bed shakers, close captioned TV, menus in Braille, emergency evacuation procedures, and a range of wheelchair accessible rooms. Whenever we book a meeting for an organization, we acquire whatever adaptive equipment is needed, if we don't already have it. Front desk staff are trained in the use of adaptive equipment.... And our business has even increased a little as a result of working with disabilities groups.

* *Gary Tidmore, at a 1995 town hall meeting on the ADA in Wisconsin.*

I see the world in a different way than I saw it before. I was a very conceited, cocky guy. I paid attention to nothing that anybody else said except for what I thought and did. And now I'm in a wheelchair and I see things from a different perspective. And I have empathy for people I didn't even notice before. I appreciate what I had. I had perfect hands, just

perfect hands. I didn't think there were hands that could be better.... But now I can teach people to do what I could do, and they become my hands, and then they do what I want, but they learn something that I know. So they get something and I get something. My gift is being given to other people and so my gift is growing. Before it wasn't being shared, and now it is, so that's the prize.

* *William Newman, a Washington, D.C., artist, who has maintained his full teaching schedule at the Corcoran School of Art since being diagnosed with multiple sclerosis more than 20 years ago.*

When I first went to [Actor's] Equity on an open [audition] call, about a week out of rehabilitation, I remember waiting my turn to go in and do my monologue. The casting person at the audition thought my wheelchair was a prop. On learning it wasn't, with a great amount of disgust, she asked me what did I expect her to do with that. I became an activist as a result of that. I told her I expected her to listen to my audition.... We still have miles and miles and miles to go, in terms of changing societal attitudes toward PWDs [Performers With Disabilities] in general. There's still the perception that, if you're disabled, you're an invalid that couldn't possibly do anything.

* *Actress Kitty Lunn, chair of the Actor's Equity Association's PWD committee, who plays a disabled character on daytime television's drama, "As the World Turns."*

Last August [1998], with the support of the South Dakota Rehabilitation Services, Easter Seals of South Dakota and several other agencies, I secured full-time employment as a dispatcher for River Cities Transit System, my first job since raising my daughter. It is a new accessible coordinated community transit system. I have worked hard to learn everything they have asked of me, from voice recognition technology software — which helps me use my computer and type just as fast as everyone else — to scheduling of clients. I am good at what I do and love my job. Interestingly, since going to work full-time, I find I need less medical care. I am making friends and acquaintances, and even my

relationship with my family has improved. I feel better about myself while contributing to my community. I have reduced [my] Social Security Disability Income benefits, helping to save the trust fund that everyone agrees is so important to our children's futures.

* *Karen Moore, a Fort Pierre, South Dakota, polio survivor, in her opening remarks at a White House ceremony on new initiatives for people with disabilities, where she was recognized for her work to eliminate employment barriers for people with disabilities.*

The ADA [Americans with Disabilities Act] says you have to consider hiring people with disabilities, but it doesn't tell an employer or manager how to work with a person with disabilities. You need someone to bridge the gap; otherwise it falls apart if the workplace is not disability friendly.

* *Geri Jewell, who performed for several years on the television situation comedy, "The Facts of Life." Considered the first person with a disability to be a regular performer on a U.S. network television program, she consults with executives and managers, educating them on the realities of working with the physically disabled.*

While the ADA does guarantee access, it doesn't eliminate one of the greatest barriers faced by people with disabilities — negative images and stereotypes. The way to change attitudes and perceptions about people with disabilities is through education. ... Negative images and stereotypes are also fought through proximity — getting to know each other as friends and neighbors. People are only "strange" when they are strangers; when we work together, go to the same schools, attend the same churches and serve in the same community organizations, we recognize what we have in common. Whether we can see or hear or walk or talk the same way becomes less important than the fact that we share the same interests, ideas and values. Through

education and proximity we create access and opportunities for all people, building a nation that values what we have in common and celebrates what we have that is unique.

* *Justin Dart, corporate executive and pioneer of civil rights for people with disabilities.*

The failure to provide an accessible entrance to Torres and her children exacerbated the serious difficulties she faced getting in and out of the building daily.... This award tells landlords in the five boroughs [of New York City] that this disability-based discrimination is absolutely illegal under the Americans with Disabilities Act and the city's Human Rights Law.

* *New York State Supreme Court Justice Franklin R. Weissberg, in a decision upholding a 1998 ruling by the New York City Commission on Human Rights that ordered a [borough of The] Bronx landlord to provide access for a tenant and her two disabled children. For two years Minerva Torres requested that the landlord make improvements to a basement ramp entrance she and her children regularly used to enter and exit the building, but the request was completely ignored.*

When I saw the blind community locked out of the Internet because of the graphics and could see the deaf community could also be locked out by videostreaming and video clips, I knew if we're not careful with all of the audio excitement, I could be locked out of the Internet.

* *Cynthia Waddell, a disability access coordinator for the city of San Jose, California, who drafted the city of San Jose Web Page Disability Access Standard, aimed at enabling persons with hearing, visual and learning disabilities to navigate the Web. Santa Clara County has adopted San Jose's standards, and the initiative has been adopted by the World Wide Web Consortium. Waddell, who was born with a hearing disability, surfs the Web as easily as she changes stations on her television set.*

The benefits that Title IV's [of the ADA] requirement for relay services has brought are undisputed. Integration of deaf, hard of hearing, and speech-

impaired individuals through the telecommunication network brought these individuals increased freedom, independence, and privacy.

* *Michael Zeledon, at a town meeting on the ADA in Minnesota, commenting on the benefits of the establishment of telephone relay systems across the United States.*

We are installing ramps and curb cuts at 15 voting sites in Davidson County [Tennessee]. Since budgets are tight, the Elections Commission has arranged with students at Vanderbilt University to do the construction during their spring break. Architects have donated their time to develop the plans. The cost to the county? Just the price of materials. We have installed TDDs in the elections office and are trying to educate all elections officials and pollworkers about disabilities.

* *Michael McDonald, at a 1995 town meeting on the ADA in Tennessee.*

The word "culture" usually means our ideas, our art, our customs and traditions as a society. The word "cult" means a small group of people — not the majority — devoted to an idea or lifestyle... If we keep our experiences to ourselves, that's disability cult. If we share them, not only with ourselves but with the whole world, that's disability culture.

* *Greg Smith, host of "On A Roll," a radio talk show broadcast live each week on 200 local stations across the United States.*

Dependency increases the costs of entitlements, lowers our gross national product, and reduces revenue to the Federal government.... People with disabilities want to work...to be productive, self-supporting and tax paying participants in society. The Americans with Disabilities Act grants us that dignity and that right.

* *Former U.S. Congressman Tony Coelho, Chairman, President's Committee on Employment of People with Disabilities.* ■

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A national database of information on over 24,000 assistive technology and rehabilitation products available from domestic and international sources.

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*NOTE: For additional information on Web sites about
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