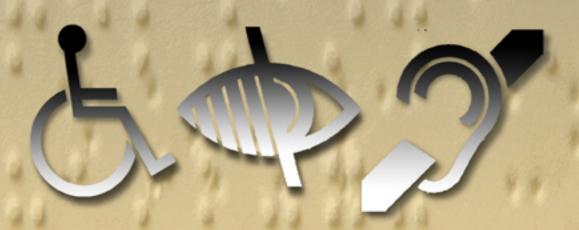


DISABILITY

ABILITY



SOCIETY & VALUES



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About This Issue

disability can directly or indirectly limit a person's ability to engage in normal life experiences. The direct effects are fairly easy to identifyan inability to see, for example, affects personal mobility and the ability to read regular print or to watch television. But the indirect effects are sometimes less easily identified, or compensated for, and just as debilitating. A disability can make getting an education more difficult, so that some people with no intellectual or cognitive disability still may be less educated than others. Depending on the disability, and access to support, other indirect effects can include reduced mobility, limited social access, more difficulty finding a job (or being able to get to work or to do the job physically), and difficulty taking care of health

and fitness and nutritional needs. Recognizing that people with disabilities, as a group, tend to be less educated, have higher unemployment, and are frequently in poorer health—often for reasons not resulting directly from their disability—the United States has developed programs and legal protections to begin addressing these issues.

In researching this topic, we found that everywhere we turned someone was taking credit for or giving someone else credit for the Americans with Disabilities Act. It became clear that, rather than indicating a conflict, these seemingly contradictory claims were, in fact, illustrating the amazing cooperation and collaboration it took for this legislation to come to pass.

From presidents and members of Congress to civil rights organizations and agencies serving people with disabilities to attorneys, business people, philanthropists, medical and technical researchers, and grass-roots activists, innumerable people contributed ideas, examples, inspiration, and support for the law and, more than that, for the cultural value that it represents—that every person has a combination of abilities and disabilities. With



Helping every person achieve his or her personal best helps everyone. Society is the ultimate winner.

support, people can overcome even severe disabilities while maximizing their abilities and lead fulfilling and productive lives, not only contributing to their own welfare, but also enriching the rest of society in innumerable ways.

This journal presents some of the aspects of that effort. We hope you will enjoy reading about the Americans with Disabilities law and about the programs underway to help turn disabilities into abilities, from accommodation to technology and medical research. In particular, we hope you will be as inspired as we have been to read about the individuals and groups who show—every day—that amazing gifts can come from those too easily overlooked. Opening opportunities and

removing barriers to people with disabilities is a work in progress, and we also address some of the gaps that still exist and discuss efforts to bridge them.

Some of the programs presented in the journal, such as the tips on searching for employment, were created originally to help people inside the United States. We have included information about them, however, because they help illustrate the wide range of issues involved in the implementation of the Americans with Disabilities Act and because they may prove useful in designing programs in other locales.

In researching the journal, we came across reports of individuals, organizations, and governments around the world engaged in important work on behalf of those with disabilities. We hope information about programs in the United States will prove as interesting and useful to them as learning about their inspiring work has been for us.



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The Americans with Disabilities Act: A Proclamation on the 16th Anniversary

President George W. Bush

♦ The Americans with Disabilities Act (ADA) has helped fulfill the promise of America for millions of individuals living with disabilities. The anniversary of this landmark legislation is an important opportunity to celebrate our progress over the last 16 years and the many contributions individuals with disabilities make to our country. When President George H. W. Bush signed the ADA into law on July 26, 1990, he called this legislation a "dramatic renewal not only for those with disabilities but for all of us, because along with the precious privilege of being an American comes a sacred duty to ensure that every other American's rights are also guaranteed." The ADA's far-reaching reforms have played a significant role in enhancing the quality of life for millions of Americans who must overcome considerable challenges each day in order to participate fully in all aspects of American life. My administration continues to build on the progress of the ADA through the New Freedom Initiative. We have established an online connection to the federal government's disability-related information and resources at DisabilityInfo.gov, and the job training and placement services of the Ticket to Work program and One-Stop Career Centers are promoting greater employment opportunities. We are also expanding educational opportunities for children with disabilities, providing them with the tools they need for success in their classrooms, homes, and communities. In addition, we are fostering technological advancement and encouraging increased distribution of assistive technology to help people with disabilities live and work with greater independence. My administration will continue its efforts to remove barriers confronting Americans with disabilities and their families so that every individual can realize their full potential.

On this anniversary of the ADA, we underscore our commitment to ensuring that the fundamental promises of our democracy are accessible to all our citizens. As we strive to be a more caring and hopeful society, let us continue to show the character of America in our compassion for one another.... I call on all Americans to celebrate the many contributions of individuals with disabilities as we work towards fulfilling the promise of the ADA to give all our citizens the opportunity to live with dignity, work productively, and achieve their dreams.



Over the years, President Bush has supported a number of programs and laws related to disability. In this 2004 picture, he chats with a mother and daughter before signing the Individuals with Disabilities Education Improvement Act (IDEA).

U.S. Society and Laws Protect the Rights of Persons with Disabilities

Peter Blanck

Peter Blanck is university professor and chairman of the Burton Blatt Institute of Syracuse University. He was involved in the process of drafting and passing the Americans with Disabilities Act, he has testified on the issue before the U.S.

Congress, and he has pled legal cases related to this issue before the Supreme Court of the United States. He has written and lectured extensively on the subject.

In the United States, the understanding, legal definitions, and attitudes regarding disabilities and persons with disabilities have changed over the years. Traditionally, a disability was seen as a defect that prevented someone

from participating in "normal" life activities. It could be a physical or mental problem and could have been lifelong or one that resulted from an accident or illness later in life. Attitudes ranged from the desire to protect the person to concern that the person's abilities, and therefore value, were diminished to shame and blame toward the individual and the family. In many cases, the person was closeted away, at home or in an institution, and had little interaction with general society; and in most cases, the disability was regarded as permanent and debilitating,

certainly not something that could be improved through treatment or mitigated through accommodation.

In the United States, an early legal definition of disabilities resulted from the large number of injured

Signing of the Americans with Disabilities Act. President George H.W. Bush (center) is flanked by Evan Kemp, Chairman, Equal Employment Opportunity Commission (left) and Justin Dart, Chairman, President's Committee on Employment of People with Disabilities (right). Standing are the Rev. Harold Wilke (left) and Sandra Swift Parrino, Chairperson, National Council on Disability (right).

soldiers returning from the Civil War (1861-1865). According to the Civil War Pension laws, disabled Union Army (northern) veterans were awarded pensions based on their "incapacity to perform manual labor." This model essentially defined disability as an infirmity that precluded equal participation in society (and the ability to earn an independent living). Not all disabilities were regarded equally, however; certain stigmatized disorders, mental disorders.

and infectious diseases were sometimes deemed unworthy of assistance, and persons with these disabilities were discriminated against.

A hundred years later, in the 1960s, the Social Security entitlement program sought to provide support for a much broader group of people living in poverty and those with disabilities. But these programs continued the traditional approach of looking at a person's ability to adjust to a world designed for those without disabilities and of segregating people who were not able

to participate in normal activities, and they continued to carry value judgments about people who received benefits or services.

CHANGES IN ATTITUDE

Just a few years later, in the 1970s, people with disabilities began to be viewed as a minority group within society—a group with civil rights to be protected similar to the other minority groups that were asking for equality. This rights model provided a new framework for looking at disabilities, a framework grounded in inclusion, empowerment, and economic independence. Proponents of this new view soon realized there needed to be new laws addressing the rights and concerns of this group. This new model fostered the passage of laws guaranteeing accessibility to voting, to air travel, and to independence in education and housing, and it culminated in the Americans with Disabilities Act (ADA). The ADA has both reflected the changes in attitude and helped promote them, as it became the legal language for discussing the issues and cases.

With the advent of the ADA, people began to look not only at making buildings accessible, but also for ways to help those with disabilities integrate with others and participate fully in all aspects of life. Widespread in its influence, the ADA has implications for schools, businesses, communities, and public facilities; for all branches of government; and for health and social services. Among the practices reflected by this new consciousness are a number of changes in terminology: for instance, referring to an individual as a person with a disability, rather than as a disabled person; discussing different abilities rather than one standard for normal; and talking about students with learning differences, rather than learning disabilities. At the same time, there has been a conscious effort to expand our definition of disability to include differences in learning or processing information, physical limitations, and other conditions that prohibit someone from participating in a major life activity.

Many groups and individuals worked for several years to draft the law and get it passed. The preface of the ADA sets the nation's goals regarding individuals with disabilities as assuring "equality of opportunity, full participation, independent living, and economic self-sufficiency." When President George H. W. Bush signed

the law in July 1990, he called the legislation a "dramatic renewal not only for those with disabilities but for all of us, because along with the precious privilege of being an American comes a sacred duty to ensure that every other American's rights are also guaranteed." The text of the law is divided into subcategories called titles. Each title is numbered and deals with a certain issue or audience and the protections or entitlements associated with that group.

THE ADA AT WORK

ADA Title I makes it illegal for most private employers to discriminate against an individual with a disability in any aspect of hiring or employment. Title II covers discrimination by state or local governments. Title III prohibits discrimination in public accommodations—hotels, restaurants, shopping malls, and so forth. Title IV requires providers of telecommunications to make their services accessible to people with disabilities. I have been fortunate to advocate with individuals at the forefront of the disability rights movement. The stories I share next are about individuals who fought to be equal participants in society.

I met Don P. and his family in 1999 in a sheltered workshop in Wisconsin. A sheltered workshop provides a supportive environment for physically or mentally challenged persons to learn job skills and gain work experience. Don is a person in his early fifties with mental retardation. Don had worked at a restaurant as a janitor. His job performance was excellent and his coworkers enjoyed working with him. One day the regional manager visited the restaurant and seeing Don working, criticized the local supervisor for hiring one of "those people." After returning to the restaurant, the regional manager fired Don when the local supervisor refused to do so. The local supervisor and restaurant staff quit in protest.

At trial on ADA Title I grounds, the defense argued that Don was not qualified for the job, and the company did not discriminate against him. In my testimony for Don, I spoke about the stigma facing persons like Don in employment. There was nothing deficient about Don's work; instead, the fault lay with the management's attitudes. The jury found the restaurant had violated the ADA and awarded Don \$70,000 in back pay and compensatory damages. To make its point that disability discrimination would not be tolerated, the jury awarded

him an additional \$13 million in punitive damages, to that time the largest monetary award from a jury in an ADA employment case.

ADA Title II requires that the services of state and local governments be available to people with disabilities. One element of Title II is that public entities administer programs in integrated settings. In Olmstead v. Zimring (1999), the Supreme Court considered the reach of this integration mandate. Two women with mental retardation sued under Title II, claiming the state of Georgia discriminated against them by serving them in institutionalized rather than community settings. The state's professionals determined community placement (treatment at a local facility rather than a distant institution requiring the women to be removed from their home, family, and community) was appropriate for their specific conditions, but none was available. The Supreme Court held this to be discrimination under the ADA and required the state to provide the services locally.

In the early 1990s, like many others, I was involved in litigation to improve conditions in state facilities for persons with disabilities and, where appropriate, to provide residents the opportunity to live in the community. I met Sara K. in 1991 when she was a resident of the health care unit of the Wyoming State Training School. Sara had spent most of her young life in the hospital unit at the training school. She was a smart and bright-eyed 10-year-old who had spina bifida and other serious health conditions. The settlement of the case mandated that Sara would be among the first to move to community settings. Understandably, Sara's parents were concerned, but they agreed she could leave the hospital facility to live at home. The rest was an amazing story. Sara adapted to her home life and flourished in mainstreamed classrooms. Not many years before, Sara would have spent her life at the training school in a hospital bed in a remote part of Wyoming. As a result of the change, she was carrying on a more normal life, engaged with her family, schoolmates, and community, and able to move toward a more promising future.

THE FUTURE

The ADA disability rights model is succeeding. Indeed, it is uniting countries around the world in the pursuit of policies to improve the lives of persons with disabilities. During the summer of 2006, the

United Nations Convention on the Rights of Persons with Disabilities, an international treaty on the human rights of persons with disabilities around the world, was adopted.

In the United States, the ADA is helping to reduce discrimination and encourage employers to make workplace accommodations. The 2004 N.O.D. (National Organization on Disability)/Harris Survey of Americans with Disabilities showed the percentage of people with disabilities who report discrimination in the workplace had declined significantly in the previous four years. The economic benefits to companies employing and accommodating workers with disabilities are documented.

ADA Title II's integration mandate has reached thousands of individuals. In *Tennessee v. Lane* (2004), George Lane, who has a physical disability, was a defendant in a traffic case. He had to crawl up two flights of steps to attend his court hearing in a building that lacked an elevator. For a subsequent hearing, he refused to crawl again. He sued to vindicate his right to access. In a judgment in his favor, the U.S. Supreme Court declared that Title II requires states not to discriminate against people with disabilities in their right of access to the courts.

ADA Title III's premise is straightforward—shopping centers and malls, professional offices, and businesses such as hotels may not discriminate against people with disabilities. Increasingly, places of public accommodation are accessible. One current issue with far-reaching implications is using Title III to ensure the Internet is accessible; for example, that Web sites work with screen reader software used by blind persons. Web sites offered by public entities for public audiences have a set of standards they must meet to qualify as accessible.

I have highlighted Americans with disabilities and their quest for civil rights—past, present, and future. Some attitudes die hard, and today individuals continue to battle stigma about disability, not only from business and government, but also among associates and even family members.

I was co-counsel in a custody proceeding between the parents of two young boys, Mike and Sam. Mike was diagnosed with autism and attended classes to address his educational and social needs. At a court hearing related to the parents' divorce, the father told the court he believed Mike's autism had been holding back Sam's development. He requested custody of Sam. The judge

granted the request, and the children were separated. The court's decision to separate the brothers was based on an unsupported assumption of the negative impact of having a child with autism in the family. The court did not fault the mother's parenting but discounted the brothers' right to live together.

We appealed the judge's ruling, and the California Court of Appeals agreed with our position. The subsequent reuniting of brothers Mike and Sam reminds us that disability rights continue to have as much to do with battling prejudice faced by persons living with disabilities as they have to do with overcoming physical barriers in the world. I am optimistic we will achieve the ADA's aspirations. How we address these issues will shape the lives of the next generation of children with disabilities. Unlike any before them, our children will not know a world without the ADA, a world without its vision for equality.

The opinions expressed in this article do not necessarily reflect the views or policies of the U.S. government.

Securing Access for People with Disabilities: A Community Affair

Michael Jay Friedman



Mobility contributes to personal and economic independence. Providing accessible transportation is one way cities serve all segments of the population.

Cities and towns across the United States have embraced the challenge of making public areas accessible to all their citizens. Michael Jay Friedman is a writer for the U.S. Department of State in the Bureau of International Information Programs.

merica's local communities are full partners in the national effort to secure those with disabilities their full legal rights as guaranteed by the Americans with Disabilities Act (ADA). Title II of the ADA guarantees equal access to the benefits of public services, programs, and activities. The goal is a worthy one but can require considerable public resources—the cost of adding a wheelchair lift to a bus and making the necessary modifications, for instance, has been estimated at \$40,000 or more.

Even so, municipalities nationwide have moved aggressively to meet the challenge. From the largest cities to the smallest towns and villages, local governments have answered President Bush's 2001 promise to the disabled: "Wherever a door is closed to anyone because of a disability, we must work to open it.... Wherever any barrier stands between you and the full rights and dignity of citizenship, we must work to remove it, in the name of simple decency and simple justice."

A MILLENNIUM PARK FOR ALL

Chicago Mayor Richard M. Daley set himself the goal of making his city, the nation's third largest, its most accessible. When the city determined to convert a blighted area of railroad tracks and parking lots into a showpiece recreation area, Daley turned to architect Edward K.

Uhlir, who resolved to design "a world-class park that could be enjoyed by all residents and visitors, regardless of their ability."

Dedicated in 2004, Millennium Park incorporates numerous amenities that permit visitors with disabilities to enjoy fully its many attractions. A central fountain and shallow reflecting pool are fully accessible. Zigzag-shaped "switchback" ramps to elevated attractions allow for 180-degree wheelchair turns. The main grassy area is reinforced with a subsurface structural mesh. By keeping the ground rigid, the mesh eases wheelchair navigation.

The Paralyzed Veterans of America organization awarded Uhlir its Barrier-Free America Award. The group's president expressed gratitude "for the efforts of individuals like Ed Uhlir who make it a priority to not only address the everyday challenges facing the disability community, but more importantly, provide a blueprint for accessible solutions to these challenges."

AWARD-WINNING EFFORTS

Beginning in 2001, the private sector National Organization on Disability has awarded its Accessible America prize to municipalities that best afford the disabled full and equal opportunities for participating in community life. Winners have demonstrated a strong commitment to providing access to education, jobs, voting, transportation, housing, religious worship, and a full range of social, recreational, cultural, and sports activities.

Pasadena, California, the 2004 winner, is best known as the home of the New Year's Day Tournament of Roses Parade and the Rose Bowl football game. Less widely known is that three wheelchair-accessible, parade-viewing sections are reserved for disabled persons and their guests, that audio descriptions of the festivities are offered for the visually impaired, and that sign language descriptions are provided for the deaf and hard of hearing. All persons with disabilities are afforded a special time to view the floats up close immediately after the parade.

Pasadena works aggressively to accommodate the needs of its residents with disabilities. Its central library, built in 1927, has been retrofitted with chair lifts, wheelchair-accessible computer stations, and elevators. An annual career conference matches high school students and professionals with disabilities for networking and to discuss career options, self-advocacy, and how to request

reasonable workplace accommodations. Many city documents are embossed in Braille, for the benefit of the blind.

The city's commitment to integrating those with disabilities fully into communal life is "strong and longstanding," says its mayor, Bill Bogaard. Pasadena "celebrates diversity and seeks to offer an inclusive style of life ... nurtured over time by able and dedicated persons with disabilities and their families and friends."

COMMUNITIES LARGE AND SMALL

Large cities and smaller rural communities alike have striven to meet and exceed the ADA's standards. San Antonio, Texas, the nation's ninth largest city, features a River Walk of cobblestone and flagstone paths running along each side of the San Antonio River through the business district. Today, three access ramps, four elevator routes, and a cross-river bridge provide wheelchair access to this important social hub. Hotels and other businesses along the River Walk are moving to provide similar access from their properties. "Access has improved greatly and mobility is much easier," a blind San Antonian says. "So much has changed!"

Meanwhile, rural Summers County, West Virginia, has moved to assure that its disabled citizens can access and transact business at its county courthouse. Parking is accessible and an access ramp is wheelchair friendly. The wheelchair-bound can easily reach the newly lowered service counters. In the courtroom itself, jury and witness boxes now accommodate wheelchairs. Signage includes raised Braille lettering, and assistive listening devices help those with hearing difficulties. One disabled resident recalls that before these improvements he could not pay his taxes in person because he could not navigate his wheelchair up the stairs to the cashier's second-floor office. "Now I feel good ... great really, when I look around at the changes made here."

One finds similar examples across the nation. The details vary, but the determination to improve the lives of people with disabilities is the same. In the end, the benefits are shared: cyclists and parents pushing baby strollers, for instance, also appreciate curbside cutouts, and elevators and ramps are often a boon to the elderly. Most of all, by empowering their neighbors with disabilities to contribute to the common good, Americans strengthen their communities even as they act justly.



This carousel welcomes all.

Hiring People with Disabilities: Good for Business

Elizabeth B. Kelleher

Companies are learning that employing people with disabilities has a positive impact on business and that making accommodations generally is less costly than expected. Elizabeth B. Kelleher is a writer for the U.S. Department of State in the Bureau of International Information Programs.

In 1998, a Belgian student named Sacha Klein left Brussels to spend a semester at a U.S. university. He ended up enrolling as a four-year student, graduating with a computer-science degree, and landing a summer internship at Virginia-based consulting firm Booz Allen Hamilton, where management liked him enough to offer him a full-time position. Today, he designs information systems for Booz Allen, studies toward a master's degree in business, and dreams of someday being his own boss.

He is deaf.

"This is truly the land of opportunity," Klein said in a conversation using an instant-messenger computer program. "Employers do not look at your disability, but at your abilities."

Since the Rehabilitation Act of 1973, which obligated government agencies to hire people with disabilities, Congress has passed 11 major laws to improve access to education, transportation, technology, and housing. In 1990, the Americans with Disabilities Act (ADA) opened the door for people like Klein to contribute to the U.S. economy in ways no one imagined before.



Many technical careers once were inaccessible to the blind, but new tools, such as this tactile map, allow students with disabilities to pursue careers in science, computer technology, and engineering.

The ADA is a civil rights law that bars discrimination by employers. It requires businesses to make accommodations to allow a person with a disability to do a job for which he or she is qualified. This might mean giving a diabetic breaks during the workday to check blood-sugar level or providing software for a blind person to use a computer.

In addition to workplace accommodations, the ADA requires public facilities to remove architectural barriers that hinder people with disabilities from shopping, going to the theater, or using public toilets.

Some experts believe such widespread architectural

changes have put the United States ahead of the 44 other countries with disability-discrimination laws. Katherine McCary, a vice president of SunTrust Banks Inc. and president of a business group that promotes hiring people with disabilities, said European managers tell her they want to hire people with disabilities, but that they can't get to work. "The ADA did a lot for us, in terms of creating access into and out of buildings," McCary said.

Roy Grizzard, assistant secretary of labor, has held recent seminars in EU countries and Vietnam on architectural solutions. "Curb cuts [ramps from sidewalks to streets at intersections] almost everywhere and transportation accommodations ... allow people to go to work," he said.

Klein thinks attitudes matter, too. Had he stayed in Europe, he said, he would not have been able to become a white-collar professional, but would have been put on track for factory work.

While one can paint a rosy picture of U.S. companies embracing people with disabilities, in the early 1990s, the ADA was greeted with panic by the business community, which predicted enormous costs and out-of-control litigation. A federal hotline offering advice on workplace accommodations went from handling 3,000 calls per year before the law to 40,000 calls per year in the mid-1990s.

The cost of accommodations turned out to be zero in half the cases and average about \$500 in the other half, according to the Labor Department. Employers report that workers with disabilities are loyal and productive, Grizzard said, so "balance that [\$500] with the cost of a good day's work for a good day's pay from a long-lasting employee."

As to lawsuits, Peter Susser, an attorney for the employment and labor law firm Littler Mendelson, said there still is a lot of litigation, despite court rulings narrowing the definition of disabled under the law. The Equal Employment Opportunity Commission, which handles claims of discrimination under the ADA, has received a steady stream of charges—averaging 16,000 per year and representing about one-fifth of all discrimination charges—since the law took effect. The government found 18 percent of the charges to have merit.

Beth Gaudio, of the National Federation of Independent Business, said much of the burden for small businesses today comes from state laws. The federal law's accommodation requirement applies to companies with 15 or more employees, but some state laws apply to firms of two. "It falls on the bookkeeper or the owner's spouse to figure out what needs to be done," Gaudio said.

It can be argued that compliance with the law is good for business, too: 87 percent of consumers prefer to patronize companies that hire people with disabilities, according to a January 2006 survey by the University of Massachusetts. In addition, workers with disabilities could help relieve a labor shortage. In the next eight years, 36 million Americans will be eligible to retire and leave the workforce. Census Bureau reports indicate that nearly half of the 33 million working-age people with disabilities were unemployed as of 2000.

"The ADA ... was an important beginning, but in no way an end," said Tom Ridge, the chairman of the board

of the National Organization on Disability and former governor of Pennsylvania. Businesses have policies to comply with the ADA, but need to step up recruitment, Ridge said.

The Department of Labor encourages disability-friendly companies with annual awards, and *DiversityInc* magazine recently published its first list of "top 10 companies for people with disabilities."

Five thousand businesses have formed chapters of a U.S. Business Leadership Network in 32 states to foster hiring people with disabilities. Through that network, the Booz Allen internship program that attracted Sacha Klein expanded in 2003 to include dozens of other companies and in 2006 to locate internships beyond Washington and New York.

The Cincinnati Children's Hospital recently decided to imitate a year-long mentorship program that SunTrust's banks offer to students with developmental disabilities. Executives from the national drugstore chain CVS Corporation met with the Labor Department's Ray Grizzard in October 2006 to discuss plans to introduce people with disabilities to pharmacy occupations. The Marriott Foundation for People With Disabilities, established by the founder of Marriott International, the hotel operator/franchisor, has formed links with several companies to train and place high school graduates with disabilities in jobs.

Small companies are taking the leap too. Seven of the 20 employees at Michigan manufacturer A&F Wood Products have disabilities. The company has rebuilt workstations, provided job coaches and special software, reconfigured telephones, and adjusted work schedules.

Companies hiring workers with disabilities do it for business reasons. They say they gain valuable employees who, often because of their disabilities, are skilled at planning ahead or communicating creatively.

Klein said he has learned a lot at Booz Allen about teamwork and communication. But early-on, he himself shared communication tips with colleagues. He asked them to speak one at a time at meetings and to look at him, not at his sign-language interpreter, when speaking to him. "They learn fast once you educate them a little bit," he said.

How One Company Approaches Disability

From hiring and training employees to product development, the Microsoft Corporation is a leader in serving people with disabilities.

Technology has changed all our lives, but perhaps has had the most impact for persons with disabilities, opening new worlds of communication, access, work, and education. With the current estimate of more than 54 million people in the United States with some form of disability, people with disabilities and their caregivers and family members are a highly attractive market. Microsoft realizes that to understand this group, to know what will meet their needs, and to know how to reach them, the company can benefit from the insights provided by employees with disabilities.

If you use the Microsoft Encarta encyclopedia and look up the "I Have a Dream" speech of Martin Luther King Jr., you will be able to hear his voice giving the speech. But you can also see the text written across the bottom of the screen. This addition, unique for this type of product, makes Encarta more useful to many customers and potential customers. Adding closed captioning to Encarta was the suggestion of a Microsoft employee who is deaf. This is only one example of the kind of contribution employees with disabilities can make to product development and marketing.

Microsoft has developed a multifaceted strategy to attract and retain qualified employees, including employees with disabilities, and to help them create products and services for people of all abilities. The company participates each year in National Disability Mentoring Day to help introduce students with disabilities to the world of work, and Microsoft encourages employees with disabilities to be involved. Students with disabilities often have had fewer opportunities to spend time in a work place, talking to professionals doing the kind of work in which they are interested, and even fewer opportunities to see people with their kind of disability succeeding in their target career. The mentoring program fills this need, while serving as an important element of Microsoft's outreach to this employee pool.

Like most companies, Microsoft has a recruitment program to attract talented individuals, including those with disabilities. But recruiters sometimes were concerned about how to approach these students, how to communicate with them, and how to make sure the team that conducted subsequent interviews was prepared to appreciate the candidates'

qualifications. Microsoft developed training for their recruiters to smooth this process. But their efforts did not stop there.

According to Mylene Padolina, Microsoft's senior diversity consultant, the company goes on to ensure that the workplace is fully prepared for the new employee. She interviews the new hires to find out what equipment and other accommodations they will need to do their jobs. The office groups or teams they will be joining receive briefings about the needs arising from the new employee's disability. There is a plan in place to ease the transition into the work environment for the new employee. Padolina says this allows the employee to be as productive as possible quickly and helps team members focus on the tasks of the office, not questions about the disability.

Accommodation can include special furniture or special computer programs or hardware, such as screen readers for the blind that produce the material on screen in spoken form or on a Braille display. Plans are made to make work meetings comfortable and productive and to be sure everyone is included, even in the more social team-building events. If the employee is blind, for example, team members will be coached on how to provide guidance from time to time to help the new employee move around. For teams gaining a deaf member, training will be offered in American Sign Language.

Microsoft has developed a coordinated approach to recruiting and employing people with disabilities, but it has not done this alone, nor dose it have all the answers. For more than 15 years, Microsoft has partnered with the National Business and Disability Council to create the Able to Work Consortium, and it is a member of Career Opportunities for Students with Disabilities (COSD). Padolina explains that this networking gives her resources for counsel when she faces a new issue and allows all participants to learn from the experiences of other members.

For its efforts, Microsoft has won numerous awards, including a New Freedom Initiative Award from the U.S. Department of Labor in 2004. In presenting the award, U.S. Secretary of Labor Elaine Chao noted that the company offers unique employment opportunities for job seekers with disabilities. The award went on to cite many of the achievements noted above. Learn more from Microsoft's 15-minute video, "Window of Opportunities" at http://www.microsoft.com/about/corporatecitizenship/citizenship/diversity/inside/access.asp.

American Indians and Disability: Montana's AIDTAC Program

Julie Clay and Gail Greymorning

Julie Clay is the director and Gail Greymorning is the executive assistant of the American Indian Disability Technical Assistance Center (AIDTAC) at the University of Montana's Rural Institute. With principal funding from the Department of Education, for the last five years, AIDTAC has supported American Indians and Alaska Natives in their efforts to improve employment opportunities and vocational rehabilitation outcomes wherever they live in the United States.

he U.S. Census Bureau estimates that 4.4 million American Indians and Alaska Natives live in the United States. (This number includes those who are mixed with other races.) The largest populations live in California, Oklahoma, Arizona, and Alaska. Native Americans speak more than 250 languages, and there are 561 federally recognized tribal governments in the United States. Some live on rural or remote reservations, in villages and pueblos, or on rancherias and tribal trust lands.

The National Council on Disability reports that the types of disabilities found in the general population also are found in the American Indian and Alaska Native population. Some disabilities, such as those related to diabetes and drug and alcohol abuse, are more prevalent among Native

American groups, and, therefore, the overall rate of disability is higher. Among Native Americans of working age (16-64), the disability rate is 27 percent, as opposed to 18 percent for the general population; among those age 65 and older, the disability rate is 57.6 percent, as opposed to 41 percent. ¹

DISABILITY IN NATIVE AMERICAN CULTURE

The concept of disability takes on new meaning when one considers that most tribal languages do not even have a word for handicap or disability. Disability is an idea familiar to Western culture but with no direct parallel in American Indian culture. The closest American Indian concept does not look at physical characteristics but views disability as disharmony of spirit. (In addition,

the cultures and traditional beliefs of the many tribes vary significantly, each with a unique set of creation stories, religious doctrines, and sacred taboos.)

Julie Clay, a member of the Omaha tribe, has a disability and is director of the American Indian Disability Technical Assistance Center (AIDTAC) at the University of Montana's Rural Institute. She explains, "The concept of unwellness is described as disharmony in body, mind, and spirit. If one of these areas is in disharmony then the whole being is affected. Just because a person may have a physical or mental disability, however, does not mean one is in disharmony or in a state of unwellness. But if there is disharmony in one's environment or reactions to certain events, then a state of unwellness is present." Indeed, while many American Indian people

have assimilated into the dominant culture,

many Indians still hold to their old ways and traditions. This "living in two worlds" is problematic enough; coping with disability adds a "third world" of difficulties.

UNDERSTANDING TRIBAL COMMUNITIES

The National Council on Disability recognizes that meeting the needs of people with disabilities living on

courtesy of Julie Clay, AIDTAC

tribal lands requires an understanding of the various American Indian and Alaska Native cultures and history and an appreciation for the unique legal and socioeconomic environment of tribal communities. Consultation with tribal leaders and tribal members with disabilities is critical in understanding the depth and complexities of these cultures and the concept of disability in Native American communities.

Julie Clay observes that economic, legislative, political, social, historical, and cultural constraints forced on the people living within the reservation boundaries make life tumultuous. Resources and opportunities are scarce for the majority of people living on tribal lands. Because of the poor living conditions and barriers found on some reservations, there are few opportunities to fulfill personal life goals.

For the past five years, AIDTAC has served as a national technical assistance center. Groups that have benefited from their services include American Indians and Alaska Natives with disabilities and their families, tribal governments, tribal and state vocational rehabilitation agencies, employers and employer representatives, urban Indian centers, and others. In conjunction with other programs at the Rural Institute, AIDTAC addresses issues of employment, transportation, health, independent living, and education. With funding from the Social Security Administration and the Department of Education's Rehabilitative Services Administration, AIDTAC provides training and technical assistance to improve employment opportunities and vocational rehabilitation outcomes for Native Americans with disabilities.

¹ General population figures from the Department of Health and Human Services 2005 fact sheet "What is Disability? Who is Affected by Disability?" found at http://www.surgeongeneral.gov/library/disabilities/calltoaction/factsheetwhatwho.html)

BUILD ON THE PROGRESS

society. This section describes some of the effort being made to "rebuild on the progress" of the ADA, mentioned in President Bush anniversary proclamation, from medical and technological advances to employment issues and emargency preparedness. ■



A Coast guard veteran and champion wheelchair athlete helps an 8-year-old maneuver through the Wheelchair Games in Anchorage, Alaska.



stage
rpreter has
members who

Singer Gwen Steffani is on stage (background), but this interpreter has the attention of audience members who need help understanding the words and music. Thanks to interpreters who use American Sign Language and animated movements and facial expressions, fans with hearing disabilities can still join in the concert experience.

Tracking the News on Medical Advances

cross the United States and throughout the world researchers are pursuing breakthroughs in medical and therapeutic treatments of various disabling conditions. Some medical news is reported in the general media, but most is published in various specialized media. These include scientific and professional journals and Web sites and publications of universities, nongovernmental organizations, government agencies that deal with health and disability issues, and the foundations that help support the work. Many of the organizations—and, therefore, their journals and Web sites—focus on a special area of medical research. There are hundreds, if not thousands, of sites in the United States alone.

One excellent source is the Web site of the Waisman Center of the University of Wisconsin. The center specializes in research, training, service, and outreach dedicated to advancing knowledge about human development, developmental disabilities, and neurodegenerative diseases. The center's home page, which can be found at http://www.waisman.wisc.edu/home/html, includes news and noteworthy items. On one day in October 2006, for example, the page featured information about research on a rare condition affecting the Hmong people, a report on the benefits of meditation on the brain, and an item on research into human memory formation. Other sections of the page focus on the research center, stem cell research, the brain imaging lab, and a biomanufacturing facility.

Choosing "The Family Village" on the home page takes visitors to "A Global Community of Disability-Related Resources." Then, clicking on "Research" leads to choices for medical, disability-specific, special education, rehabilitation, disability statistics, and community services and supports. Choosing "Medical" leads to another extensive list of options. The site includes a dictionary of medical terms, tools for searching medical publications and online journals, and many other resources.

New Freedom Initiative

nnounced by President George W. Bush on February 1, 2001, the New Freedom Initiative (NFI) is part of a nationwide effort to remove barriers to community living for the more than 54 million Americans with disabilities, some 20 percent of the U.S. population. Almost half of these individuals have a severe disability affecting their ability to see, hear, walk, or perform other basic functions of life. In addition, there are more than 25 million family caregivers and millions more who provide aid and assistance to people with disabilities.

The NFI was enacted in order to address inequities that persisted more than a decade after the Americans with Disabilities Act (ADA) made it a violation of federal law to discriminate



chain has established this South Carolina training center that will be able to train 200 employees with disabilities beginning early in 2007.

against a person with a disability. For example, when compared to their compatriots without disabilities, in the United States, individuals with disabilities are often less educated, poorer and more often unemployed, less likely to own their own homes, less likely to vote, and less likely to own a computer and have Internet access.

The New Freedom Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life. The NFI's goals are to

- increase access to helpful technologies;
- expand educational opportunities;
- promote home ownership;
- integrate people with disabilities into the workforce;
- expand transportation options;
- promote full access to community life and improved access to health care.

Following is a more detailed explanation of some of these goals and just a few of the related accomplishments as of 2004 (from the initiative's 2004 progress report).

Increase Access Through Technology. Assistive and universally designed technology (products and environments that can be used by all people, without the need for adaptation or specialized design) offers people with disabilities better access than ever before to education, the workplace, and community life. Specific accomplishments include

- securing funding to promote the development of assistive and universally designed technology and to fund
 alternative financing programs, such as low-interest, long-term loans to put technology into the hands of
 more people with disabilities;
- creating a working group of federal agencies that developed strategies for improving access to assistive technology mobility devices (i.e., wheelchairs and scooters);
- establishing *DisabilityInfo.gov*, a Web portal providing information about the array of federal programs that affect people with disabilities.

BUILD ON THE PROGRESS





You do it like this. Lennette helps her friend Noah learn sign language in a preschool class for deaf children

These students in a class for children with special needs enjoy interacting with their music therapist

Expand Educational Opportunities for Youth with Disabilities. A quality education is critical to ensure that individuals with disabilities can work and fully participate in their communities. Specific accomplishments include

- securing additional annual funding for the Individuals with Disabilities Education Act Part B State Grants program;
- establishing the President's Commission on Excellence in Special Education, which issued a report in July 2002
 emphasizing, among other things, the importance of accountability under the No Child Left Behind Act for the
 educational outcomes of students with disabilities.

Promote Home Ownership. The following steps have been taken to make it easier for people with disabilities to own their own homes:

- During FY 2003, the Department of Housing and Urban Development trained more than 1,500 housing
 professionals under its Fair Housing Accessibility FIRST initiative, which helps architects and builders design
 and construct apartments and condominiums with legally required accessibility features.
- The Department of Housing and Urban Development has funded grants to enable older individuals and individuals with disabilities remain in their homes and live independently in their communities.
- The Department of Justice has vigorously enforced the Fair Housing Act, filing lawsuits against developers, architects, and civil engineers who designed inaccessible multi-family housing, and resolving other cases through consent decrees.

Integrate Americans with Disabilities into the Workforce. More than a decade after passage of the ADA, the unemployment rate of people with severe disabilities remains stubbornly high. To bring more people with disabilities into the workplace, the president has

- secured \$20 million for a fund to help individuals with disabilities purchase technology needed to telework (work from home);
- supported a proposal that would exclude from an employee's taxable income the value of computers, software, and other equipment provided for teleworking;
- ensured implementation of the landmark Ticket to Work program, which modernized the employment services system for people with disabilities.

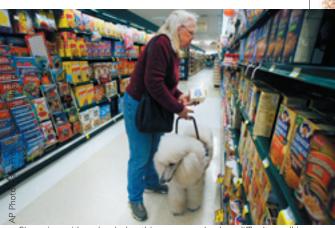
BUILD ON THE PROGRESS

Promote Full Access to Community Life. The Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), said that, wherever possible, people with disabilities should be provided services in the community, rather than in institutions. For the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing, access to transportation, access to the political process, and the right to enjoy whatever services, programs, and activities are offered to all members of the community at both public and private facilities. The president has done the following to promote full integration of individuals with disabilities into the community:

- issued an executive order calling for swift implementation of *Olmstead*, which resulted in a report identifying barriers to full integration that exist in federal programs and proposing more than 400 solutions for removal of these barriers;
- established the New Freedom Commission on Mental Health, which issued a report recommending ways to improve America's mental health care delivery system;
- secured \$15 million under the Help America Vote Act to improve access to voting for people with disabilities.



Prospective homeowners work on their Habitat for Humanity homes alongside volunteers. Here, Chris Wright, joins volunteers to construct his Birmingham, Alabama home. The special model, called Ability House, is designed to be barrier free for residents in wheelchairs.



Shopping with a dog helps this woman who has difficulty walking without assistance. Businesses and public facilities now have policies recognizing the important, legitimate role of service animals.

New techology has created an artificial hip that allowed this farmer to go back to work.

Getting the Word Out: DisabilityInfo.gov

ne important outcome of the Americans with Disabilities Act (ADA) and the resulting initiatives and programs has been the concerted effort by various governmental offices to make information available to the public and, especially, to utilize the Internet to make information rapidly, inexpensively, and easily accessible. To support the goals of the New Freedom Initiative, President George W. Bush directed federal agencies to create *DisabilityInfo.gov* in order to connect people with disabilities to the information and resources they need to pursue their personal and professional ambitions—delivering on America's promise of equal access to opportunity for all. This award-winning site offers visitors options in employment, education, housing, transportation, health, benefits, technology, community life, and civil rights. Each menu choice leads to numerous sites and links in that interest area.



Do you want to learn about adapting a car for use by someone with a disability? This site can lead you to the information. Do you run a business and want to know how the ADA guidelines apply to you? This site can take you to the answers. Do you want to know about the fair housing regulations and how they apply to house hunters or to landlords? This site will help you.

Supporting the Search for Employment



Luis Figueroa, pictured here in 2004 while playing baseball for the Nashville Sounds, dreamed of making it to the major leagues. Today, he plays second base/shortstop for the Toronto Blue Jays in Ontario, Canada. Figueroa has been deaf since age 6

ctober 2006 was declared National Disability
Employment Awareness Month by President Bush.
Noting the economic and other contributions made
by the nation's employees with disabilities, the president called
upon government officials, labor leaders, employers, and the
people to observe the month—and the contributions of disabled
Americans—with appropriate programs, ceremonies, and
activities. While celebrating those with disabilities who have jobs,
it is also valuable to look at the barriers to employment and the
resources that help address them.

According to the Employment portal page of the *DisabilityInfo.gov* Web site, the resource site for the New Freedom Initiative, "Employment is the economic engine of our nation, our communities, and our families. For people with disabilities, employment promotes greater independence and productive, fulfilling lives." This group has traditionally had a lower employment rate than the general public, so in order to

BUILD ON THE PROGRESS



Sign language students require special work on words with multiple meanings. Understanding how the language differs from written English helps prepare the students for standard tests.

address this gap, a number of resources have been created to help in the search for employment. Some are private, others offered by the various levels of government. The following are two examples of the types of support available.

The DisabilityInfo.gov employment site (http://www.disabilityinfo.gov/digov-public/ public/DisplayPage.do?parentFolderId=9) covers a variety of topics related to the employment of people with disabilities, including advice and resources for individuals with disabilities seeking work; help for potential employers; information about employee rights, laws, and regulations; resources for employment programs; and information about job accommodations for people with disabilities. Rubrics include Employer Resources, Federal Contracting, Federal Employment, Job Seeker and Employee Resources, Job Training, Self-Employment and Entrepreneurship, Vocational

Rehabilitation, Working Abroad, and Youth. Each of these sites includes specific listings of resources.

Designed specifically to help young people with disabilities find work, the National Collaborative on Workforce and Disability for Youth, funded by a grant administered by the Office of Disability Employment Policy (ODEP) at the U.S. Department of Labor, offers a collection of resources and publications, an up-to-date listing of events of interest, searchable links to Internet resources, FAQs (Frequently Asked Questions), Ask the Experts, and Pro-Bank, an online database of promising programs and practices in the workforce development system that effectively address the needs of youth with disabilities. The URL is http://www.ncwd-youth.info/.

Health and Wellness: The Surgeon General's Call to Action

In 2005, on the 15th anniversary of the enactment of the Americans with Disabilities Act, U.S. Surgeon General Richard H. Carmona announced a Call to Action to Improve the Health and Wellness of Persons with Disabilities. The surgeon general said, "The call to action is a call to caring....The reality is that for too long we provided lesser care to people with disabilities.... We must redouble our efforts so that people with disabilities achieve full access to disease prevention and health promotion services."

Disability has been defined as characteristics of the body, mind, or senses that, to a greater or lesser extent, affect a person's ability to engage independently in some or all aspects of day-to-day life. Understanding that disability is neither inability nor sickness becomes even more important when it is pointed out that everyone will have at some point in life at least one disability. The incidence of disability increases with age. By age 80, almost 75 percent of people have a disability.

Developed in collaboration with the Office on Disability of the U.S. Department of Health and Human Services, the Call to Action identifies four goals to help people with disabilities experience full, rewarding, and healthy lives as contributing members of their communities:

- Increase understanding nationwide that people with disabilities can lead long, healthy, and productive lives.
- Increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity.
- Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle.
- Increase accessible health care and support services to promote independence for people with disabilities.

According to Margaret J. Giannini, director of the HHS (Department of Health and Human Services) Office on Disability and a physician with more than 50 years of experience working in the field of disability, it is important to begin to focus on the abilities of people with disabilities. They "can learn, get married, have a family, worship, vote, work, and live long, productive lives. We need to make sure we treat them as active members of our society."

Since the Call to Action was issued in 2005, a number of steps designed to achieve these goals have been identified through an inclusive planning process involving diverse working groups, and these steps are being implemented. For instance, for the first goal, to increase nationwide understanding, one action was the creation of the *People's Piece*, a publication written at a sixth-grade reading level that explains and illustrates the key messages of the Call to Action, such as the idea that eliminating barriers to accessible treatment can prevent secondary or complicating problems from



Lee Jones works with weights as he leads an exercise class for disabled people at a community center in Mission, Kansas. Jones, who has Down syndrome, is hoping the class will help other disabled people become active and get in shape.

arising. A second set of actions involves working with health care professionals, including training facilities and medical schools, to help new professionals become aware at the earliest point in their careers of the issues and treatments related to disability. The *People's Piece* and other information can be found at *www.hhs.gov/od* and *www.hhs.gov/od/programs*. The Web site http://www.surgeongeneral.gov/library/disabilities/ contains links to speeches, press releases, and fact sheets, including some with statistics related to this program.

As U.S. Secretary of Health and Human Services Mike Leavitt said upon announcing the program, "This Call to Action is a reminder that people with disabilities are important members of our society, and that including them in all aspects of American life is not only required by our nation's laws, but also by our nation's conscience."

Educating Children Who Have Disabilities

rom communication and mobility problems to cognitive and emotional challenges, a wide variety of disabilities afflicts children, just like adults. American public schools are expected to address all children's needs and to help them reach their full potential. Programs to help teachers and parents deal with special needs children have existed for a long time, but these programs have expanded in the past 30 years.

In 1975, President Gerald Ford signed legislation that has evolved into the Individuals with Disabilities Education Act (IDEA). The law guaranteed children with disabilities access to a free and appropriate public education. Prior to IDEA, only about 20 percent of children with disabilities attended school. By 2003, the number of students with disabilities completing high school had risen by 17 percent, and their participation in postsecondary education had more than doubled.



A teacher helps this child with a motor disorder join classmates during playtime.

Although IDEA guaranteed every child an education, the law did not address academic outcomes, which sometimes led to what President George W. Bush called the "soft bigotry of low expectations." His administration's No Child Left Behind (NCLB) law was designed to get all children, nationwide, reading and doing mathematics at a grade-appropriate level by 2014, but it did not include a plan to help students with disabilities attain this goal. The Department of Education's Office of Special Education and Rehabilitative Services worked with school systems across the country to begin addressing this gap. The Tigard-Tualatin School District in the state of Oregon and the Minneapolis Public Schools in Minnesota, for example, participated in pilot programs that stressed academic outcomes, early intervention, and other improvements.

In 2006, the Department of Education issued new guidelines for IDEA, adding an expectation of academic outcomes to the requirements for special needs children and providing a Tool Kit for Teaching and Assessing Students



Sign language is used in many schools, not only schools for the deaf.

with Disabilities to aid school districts, educators, and parents in implementing the new accountability measures. Key elements of the new guidelines include flexibility in spending resources to help schools identify special needs students early and accurately and get them the support they need; a requirement that teachers of special needs children be highly qualified, not only in teaching this audience, but also in the academic subjects being presented; a streamlining of paperwork for schools; and the strengthening of parents' involvement in their children's education.

In the summer of 2006, U.S. Secretary of Education Margaret Spellings welcomed the new guidelines, saying, "No Child Left Behind and the Individuals with Disabilities Education Act have put the needs of students with disabilities front and center. We now have a laser-like focus on helping these kids."

Disability Awareness Education

The commitment to help all people with disabilities achieve as much as possible and participate fully in all aspects of U.S. society clearly includes roles for those with disabilities and for teachers, therapists, and other support personnel who work with people with disabilities. But for everyone else in society, there is also a responsibility to learn about disabilities and ways to support people who have them.

Since the enactment of the Individuals with Disabilities Education Act (IDEA), more and more schools have programs that bring children with disabilities into regular classrooms for all or part of the day. Children with and without disabilities work and play together and form friendships that enrich both parties. Educators have

discovered, however, that while children can be open to others, there are things adults can do to help them develop the comfort, understanding, and respect that makes these relationships possible.

A number of groups have developed teaching materials to help teachers and youth workers plan lessons to help children understand the challenges and perspectives of those with disabilities. A resource list that describes programs and gives contact information can be found at http://www.nichcy.org/pubs/bibliog/bib13txt.htm.

Programs range from groups such as Kids on the Block, which uses nearly life-size puppets and other materials to teach disability awareness and to present medical and Children enjoy a Kids on the Block puppet show. The puppet characters (left to right) are Renaldo, who likes sports and games and who uses a cane because he is blind; Mark, who has

Children enjoy a Kids on the Block puppet show. The puppet characters (left to right) are Renaldo, who likes sports and games and who uses a cane because he is blind; Mark, who has cerebral palsy and travels in a wheelchair; and their friend Melody. Each of the 30 kids on the Block puppet has a story that allows the plays to introduce important topics sometimes hard to raise with young audiences.

educational differences and social concerns, to New Friends Curriculum, which uses dolls to create situations for children to discuss. Interactive programs allow able-bodied children to use blindfolds and other tools to experience what it would be like to lose some ability. Trying to tie shoes with a sock over each hand to reduce the functioning of the fingers or trying to eat while blindfolded helps children empathize with their classmates with disabilities. Learning what it feels like to walk blindfolded helps them better understand how to help a classmate or friend. Visit the Kids on the Block Web site at http://www.kotb.com.

U.S. classrooms and youth organizations have added these kinds of lessons because most Americans believe that understanding the challenges of others and how best to help them is as much a part of being a good citizen as any of the other social or civic lessons that are offered. And it's not simply good for children. Businesses and other organizations have programs to help employees better understand how to work with colleagues or clients who have disabilities. ■

he Kids On The Block, Inc. in Columbia, MD

Disaster Preparedness: Meeting the Needs of Persons with Disabilities

ver time, new implications and applications for the Americans with Disabilities Act have emerged. The act addresses nondiscrimination with regard to public services and public facilities, but does not specifically mention natural disasters or other emergency situations. The implications for these situations, however, have become evident, especially as more focus has been placed on emergency preparedness in the wake of the September 11, 2001, terrorist attacks and numerous natural disasters. The Department of Homeland Security (DHS) and the National Council on Disability have issued recommendations on emergency preparation. Congress and individual states have written legislation to address these needs. In July 2004, President George W. Bush established the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities.

The purpose of the council is to

- consider, in their emergency preparedness planning, the unique needs of agency employees with disabilities and individuals with disabilities whom the agency serves:
- encourage, including through the provision of technical assistance, consideration of the unique needs of employees and individuals with disabilities served by state, local, and tribal governments, private organizations, and individuals in emergency preparedness planning;
- facilitate cooperation among federal, state, local, and tribal governments, private organizations, and individuals in the implementation of emergency preparedness plans as they relate to individuals with disabilities.



Meeting the needs of people with disabilities during disasters includes planning for medical care, transportation, communication, and other special needs.

In April 2006, Daniel W. Sutherland, chair of the Interagency Coordinating Council, spoke to attendees at the National Hurricane Conference on how to integrate individuals with disabilities into the emergency management process. Learning lessons from the hurricanes of 2005, he said:

The needs and talents of people with disabilities must be more effectively integrated throughout the emergency management process. While all Americans face difficulties during emergencies, these difficulties are often compounded for people with disabilities and their families. This is not a "niche" issue, worthy of a footnote or two as we discuss the lessons learned from [Hurricane] Katrina. ... [T]he disability community constituted approximately 20 percent of the people who lived in the Gulf Coast region. These are complex issues, affecting a large number of people, and we must do a more effective job in addressing them. ... We recognize that state and local governments are the primary first responders in a disaster.... Our role and responsibility is not to add new burdens to your work, but to identify ways that we can help you effectively deal with the complex and unique issues in this arena....People with disabilities do not want to be passive consumers of help. Rather, people with disabilities have a tremendous amount to offer because they bring a unique blend of energy, experience, ideas, and determination to these issues. People with disabilities, their families, and the organizations that serve them want to help; all you have to do is enlist them in the service.

The full text of Sutherland's remarks can be found at http://www.dhs.gov/xabout/structure/editorial_0842.shtm. ■

Disability Issues and Foreign Affairs

hile the Department of State's primary mission is the conduct of U.S. foreign policy, it also is involved in disability issues. In addition to the normal concerns about accommodating the needs of employees and their families, who are assigned throughout the world, American embassies and consulates provide services to U.S. citizens living or traveling in host countries. A consular office in France, for example, was asked by an American deaf woman to help explain the role of a service dog to local officials, who were familiar with dogs for the blind but were unfamiliar with a dog serving a hearing-impaired owner.

The State Department also sponsors cultural and educational programs dealing with the subject of disability. A number of programs and exchanges reach out to students with disabilities, including two that send U.S. teachers or student interns to work with programs for the deaf in other countries. Other programs may not focus exclusively on audiences with disabilities, but may have some connection with special needs audiences. World Cup athletes recently visited several countries and met with many groups, including deaf footballers from Bahrain's Disabled Sports Federation—a program that resulted in extensive local press interest in Bahrain and promises to lead to follow-up activities.



Members of the State Department-sponsored traveling World Cup group met with young athletes around the world. Here Women's World Cup Champion and gold medalist Cindy Parlow and a deaf member of the Disabled Sports Federation of Bahrain learn that football (soccer) is a universal language.

Another State Department office recruits and sends U.S. citizens as experts to conduct programs around the world. These programs sometimes involve unusual requirements, such as the need to send along a sign language interpreter when a hearing-impaired disability expert traveled to do programs in Shanghai or the special arrangements needed when a blind speaker visited India with her seeing-eye dog. In the United States, it is not uncommon to see service dogs working with blind, deaf, or otherwise disabled people, and "therapy" dogs even visit hospitals and nursing homes to help calm patients (research shows that the presence of these dogs improves blood pressure and pain tolerance and helps reduce depression). Making arrangements for people and their service animals to visit other countries where the regulations and cultures

are different, however, presents special challenges for program organizers. But it is well worth the extra effort, when the result is not only that the department's human emissaries

have the support needed to do their work in another country, but, as in the case in India, the speaker's dog became a bit of a media sensation herself, introducing a large segment of the population to a new concept.

To read an article about the experiences of Joyce Kane and her dog during their programs in India, go to: http://usinfo.state.gov/scv/Archive/2005/Jul/18-456527.html.

To learn more about international programs for the deaf, visit Global Deaf Connection at (http://www.deafconnection.org; and The International Deaf Partnerships Project at http://academic.gallaudet.edu/courses/spa/CREPBerw.nsf.



Joyce Kane, who is blind, was a popular speaker during her 2005 tour of India. Her dog Corey was an even bigger sensation.

Technology: Equipping People with Disabilities to Meet the Challenges of Daily Life

any government and nongovernmental programs, centers of study, publications, and research reports address issues related to disabilities and technological advances that help mitigate them. Disability-related projects involve everything from face-to-face and long-distance communication to mobility, from learning aids to robotics for the workplace. The projects currently underway and new advances recently announced are too numerous to recount in one article, or even an entire journal. One project that illustrates the kind of practical innovation that is going on is being conducted by the Burton Blatt Institute (BBI) of Syracuse University, the faculty of the university's Communications Department, and hospitals in the state of New York.

INTERNET VIDEO INTERPRETING FOR REMOTE AMERICAN SIGN LANGUAGE (ASL) SERVICES

Imagine. You cannot hear, and you cannot speak without sign language. You bring your injured child into the emergency room at the hospital. No one can explain to you what is happening, what you are supposed to do, and what you can expect. Your concern is escalating, and the doctors need information you cannot provide. What can you do?

In New York, recent amendments to the state's Official Compilation of Codes, Rules, and Regulations require health care facilities to make language assistance services available to "patients in the inpatient and outpatient setting within 20 minutes and to patients in the emergency service within 10 minutes of a request" for such services, whether the language

is Chinese or American Sign Language (ASL). Health care facilities in Syracuse and elsewhere in the state of New York are actively exploring ways to comply with this new stipulation. Video-delivered ASL services, where the interpreter makes a "house call" to the facility from a remote location over the Internet, is an innovative option under serious consideration. The Internet promises an entirely new capacity to broaden social inclusion, and ASL services of significant interest include interpreting, mental health counseling, and emergency preparedness and disaster response.

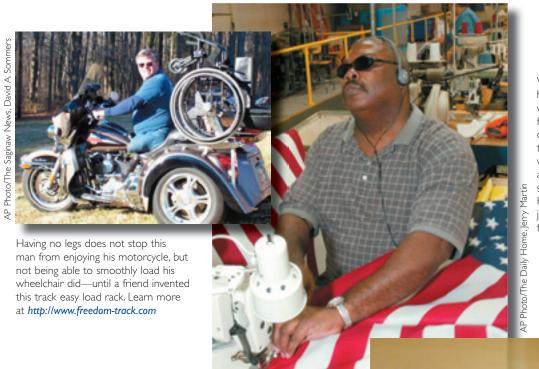
In Phase 1 of the BBI Innovation Grant research project, three research sites, all located in the city of Syracuse, are exploring ASL via the Internet. Two of the sites are hospitals that use ASL services, and the third is a nonprofit provider of such services. Research questions of interest include: What ASL services are provided and used today? What new opportunities and challenges stem from Internet-delivery of ASL services? While there are exciting new business and service opportunities from Internet delivery, there are also challenges that must be overcome before Internet-delivered ASL services become commonplace. One likely source of challenge is compliance with HIPAA (privacy regulations regarding health information that put strong requirements on medical offices to protect patient medical information). In Phase 2 of the project, health care facilities in a 14-county area in New York will be surveyed on their readiness for complying with the new stipulations on access to ASL services and on prospects for adopting Internet-delivered ASL services.



Brandon Watkins, who has prosthetic legs and fingers, is one of 13 members on the men's basketball team his Wisconsin technical college. Watkins played in 13 games and made 5-of-9 field goals, including four 3-pointers. He also helped his team with rebounds, assists and steals.

Photo/Andy №

BUILD ON THE PROGRESS



Vincent Armstrong, shown here sewing an American flag, was blinded at age 11. The father of three and graduate of the Alabama School for the Blind was twice the state wrestling champion, competing against able-bodied high school students from around the state. He's shown here working at his job at the Alabama Industries for the Blind.



Jazz pianist, composer, and singer Valerie Capers reads and writes music in Braille. One of Capers's most interesting works is "Wagner Takes the A Train," a lively instrumental jazz version of Richard Wagner's "Der Ring des Nibelungen."

Training programs help match employees with disabilities with jobs that allow them to succeed.

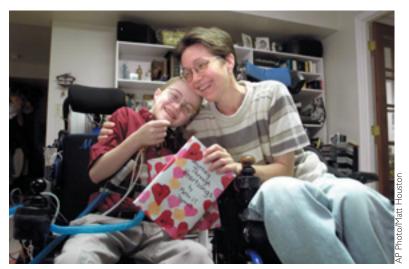
AP Photo/The Herald, Andy Burriss

Playing tennis in a specially built wheelchair helped this doctor gain enough strength to resume his medical practice.

29

Mattie J.T. Stepanek, Poet

Chandley McDonald



Pictured here at age II, Mattie and his mother, Jeni, enjoy his latest book of poetry.

A child with muscular dystrophy inspired millions with his poetry and his courage. Chandley McDonald is a writer for the U.S. Department of State in the Bureau of International Information Programs.

eartsongs figure a lot in Mattie Stepanek's poetry. As he described it, "Your heartsong is your inner beauty. It's the song in your heart that wants you to help make yourself a better person, and to help other people do the same. Everybody has one."

The young hero, who battled a rare form of muscular dystrophy for 13 years, was able to write inspirational poetry and essays, publish books, speak with his heroes, and lead a full life. Mattie succumbed to his illness in June 2004, but not without leaving a legacy of an exemplary life and wisdom far beyond his age.

Mattie's illness, dysautonomic mitochondrial myopathy, left him with impaired automatic functions—breathing, heart rate, blood pressure, body temperature, digestion, and utilization of oxygen. He attended public school until age nine, when the condition worsened and

he had to use a wheelchair and have medical assistance with his normal day-to-day living. Even so, Mattie managed to travel, to read extensively, to produce his poetry, to collect rocks, and to become a spokesperson for muscular dystrophy. Among his honors were becoming National Goodwill Ambassador for MDA (Muscular Dystrophy Association) and a volunteer for a fantasy trip sponsored by United Airlines and Children's Hospice International.

As a champion for peace and global tolerance, Mattie appeared on many television programs, where he was interviewed by famous hosts. He even got to introduce his hero, former President Jimmy Carter, at the Kennedy Center in Washington, D.C. As an inspiration to people around the world, Mattie's message reached individuals of all ages, races, nationalities, faiths, abilities, and aspirations.

"People tell me I inspire them. And that inspires me. It's a beautiful circle, and we all go around together, with and for each other. What a gift." This quote comes directly from the extraordinary heartsong of Mattie Stepanek. ■

Angela Rockwood-Nguyen: Helping Others Go Forward

Chandley McDonald

A young victim of spinal cord injury helps others in her situation through the foundation that helped her.

n 2001, just two months before her wedding to Dustin Nguyen, Angela Rockwood, then an aspiring model and actress, suffered a spinal cord injury in a car accident. She remembers waking up in the hospital thinking that this was the end of the world. In a real sense, her world as she knew it, was changed forever. "Changed," she says, "from being a fitness enthusiast and an aspiring actress, I had been transported into the realm of the paralyzed: a C4-5 quadriplegic." (C4-5 indicates the location of her injury; in this case, her neck.)

At the time, Angela quickly assessed her situation and knew that even though she could be disabled all her life, she was ready to accept it and go forward.

"Go Forward" is the motto of the foundation established by former movie star Christopher Reeve, whose

film roles included Superman. Reeve was paralyzed in a horseback riding accident in 1995. He and his wife Dana lent their names to the American Paralysis Association shortly after his accident. The organization ultimately became known as the Christopher and Dana Reeve Paralysis Resource Center (PRC).

Following Rockwood-Nguyen's accident, she received an enormous amount of support and assistance from Reeve's foundation. Even today, she says, the foundation is there to provide her with information and resources that she needs to live a healthy and productive life.

Rockwood-Nguyen and her husband, Dustin, an Asian-American actor, are spokespeople for the Paralysis Resource Center's Minority Outreach Campaign.
They are encouraging others to "Go Forward," just as the Reeves envisioned.

"Shortly after my accident, in the midst of therapy, I learned of the PRC and can vouch for the level of

Courage

Christopher Reeve

Angela, (center) is pictured with (right to left) her husband, Dustin; Kathy Lewis, president and chief executive officer of the Christopher Reeve Foundation; and Dana Reeve, who died in 2006, two years after her husband.

support they were able to provide—that there are people who can get you the information you need in desperate and confusing times. There are so many paras

and quads [paraplegic and quadriplegic people] who can use the help—especially in the Asian-American community—and I plan to do everything I can to get them to do so," Rockwood-Nguyen says.

And there is hope for the future for paralysis patients. The Paralysis Resource Center reports, "Today, our belief in a cure is shared by the neuroscientists, researchers, clinicians, and, perhaps most importantly, thousands of people living with spinal cord injuries and their families."

Rachael Scdoris Competitive Musher

Chandley McDonald

A 20-year-old woman from the state of Oregon became the first blind competitor in the Iditarod Trail Sled Dog Race in 2006.

t is really hard to imagine. Think about bracing

yourself against the cold of minus 52 degrees Fahrenheit (minus 46.7 Celsius), enduring 12 days of unrelenting wind, and racing across more than 1,110 miles (1,776 km) of difficult Alaskan wilderness. Competitive "mushing," piloting a sled and 12 to 17 sled dogs in the Iditarod Trail Sled Dog Race, is the realization of Rachael Scdoris's lifetime dream, even though she has been legally blind since birth. The 20-year-old woman from Oregon is the first blind musher to compete in the Iditarod. Scdoris and her visual interpreter, Tim Osmar, finished in 56th and 57th places in the Alaskan race in March 2006. An Iditarod veteran, Osmar drove his dog team in front of Scdoris, operating as her "eyes," alerting her to trail conditions during the race. They communicated by two-way radio.

The Iditarod is sometimes called "the last great race on earth." Every year since the competition began in 1973, the race has begun in Anchorage, Alaska, during the first weekend in March. Each team of dogs and their mushers cover the distance across Alaska to Nome in approximately nine to 17 days. Scdoris and Osmar finished the race in 12 days, 11 hours, and 42 minutes. Finishing and placing in 2006 was particularly gratifying for Rachael. In 2005, she had to drop out after

completing more than half of the race, because some of her dogs became ill.

Scdoris's condition is called congenital achromatopsia, a rare vision disorder. She is colorblind, and her condition makes her extremely sensitive to light. Congenital

achromatopsia is a hereditary disorder that affects one person in 33,000 in the United States; the condition generally is stable over the course of a person's life. The incidence of congenital achromatopsia varies in different parts of the world. Many achromats can function normally with the aid of darkened glasses, while others use guide dogs or canes and are considered legally blind.

Even though she is visually impaired, Scdoris has not let this stand in the way of challenges. "It has been my plan to race the Iditarod since I was eight years old, as it is the biggest and most prestigious sled dog race in the world," says Scdoris, who started mushing when she was three years old. As a student in Oregon, she was captain of her high school track

and cross-country teams. Voted one of the top women athletes in America

by the Women's Sports Foundation in New York City, she had the honor of carrying the Olympic Torch to the Salt Lake City Winter Olympics in 2002. Now, Scdoris divides her time between competitions and working as a sled dog tour operator.



Rachael Scdoris and her dogsled team compete in a preliminary race in 2004.

Michael Naranjo, Sculptor

Chandley McDonald

A blind sculptor creates and shares touchable art.

Please touch! Please touch these beautiful bronze statues. This uncommon invitation was made by the Heard Museum in Phoenix, Arizona. The exhibit is a collection of statues created by Michael Naranjo, a New Mexico native who was blinded as a soldier in Vietnam. His

inspiration is nature and what art he remembers seeing in galleries growing up in his hometown of Taos, New Mexico.

Michael Naranjo was born in the Santa Clara Pueblo with nine siblings, many of whom are practicing potters. His mother, Rose, was a celebrated ceramic artist who taught her children and grandchildren the art of pottery. For Naranjo, learning to make things from clay was a natural outgrowth of his artistic spirit.

After returning from Vietnam, Naranjo attended the California School for the Blind. He returned to Santa Fe, New Mexico, where he began the challenge of trying to sculpt without having sight and with greatly reduced use of his right hand, which also had been injured. He married and set to work learning his craft, while he and his wife raised two daughters.

Working with intuition and touch, his art began to emerge, to flow with composition, balance, and movement. Naranjo's style is simple; he uses his fingers and fingernails to etch the details in his sculptures. He does not use traditional sculpting tools since he cannot see what impact the tool has on the clay. Understandably, Naranjo will scrap a piece of work if its "feel" isn't right. Laurie, his wife of 27 years, sometimes has to rescue his work before he destroys it in his quest for perfection.



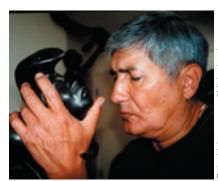
Sculptor Michael Naranjo explores Michelangelo's masterpiece.

An interesting aspect of Michael Naranjo's sculpture is that over the last 30 years, his sense of touch has been refined by contact with the masters. The Academy in Florence, Italy, and the Louvre in Paris allowed him to examine their treasures—in Paris, the Medici *Venus*, and in Florence, Michelangelo's *David*. The authorities granted the rare privilege of allowing him

to observe the masterpieces by touching them. By touch, Naranjo was able to observe minute details of the statues, such as the fact that in the eyes of Michelangelo's statue, the pupils are shaped like hearts. But while he observes the eyes of others' work, his own statues never have eyes, something it takes a while to realize as one appreciates the many other aspects of his work.

Through the traveling exhibit of his touchable art, organized by the Heard Museum, Naranjo seeks to share

with others what he views as an opportunity for transformation through direct contact with art. He and his wife have established the Touched by Art Fund, a Santa Fe community foundation to



Naranjol and one of his own sculptures.

enable public school students in New Mexico to visit museums and galleries. The gallery that currently carries Naranjo's work is the Nedra Matteucci Gallery in Santa Fe. The gallery's Web site is http://www.matteucci.com. ■

Jim Hall, courtesy of Michael an Irie Naranjo

The American President Who Used a Wheelchair

Phyllis McIntosh

U.S. President Franklin D. Roosevelt's use of a wheelchair was hidden during his lifetime but is now celebrated in bronze. Phyllis McIntosh is a Maryland-based writer who frequently contributes to Department of State publications.

ranklin Delano Roosevelt (FDR), who was elected four times as president of the United States, serving from 1933-1945—some of the most turbulent years in U.S. history—was the very image of a strong leader. Hidden from the public was the fact that Roosevelt, a victim of polio, could not walk. He was almost never photographed in his wheelchair.

Although attitudes toward disabilities had changed dramatically by the time a memorial to FDR opened in Washington, D.C., in 1997, a statue of the former president, nevertheless, depicted him wearing a large cloak that all but obscured his wheelchair.

"We felt it would be unconscionable for school children for years to come to go through that memorial and have no sense that Roosevelt led this country through the Great Depression and to victory in World War II from his wheelchair," says Michael Deland, president of the National Organization on Disability.

Deland, with help from honorary chairman, former President George H.W. Bush, launched a campaign to raise funds for a second, more honest statue. They welcomed their first donation—\$378.50 from a bake sale held by a group of New Jersey schoolchildren—and went



"Franklin's illness gave him strength and courage he had not had before. He had to think out the fundamentals of living and learn the greatest of all lessons—infinite patience and never-ending persistence."

Eleanor Roosevelt

on to secure \$1.65 million more from private donors.

Dedicated in 2001, the second statue shows Roosevelt seated in the wheelchair that he designed and used every day. Installed at ground level, the sculpture is easily accessible. Children gravitate to it and clamber onto the lap of the bronze president. People in wheelchairs can reach out and touch it and read the inscription on the wall behind, which is also printed in Braille.

"The constant refrain," Deland says, "is from older people with disabilities or from teachers or parents saying to kids, 'Look, Roosevelt led this country from this wheelchair. You can do anything you set out to do, disability or not."



Not wanting a conventional wheelchair, Roosevelt designed his own by using a wooden kitchen chair and adding two bicycle and two tricycle wheels

-- inscription on the back of the sculpture.

Mathew Sanford, Yoga Instructor

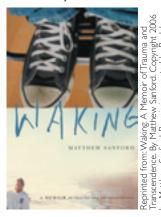
Phyllis McIntosh



Matthew Sanford and his son, Paul, enjoy a trip to the zoo.

A paraplegic adapts yoga movements for people with disabilities so they can achieve a mind-body connection.

t age 13, Matthew Sanford's life changed in an instant, when a horrendous car accident killed his father and sister and left him paralyzed from the chest down. After 12 years of regarding two-thirds of his body as an object, living as he says "like a head on a stick," he desperately wanted to get in touch with his whole body.



Waking: A Memoir of Trauma and Transcendence

Sanford turned to yoga and discovered that its poses and postures gave him a renewed sense of energy, a "buzz" or "hum" throughout his body. In 1998, he began adapting yoga movements for people with a range of disabilities, including paralysis, brain injury, multiple sclerosis, and cerebral palsy. At the same time, he realized that his

unique perspective was a valuable asset for teaching ablebodied students as well. "Living vibrantly through one's whole body, whether paralyzed or not, is a powerful part of living," he says.

Sanford went on to found Mind Body Solutions, a nonprofit organization dedicated to improving the mind-body connection in everyday life. Today, he offers a range of yoga classes through his studio, presents workshops and seminars for corporations and health care and community organizations, and continues to teach adaptive yoga at the Courage Center, a leading rehabilitation facility in Minnesota, where he lives.

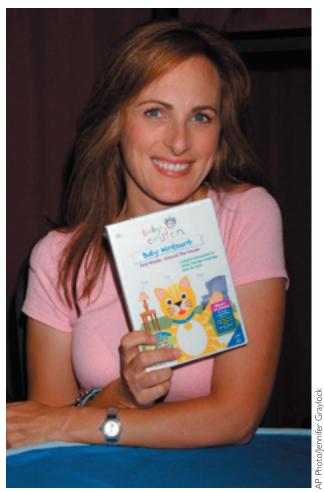
Through programs called "Bringing Your Body to Work" and "Yoga at the Desk," he teaches employees how to use yoga to boost energy, reduce stress, and improve their mental outlook.

A husband and father of a six-year-old son, Sanford also has found time to write a book, *Waking: A Memoir of Trauma and Transcendence*, which chronicles his experiences and explores the importance of the mind-body relationship.

He sums up his philosophy this way: "Connecting mind and body is not just a health strategy. It is a movement of consciousness that can change the world."

Marlee Matlin: Actress

Phyllis McIntosh



Actress Marlee Matlin has written several children's books.

A deaf actress reaches the top of her profession.

nyone who wants proof of what a deaf person can achieve in a hearing world need look no farther than the beautiful, accomplished actress Marlee Matlin. "The only thing I can't do is hear," she declares—a statement that sums up her approach to life.

Deaf since the age of 18 months, Matlin made her stage debut at seven as Dorothy in a children's theater production of *The Wizard of Oz.* At 21, she became the youngest winner

of the Academy Award for best actress for her role as a young woman afraid to leave the safe confines of a school for the deaf in the film *Children of a Lesser God*. She went on to star in 14 other movies and to earn four Emmy Award nominations for her work in television. Most recently, she appeared for seven seasons as a White House adviser in the popular political drama *The West Wing*.

In addition to acting, Matlin is a celebrity spokesperson for the American Red Cross, serves

on the boards of a number of charitable organizations, and has written several children's books about children who are deaf. In 1990, she was instrumental in persuading Congress to pass legislation requiring that all televisions manufactured in the United States be equipped with closed captioningwords that scroll across the bottom of the screen—to aid the hearing impaired.

The wife of a police officer and mother of four, Matlin says, "I am also a

Girl Scout leader, cook, car pool driver, mediator, closet organizer, and pretend math whiz."

She credits her own parents for encouraging her to be independent. Now, she says, "I work every day to help people understand, like my parents taught me, that deaf people not only deserve respect, they deserve to be heard."

Special Olympics

Phyllis McIntosh



Two young athletes from the New York metropolitan area celebrate their local Special Olympics games.

From a backyard day camp, Special Olympics has grown into a worldwide movement.

hroughout the world, more than 2 million children and adults with intellectual disabilities develop physical fitness and experience the thrill of athletic competition through the Special Olympics.

Founded in 1968 by Eunice Kennedy Shriver, sister of the late President John F. Kennedy, the organization was inspired by a day camp for children with intellectual disabilities that Shriver had established at her Maryland home. Over the years, Special Olympics has become a truly global movement with more than 200 programs in 150 countries. Currently, for example, there are almost 550,000 participants in the United States, 500,000 in China, 4,400 in Rwanda, and 600 in Afghanistan. As a grass-roots, nonprofit organization, Special Olympics relies on the help of 700,000 volunteers worldwide to ensure that every one of these athletes enjoys a quality experience.

At no cost, athletes age eight and over can train yearround and compete in 30 Olympic-type sports, from alpine skiing to volleyball. In the process, they condition their bodies, develop skills and friendships, and become productive and respected members of society. Through the Special Olympics Young Athletes Program, children ages two through seven build skills for future sports participation.

Thousands also participate in the Special Olympics World Summer Games and World Winter Games, each held every four years. The 2007 summer games will take place in Shanghai, China; the next winter games in 2009 in Boise, Idaho. Between World Games, athletes compete in local, state, national, and regional games. In 2006, Special Olympics is hosting regional games in Latin America, the United States, Europe, and the Middle East/ North Africa and is sponsoring the First International

Cricket Cup in Marian India. In additional competition, the offer free health for athletes, spewhere families coideas and resourt youth summits understanding by young people we without disabilities.



Eunice Kennedy Shriver

Chris Burke, Editor and Actor

Phyllis McIntosh



Editor-in-Chief Chris Burke (right) meets with NDSS (National Down Syndrome Society) Publications Manager Kim Rossi.

An actor who has Down syndrome reaches a different audience with Upbeat Magazine.

The words that best describe the content of *Upbeat*, currently the only magazine in the United States written by and for people with Down syndrome, "inspirational" and "uplifting". Published by the National Down Syndrome Society and directed also to family and friends of cognitively impaired people, the magazine is a mix of news and personal



says, each piece written by someone with Down syndrome.

"These are stories from our hearts about what it's like to grow up with Down syndrome and how to speak up for ourselves," says the decidedly upbeat editor-inchief, Chris Burke, a popular role model in the Down syndrome community. Launched by Burke and the society's staff as *News and Views* in 1994, the magazine was, he says, inspired partly by a newsletter at the private school he attended.

Also an actor, musician, and goodwill ambassador for the National Down Syndrome Society, Burke is best known for his ground-breaking role as a young man with Down syndrome growing up in a loving family but struggling for acceptance in the outside world on the television show *Life Goes On*, which aired in the early 1990s and has just been released on DVD.

Today, Burke presents musical concerts with two long-time friends, twin brothers Joe and John DeMasi, spreading a message of love and inclusion through hundreds of performances a year at schools, festivals, and conferences.

When Burke was born in 1965, doctors advised his parents to place him in an institution. Instead, they treated him the same as his siblings and made sure he received a first-rate education. He likes to share with others the motto that has guided his life: "Obstacles are what you see when you take your eyes off the goal. Always say to yourself, 'Yes I can.' Believe in yourself, work hard, never give up!"

Getting the Best Education: Advocacy, Hopes, and Dreams

Jeanne Holden

The mother of a child with Down syndrome says that educational opportunities are available for disabled children in the United States, but that parents must be advocates to ensure their children get the best education possible. Jeanne Holden, her daughter Jenny, and the rest of the family live in Virginia, near Washington, D.C.

am a writer, a wife, and the mother of three children. My daughter Jenny is 18 years old. She is pretty, creative, and inquisitive. She is 4 feet 6 inches tall and weighs 85 pounds—about the size of a 10-year-old. She is also intellectually disabled. I couldn't be more proud of her.

But it wasn't always like that. When I found out that my new baby daughter had Down syndrome, my dreams for her were shattered. Down syndrome is a genetic disorder that delays a person's physical and intellectual development. Most children with Down syndrome have mild-to-moderate mental retardation. I was told that Jenny's life would be very limited—if she survived. She needed heart surgery as soon as possible.

After Jenny's operation, I stayed by her hospital bed, following the directions of numerous nurses. Then, two young doctors, still in training, asked me to leave so they could draw Jenny's blood. My presence made them nervous. A half hour later, I was still waiting outside Jenny's door, fearful and wondering if my daughter was all right. Her cardiologist walked by and asked what I was doing. When I explained, this gentle doctor did the verbal equivalent of shaking me. "You are your daughter's advocate!" he exclaimed. "They cannot throw you out. What if she needs a specialist? You have to speak up and protect her interests." How lucky I was to have been taught this lesson when my daughter was so young!

Advocacy. That above all is needed if a parent is going to get the best education for a child with a disability.

My daughter was born at an exciting time in the United States. Legislation had been passed requiring

public schools to provide an appropriate education to all children with disabilities. Prior to the implementation of the Individuals with Disabilities Education Act of 1975, many children with intellectual disabilities were not even allowed to attend school. But despite the new laws, my role as advocate has remained critical.

My first step as an advocate was to learn as much as I could—about my child's disability, about federal and state laws governing special education, and about my local school district. I joined a support group for parents of children with Down syndrome before my daughter was a month old. Not only did I learn that there is a wide range of ability among children who have Down syndrome, I learned that educators were reassessing the intellectual potential of these children because their achievements were growing in response to increased educational opportunities.

One of these was "early intervention." Shortly before Jenny was born, a federal law was enacted requiring individual U.S. states to provide educational and therapeutic services—without charge—to infants and toddlers with disabilities. In Virginia, where we live, Jenny was entitled to physical and speech therapy during her first year of life. But demand for services far outpaced the supply of therapists. It was a perfect opportunity to try out my new role as advocate. I was firm, courteous, persistent, and, surprisingly enough, successful. I convinced the program's administrator, a former physical therapist, to provide Jenny's therapy herself.

This scenario has repeated itself many times during my daughter's school years. Quality educational services exist, but a parent has to be knowledgeable enough to locate them and activist enough to get her child access to them. Jenny entered the preschool program for students with disabilities at our public school at two years of age. She also attended an innovative private preschool that included two children with disabilities in each of its regular classes of 10 children. Jenny thrived in

this program, where she learned by playing with her nondisabled peers.

But educating a child with a disability is more than therapy and the right preschool. It means reinforcing every lesson at home, practicing letters or numbers or how to pronounce words. It means teaching appropriate behavior, praising small achievements, and saying, "Just try to do the best you can." It is reveling in your child's abilities and believing that, with sufficient practice, your child will succeed. For example, during preschool, an occupational therapist predicted that Jenny would never learn to write because her muscle tone was so low. Today, she has a neater handwriting than her brother or her sister.

Looking ahead to kindergarten, I met with the director of special education for our town's public schools. Students with disabilities are, by law, to be educated in the least restrictive environment in which they can progress, and this official believed that Jenny would bloom in a regular education classroom. I was delighted! However, neither she nor I had anticipated the resistance we would encounter. The local school's principal didn't want special education students in regular education classes. She didn't even want students with disabilities walking into school with their nondisabled peers.

I could have protested in court. Instead, I convinced the special education director to enroll Jenny in a more progressive public school. This official also appointed me to two educational advisory committees. I was able to collaborate with teachers to improve special education programs and to change the attitudes of those who saw students as their disability labels, rather than as children first.

By the time Jenny was in third grade, she was fully included in a class that was team-taught by a regular education teacher, a special education teacher, and an aide. Jenny gained new friends and role models. The other students gained compassion for children who looked or sounded different.

My role was to help Jenny's teachers create her Individualized Education Program (IEP)—a cornerstone of U.S. special education law. We needed to fashion a totally individualized plan to determine which supports and services Jenny would receive to enable her educational progress. Most teachers welcomed my input. Some, however, wanted me to simply agree with

their suggestions. But I wouldn't be intimidated. Who else knew that Jenny was a visual learner who would be overwhelmed if math problems were crowded together, but could do them if they were spread out? I had important insights to provide.

Throughout elementary school, Jenny worked on the same curriculum as her nondisabled classmates, but her assignments were reduced in length and complexity.

Jenny's success in school made it easy to encourage her outside interests. She won medals running races in Special Olympics. She played soccer in a regular league and "Challenger" baseball for children with disabilities. Jenny joined Girl Scouts, and I became an assistant leader because it made others more comfortable about including her.

Like her siblings, Jenny was enrolled in our synagogue's religious school. I asked for an older student to be assigned to help Jenny in class because there was no special education program. They worked hard, but it was worth it: At age 14, Jenny led her own Bat Mitzvah service in English and Hebrew, accomplishing the same goal as the students who did not have a disability. It was her proudest moment. Now, Jenny is a teacher's aide in the religious school's kindergarten.

While the public elementary school program provided a good experience, middle school presented problems. Because the public school program for students with mental retardation was not academically challenging, and it was physically isolated from the rest of the school community, I enrolled Jenny in the local middle school, which only offered limited support for students with intellectual disabilities. But this created another problem—too much material was being taught too rapidly for Jenny to absorb. I had to find a solution in time for high school.

I enrolled Jenny in a small, private Catholic high school that had a "modified inclusion" program called "Options" for students with intellectual disabilities. Options students are taught academics in special education classes and are included with regular education students for electives such as art or acting. More importantly, the school strives to fully include Options students in the school community. About 90 regular education students volunteer each semester to give up study halls and, instead, help Options students in their classes. Many of these students join Options students for

lunch and after-school activities. It is considered "cool" to hang out with students with special needs.

Jenny couldn't be happier. She takes part in the school's clubs, sports events, and dances. She has written a recurring column for the school newspaper. She was in the school play. It's really quite incredible. Until she was five, Jenny didn't speak a full sentence. Today, she reads school announcements on a closed circuit television program broadcast throughout her high school, a school where the vast majority of the students do not have disabilities.

Of course, I've had to intensify my daughter's lessons in self-advocacy. When she arrived at Catholic school, the regular education students assumed that she was not crossing herself before prayers because—as a special education student—she could not remember how. It never occurred to them that Jenny might have made

a choice not to cross herself because she is Jewish. But a parent of a child with a disability must teach selfadvocacy. If we do not teach it, how can we hope our children will achieve any independence?

Jenny is currently a high school senior. What will she do next? We have looked at public school vocational programs. But Jenny has her heart set on attending one of the new college programs for students with intellectual disabilities. Such programs are expensive, but we are considering it because she loves to learn.

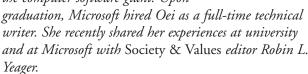
Jenny's goals include getting a job working with children. She also dreams of having a boyfriend and getting married. My hopes for Jenny have been replaced by her own. A good education has given her a promising future.

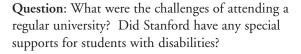


Jenny and Jeanne get into the spirit of the 2006 Maryland Renaissance Festival.

Meet Mandy Oei

Mandy Oei grew up in Texas, the child of Indonesian immigrants. Profoundly deaf, Oei spent four years at a special school where she received speech therapy and learned to lip read, while studying traditional school subjects. She then attended regular schools and graduated from secondary school. She attended Stanford University in California where she earned a Bachelor of Arts in English, with a concentration in creative writing. While in college, Oei applied and was accepted for an internship at Microsoft Corp., the computer software giant. Upon





Oei: I wasn't too worried about accommodations at Stanford.... They had good support for students with disabilities. Other than that, the challenges that I faced were those of any other student.... Stanford provided American Sign Language (ASL) interpreter support for classes. I lived in the dorms for four years, and I was given TTY access, and my room was fitted with a special fire alarm that has a strobe light for emergencies. The residential staff also was made aware of my needs so that they would be prepared. [Note: TTY is a system that connects the telephone to a screen and keyboard, turning spoken communication into written form.]

Q: How was the transition from university life to "real" work, including the internship experience?



Mandy Oei

Oei: During my senior year, I was contacted by Microsoft. They had received my resume and were interested in interviewing [me]. I went through a phone interview with the hiring manager. This meant using a relay service as the medium for the interview, which is a little slower than if it had been a direct phone call between two people. The hiring manager was very patient [with this

process] and by the end of the interview, I came away with a good general impression of Microsoft because of the experience. The next step was to fly me from Stanford to Redmond [near Seattle, Washington] for an in-person interview with a number of different people. The Microsoft recruiter asked me about accommodations, and when I requested interpreters, they did not ask many questions other than to ask what kind of sign language I preferred to use. That was very impressive to me because it showed that they were familiar with deaf people and their needs.

In the interview process itself, I was provided with two ASL interpreters. I must have spoken with about 12 people throughout, and I liked that none of them showed discomfort at what was likely a new experience for many of them—talking to someone using interpreters. So I was very pleased that they offered me an internship as a technical writer. This set the tone for my future interactions with Microsoft.

Q: What is the work you do at Microsoft?

Oei: At Microsoft, I work as a technical writer. My group owns the documentation for the Windows Embedded and Windows Mobile operating systems (OSes) and for the tools that computer programmers use to make custom

versions of these OSes, which are used in a wide range of devices that include industrial machinery, cash registers, and Smartphones and Pocket PCs. I work with programmers to create documentation for these tools, and also the text that is used in the menus, dialog boxes, and other parts that you see on the screen when using these tools. I make sure that the wording is clear and accurate without being too wordy.

Q: What do you think is the primary reaction of other employees to your disability?

Oei: People at Microsoft are used to working with people from a very wide variety of backgrounds, and I've found that this makes for an environment where people are very openminded and willing to learn about and accept differences. For example, several times I've dropped in on someone that I've never met before, and when they find out that I'm deaf and that we might need to use a whiteboard [a surface on which one writes with an erasable marking pen] or a word processor to have a conversation, they take it all in stride and treat it as usual. I typically don't mention that I'm deaf at all, except when it's required to explain the need for an interpreter, which I think helps provide cues about how to behave in relation to my disability. When someone new joins our group, they usually only need a few tips about how to talk to me effectively, such as remembering not to talk all at the same time in meetings so that the interpreter can follow what is said. Or remembering to face me and talk a little slower so that I can read their lips.

Q: Does your impaired hearing ability impact your work, your ability to travel, or your interactions with colleagues in other offices? If not, how do you manage these activities?

Oei: Being deaf doesn't really impact my ability to travel. For example, I recently returned from a personal trip to California, and I didn't encounter any difficulty making the travel arrangements. The only problem that I had on the trip itself was avoiding getting lost when driving around there, really. At Microsoft, everyone depends heavily on e-mail, instant messenger, and internal Web sites to communicate with each other. These are visual types of communication that don't require sound, which means that being deaf isn't a big issue when it comes to talking to coworkers and to employees at other offices.

For meetings I usually have an interpreter to translate what is said for me, and I have access to relay services for

the occasional phone calls that I might need to make. When I talk to individual coworkers in person, if it's an important discussion, sometimes I use an interpreter to make communication easier. But a lot of the time I prefer to speak for myself and read the other person's lips. If I or the other person can't understand something that's been said, we write on something.

Q: How many people work in your unit? Are you the only one with a severe disability?

Oei: My group contains almost 40 full-time employees. While there are other employees in my group who have different disabilities, I'm the only one who is deaf and who uses an ASL interpreter. Medically, you could interpret my deafness to be a severe disability because without a hearing aid I cannot hear anything at all. But I don't think of it that way. Deafness is a part of me, but it's not the first thing I think of when I'm asked to define myself as a person. Being deaf has impacted my life, but it hasn't stopped me from having a productive job, living independently in my own house, or having a lot of friends.

Q: Do you think Microsoft benefits from the investment it makes in its employees with disabilities, including investment in training of other staff?

Oei: Absolutely. For example, before I was hired as an intern, my group manager had an outside consultant come in and do a seminar for my group where they learned how to work with someone who is deaf. This helped a lot with the initial period where we adjusted to working together. Also, several coworkers have taken American Sign Language classes because they are interested in learning the language and want to make talking to me easier. These factors helped with the decision to express my interest in becoming a fulltime employee after my internship ended. By being inclusive of people with disabilities when searching for people to hire, Microsoft gains a bigger pool of candidates in which to search and increases the odds of discovering someone who has a lot of talent and who will make a great employee. Having people from many different backgrounds helps provide different perspectives and helps encourage creative thinking. ■

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The U.S. Department of State assumes no responsibility for the content and availability of the resources from other agencies and organizations listed above. All Internet links were active as of October 2006.

Internet Resources

Selected Web sites on Disability Issues

U.S. GOVERNMENT

DisabilityInfo.gov

http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=500

Developed as a partnership of more than 20 federal agencies in response to President Bush's New Freedom Initiative, this is a one-stop, comprehensive gateway of annotated links to disability-related resources, primarily from the government, although the nongovernmental sector is represented as well. Subjects covered include education, emergency preparedness, employment, health, technology, transportation, housing, community life, and civil rights. Within each of these major categories are a number of subcategories as well as related news, upcoming events, state and local resources, grants and funding information, and laws and regulations.

ADA Home Page

http://www.ada.gov/

From the U.S. Department of Justice, this page provides in-depth information and technical assistance on the Americans with Disabilities Act.

Disability Rights

http://usinfo.state.gov/scv/history_geography_and_population/civil_rights/disability_rights.html

This Web site from the Office of International Information Programs of the Department of State includes staff-written articles and links to reports and other resources.

Federal Employment of People with Disabilities http://www.opm.gov/disability/

This site provides access to information that is "relevant to the recruitment, employment, and retention of individuals with disabilities in the Federal Government." Included are federal and state laws, other governmental and nongovernmental sites, and success stories of federal employees with disabilities.

JAN: Job Accommodation Network

http://www.jan.wvu.edu/

JAN is a toll-free information and referral service for employers, people with disabilities, rehabilitation professionals, and people affected by disability. A service of the Office of Disability Employment Policy of the U.S. Department of Labor, JAN focuses on job accommodations for people with disabilities, the employment provisions of the ADA, and resources for technical assistance, funding, education, and related services.

National Council on Disability

http://www.ncd.gov/

An independent federal agency that recommends policies to the president and Congress to enhance the quality of life for the disabled. Publishes reports, a newsletter, and a listsery.

National Library Service for the Blind and Physically Handicapped (NLS)

http://www.loc.gov/nls/index.html

Part of the Library of Congress, NLS circulates materials through a national network of cooperating libraries. A valuable section of this site is the NLS Reference Materials. See, for example, the resource guides on Assistive Technology Products, and the Employment of People with Disabilities, the bibliography on Disability Awareness, and Added Entries, a database of new materials.

U.S. Census Bureau: Disability

http://www.census.gov/hhes/www/disability/disability.html

Reports, briefs, and data on disability and links to other sites with disability statistics are provided by the statistical arm of the U.S. Department of Commerce.

U.S. Department of Education. Office of Special Education and Rehabilitative Services (OSERS)

http://www.ed.gov/about/offices/list/osers/index.html?src=oc
Serving people with disabilities of all ages, OSERS
provides news, information, and resources on the
Individuals with Disabilities Education Improvement Act
of 2004 (IDEA), as well as a tool kit for teaching and
assessing students with disabilities. The three components
of OSERS are: the Office of Special Educations
Programs, the Rehabilitation Services Administration, and
the National Institute on Disability and Rehabilitation
Research.

NONGOVERNMENTAL ORGANIZATIONS

National Disability Organizations

http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=5195

This is a comprehensive, annotated list of national organizations covering all manner of disabilities from *DisabilityInfo.gov.* Additional selected organizations are listed below.

ABLEDATA

http://198.178.200.166/?CFID=202149&CFTOKEN=53

ABLEDATA consists of a database of 19,000 "assistive technology products and rehabilitation equipment available from domestic and international sources." Information is also provided on the companies that sell these products, though none are sold on the site. ABLEDATA is maintained for the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.

American Association of adaptedSPORTSTM Programs (AAASP)

http://www.aaasp.org/

An interscholastic athletic program for students in grades one through 12 with visual or physical impairments, AAASP develops and operates statewide league programs, as well as a training and certification infrastructure for coaches, officials, and coordinators.

American Congress of Community Supports and Employment Services (ACCSES)

http://www.accses.org/

State rehabilitation associations and community rehabilitation programs work together to maximize "employment opportunities and independent living for individuals with mental and physical disabilities." This site links to networking opportunities, advocacy information, issue briefs, and other materials.

Association of University Centers on Disability (AUCD)

http://www.aucd.org/

This network of interdisciplinary centers focuses on research, education, and service to "individuals with developmental and other disabilities, their families, and communities."

Best Buddies

http://www.bestbuddies.org/site/c.ljJ0J8MNIsE/b.933717/k.CBF8/Home.htm

This nonprofit organization is dedicated to enhancing the lives of people with mental retardation by providing opportunities for one-to-one friendships and integrated employment. Best Buddies International currently has chapters in 25 countries and is planning to expand in the future.

Center on Human Policy, Law, and Disability Studies (CHPLDS)

http://disabilitystudies.syr.edu/

CHPLDS is "a network of academic programs, centers, student organizations, and affiliated faculty." Resources on public education, research, training, advocacy, and academic programs are accessible on this site."

Disability Rights and Independence Living Movement Project

http://bancroft.berkeley.edu/collections/drilm/

Launched in 1996, this collection of primary documents consists of more than 100 oral histories with leaders, participants, and observers of the movement in the 1960s and 1970s, as well as personal papers and the records of key disability organizations. Housed at the Bancroft Library at the University of California, Berkeley.

Disabled Sports USA

http://www.dsusa.org/

This nonprofit organization offers nationwide sports rehabilitation programs to anyone with a permanent disability. DS/USA also prepares and selects athletes to represent the United States at the Summer and Winter Paralympic Games, competitions for individuals with disabilities that are recognized by the International Olympic Committee."

Independence, Inc.: Magazines, Books, Newsletters, Arts, and Other Media Links

http://www.independenceinc.org/giant/magaz.htm

This comprehensive, annotated guide to resources comes from a Kansas-based independent-living resource center.

Independent Living Institute

http://www.independentliving.org/

To promote disabled people's self-determination, self-respect, and dignity, this policy association provides information, training materials, consultancy, and technical assistance. It also works with similar local, national, and international organizations, including self-help groups in developing countries.

International Day of Disabled Persons, December 3, 2006

http://www.un.org/esa/socdev/enable/disiddp.htm

The theme of this year's International Day of Disabled Persons is "E-Accessibility." The annual observance seeks to increase awareness of disability issues and increase support for the rights, dignity, and wellbeing of persons with disability. Sponsored by the Division for Social Policy and Development of the United Nations' Department of Economic and Social Affairs.

Mobility International USA

http://www.miusa.org/

This nonprofit organization promotes "international educational exchange, leadership and disability rights and travel for persons with and without disabilities." MIUSA sponsors the National Clearinghouse on Disability and Exchange.

National Clearinghouse on Disability & Exchange (NCDE)

http://www.miusa.org/ncde

Sponsored by the Bureau of Educational and Cultural Affairs of the United States Department of State and administered by Mobility International USA, the clearinghouse is a comprehensive source of information on international disability and exchange. The site includes guides, tip sheets, personal stories, links, mailing lists, and an online magazine, *A World Awaits You*.

National Coalition for Disability Rights (NCDR)

http://www.ncdr.org/

NCDR, an alliance of hundreds of disability, civil rights, and social justice organizations, provides resources for advocacy and awareness, including the ADA Watch news and alert service and the ADA Document portal page.

National Dissemination Center for Children with Disabilities (NICHCY)

http://www.nichcy.org/index.html

NICHCY acts as "the central source of information" on disabilities in all children, the Individuals with Disabilities Education Act (IDEA), the No Child Left Behind presidential initiative, and research-based material on effective educational practices. See, for example, the resource list on Disability Awareness. Information is available in English and Spanish.

National Organization on Disability (N.O.D.)

http://www.nod.org/

N.O.D. focuses on community involvement, economic participation, and access to independence for people with disabilities. Calendars of upcoming events, statistics and surveys, links, and a newsletter are accessible through this site.

U.S. Paralympics

http://www.usolympicteam.com/paralympics/

Official site of the U.S. Paralympic team, which offers competition to athletes who are physically impaired. The international Paralympic Games follow the Olympic Games and Olympic Winter Games at the same venues and facilities.

VSA arts

http://www.vsarts.org/

This international nonprofit organization works through a network of affiliates in the United States and in more than 60 countries to promote access to the arts for millions of people with disabilities, to support arts programming in schools, and to showcase the accomplishments of artists with disabilities. Of note is a list of books, plays, and films http://www.vsarts.org/documents/programs/pwd/books_plays_films.pdf.

World Institute on Disability (WID)

http://www.wid.org/

An international public policy center dedicated to strengthening the disability movement through "research, training, advocacy and public education so that people with disabilities throughout the world enjoy increased opportunities to live independently."

Whirlwind Wheelchair International (WWI)

http://www.whirlwindwheelchair.org/

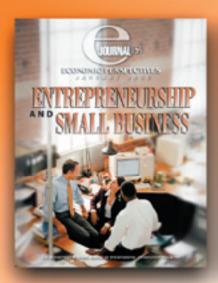
Active in over 45 countries in Africa, Asia, and Latin America, WWI designs off-road wheelchairs for production and use in developing nations. Recent initiatives include building chairs in India, which are then shipped and assembled for use in Afghanistan, and a project to promote "conflict resolution, economic development and the socio-economic integration of children and adults with mobility impairments in the South Caucasus."

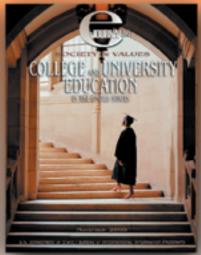
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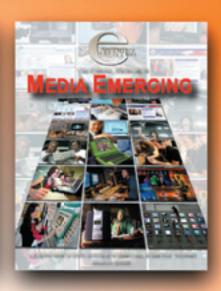


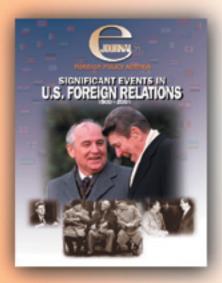
Jeremiah enjoys participating in a therapy program for blind children. He especially likes getting to "see" horses through touch.



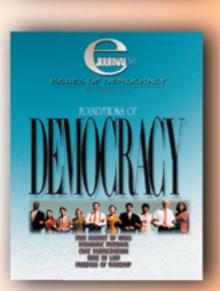








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