



The State of Disability in America

An Evaluation of the Disability Experience
by the Life Without Limits Project



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STATE OF DISABILITY IN AMERICA

PRESIDENT FRANKLIN ROOSEVELT is viewed around the world as one of the greatest American Presidents. He ended the Great Depression. He provided extraordinary leadership during the Second World War. Roosevelt's quick mind, marvelous wit and determination took America through some of its toughest moments. Roosevelt had a disability.

During his administration, Roosevelt and his staff went to great lengths to prevent the public and the media from seeing him in a wheelchair. Common sense tells us that they believed a photograph of Roosevelt in a wheelchair would undermine his political strength and leadership. It seems that even the perception of disability would signify weakness.

There are only a handful of photographs of Roosevelt from his dozen years in office showing him relaxing in a wheelchair. Privately though, he enjoyed his longtime retreat in Warm Springs, Georgia, because he was free to be open about his disability among others who shared his experience.

It should not be said that Roosevelt ran away from his disability. He was instrumental in creating the March of Dimes to help other people who experienced the consequences of polio. Throughout his life, however, his efforts focused on preventing the underlying medical condition, rather than embracing his own physical disability. Had he done so, he might have demonstrated to the American people that it's possible to live a full life with a disability.

Even in death, the shame associated with his disability did not disappear. When a national commission was created to build the beautiful Franklin Roosevelt Memorial along the tidal basin in Washington, DC, a great controversy erupted about whether he should be shown in a wheelchair. Many members of the commission felt that because he refused to be photographed in a wheelchair during his administration, it would be wrong to show him in one at the memorial. Common sense won out in the end however, and the first statue of Roosevelt at the memorial entrance shows the president in a wheelchair.

In many ways, Roosevelt's insistence that he not be photographed or seen in public in a wheelchair set back the disability rights movement. He subtly reinforced the longstanding negative perception of disability among the media, who knew of his condition, and the public, who didn't.

It is easy to look back and say that Roosevelt could have or should have been more open. At the time, however, the public perception of disability was at its worst. The eugenics movement, which sought to eliminate the "unfit" from the gene pool, was at its height. Additionally, state-supported institutionalization of people with disabilities was gaining momentum nationally. It's ironic that the most powerful man in the United States had a disability during this time. But it's also unfortunate that Roosevelt had to keep his disability "in the closet."

Few might remember the name of Senator Thomas Eagleton from Missouri. He was a distinguished and brilliant senator whose knowledge of foreign affairs was respected around the world. Eagleton also had a functional mental disability. Three times, between the years of 1960 and 1966, he checked himself into a hospital because of serious depression and anxiety. He received electric shock treatments twice during those visits.

In 1972, Senator and Democratic presidential candidate George McGovern selected Eagleton as his running mate. The press and pundits applauded McGovern's wise and stable selection of Eagleton. But in the early stages of the general election campaign, columnist Jack Anderson sensationally revealed Eagleton's disability to the world. Overnight, the press was in an uproar and attacked Eagleton's ability to serve as vice president. Others made cruel jokes, saying that Eagleton would make a "crazy vice president." The media, decision makers and even religious leaders demanded that Eagleton step down from the national ticket because of his disability.

After backing him fully, McGovern was forced to remove Eagleton as his running mate. Many proclaimed loudly that they had no problem with his disability because he had voluntarily sought assistance for his depression. But they dishonestly wrapped their opposition to his candidacy in the fact that he hadn't disclosed his disability. Senator Eagleton went on to be re-elected two more times despite the political crisis and became an outspoken advocate for those experiencing depression.

In many ways, the experience of these two complex but great leaders illustrate a chief obstacle for people with disabilities today – the common perception that people with disabilities will never be able to live, work and be productive in society. Today, attitudinal and cultural barriers continue to exacerbate the environmental constraints – such as inaccessibility and discrimination – that define the disability experience.

The Perception of Disability in America

From Section 504 of the Rehabilitation Act to the Americans with Disabilities Act (ADA), the current generation of disability rights activists has made tremendous strides in bringing freedom to their fellow Americans with disabilities. But things are still not right. By and large, people with disabilities are more likely to live in poverty and be dependent on government services. They are less likely to have positive educational opportunities and outcomes, be employed or own a home. These facts beg the question, why haven't things gotten better for people with disabilities?

As other American civil rights movements have experienced, laws and government programs – while critically important – can only do so much. Subversive cultural stereotypes of disability have undermined some of the most important milestones in disability rights. For example, the business community has successfully restricted protections against employment discrimination included in the ADA through the courts. These lawsuits and court rulings don't necessarily amount to bigotry, but on the whole they demonstrate an unwillingness to view Americans with disabilities as full citizens.

Historically, Americans have only seemed to be able to embrace two kinds of people with disabilities. The first are poster kids or children with disabilities who invoke pity. These young children are often called victims and are used in public relations and fundraising schemes such as telethons. Older people with the same type of disability may not be offered the same charity.

America also accepts so-called "super crips" or heroic figures who have overcome the horrible



plight of disability to assimilate to their inaccessible environments. These might include Helen Keller or Christy Brown, two famous authors with improbable personal stories of overcoming adversity.

The fact remains, however, that about 54 million people or about 19 percent of the U.S. population has a disability and the vast majority of these people fall into neither category. They aren't poster kids or "super crips" – they simply want to live full but ordinary lives. They want a good education, a fulfilling job, a home of their own and a family. They want the right to live their lives.

Public perceptions further rely on the medical model of disability. Society tends to understand the disability experience largely as underlying medical conditions such as cerebral palsy or paralysis, rather than recognizing the environments that cannot or will not accommodate these disabling conditions. Does cerebral palsy disable a young adult wheelchair user, or do sidewalks without curb cuts and inaccessible public transportation provide the disability? It may sound simple, but this is a fundamental and inescapable question.

These stereotypes and perceptions of disability have been constructed by a complicated and difficult history. Since the birth of the United States and before, people with disabilities have been abused, tortured, imprisoned, driven from communities and even killed. Some have been forced to live in the most horrendous conditions imaginable in state-supported institutions.



Dorothea Dix, a Boston schoolmistress, led reformers in 1840's who demanded that the state take control of miserable local almshouses, where adults and children, the disabled and non-disabled, criminals, and those with retardation, epilepsy and mental illness were all thrown together. Dix had found people with mental illness and retardation in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods and lashed into obedience.

— Source: *No Pity*, 1994

Some states and communities enacted policies to warehouse and sterilize people with disabilities. Physicians were complicit in some of these crimes, even engaging in highly unethical medical experiments without the consent of their subjects with disabilities. Religious orders have at times portrayed disability as a sign of wickedness, further reinforcing negative stereotypes. Even today, communities too often oppose the development of small group homes and other supportive housing for people with disabilities simply because neighborhood residents are uncomfortable with people with disabilities living among them.

Writers, artists and other cultural historians have made significant and lasting contributions to these stereotypes. The renowned progressive writer Robert Louis Stevenson gave his villain a peg leg in *Treasure Island*. The lonely and pitied *Hunchback of Notre Dame* became a classic character and John Steinbeck's Lenny in *Of Mice and Men* was a murderer with a cognitive disability. In addition, harmful portrayals of disability in modern pop culture abound. Horror movies with characters such as Michael Myers or Freddy Krueger make their physical or cognitive disabilities plot points.

With some exceptions, the art and entertainment communities have yet to embrace mainstream characters with disabilities that are healthy, non-threatening and affirming of the broader disability experience.

Some prominent intellectuals have also reinforced negative perceptions of disability, especially early 20th century proponents of the eugenics movement, a social philosophy aimed at improving human hereditary traits through intervention. Inventor and academic Alexander Graham Bell was a leading supporter of eugenics in the United States. Focusing on the deaf, his advocacy was based upon a benevolent but ignorant belief that hearing impairments were defects in the human condition. In addition to promoting oralism over the use of sign language in deaf education, Bell worked to allow the sterilization and prohibition of marriage between people who were deaf.

Philosopher Friedrich Nietzsche's work is still discussed in just about every college philosophy class today, but his sentiment towards disability seems like it could be found on a hate group flyer.



The invalid is a parasite on society. In a certain state it is indecent to go on living. To vegetate on in cowardly dependence on physicians and medications after the meaning of life, the right to life, has been lost ought to entail the profound contempt of society.

— Source: *Twilight of the Idols and The Anti-Christ: or How to Philosophize with a Hammer*, 1990

While these views on disability and those of other thought leaders may be discounted today, their collective influence has had a lasting impact on the perception of disability.

Paradoxically, war has contributed to both medical and attitudinal advances in how our nation deals with disability. After the Civil War, the United States had to deal with large numbers of citizens with physical disabilities for the first time. The South was particularly affected because its Army experienced so many casualties and offered limited medical care on the battlefield. In 1866, Mississippi spent nearly 20 percent of its state revenue on artificial arms and legs.

So many wounded and disabled veterans returned home from fighting World War I that President Hoover created the Veteran's Bureau (later to become the Department of Veteran Affairs) and Congress appropriated funding for programs dealing with rehabilitation for the first time.

During World War II, the country expanded its commitment to rehabilitation programs and veteran services. The Paralyzed Veterans of America was formed in 1946 to promote medical care, and a new President's Committee on Employment of the Handicapped was also created to assist veterans' transition from rehabilitation to meaningful employment. Meanwhile, pioneers in medical sciences were advancing rehabilitation concepts – including physical and occupational therapy – in order to rally a broad range of available services to return newly disabled veterans to normal life.

The Vietnam War led to the first organized effort to deal with mental and emotional trauma derived from physical and emotional wounds. Widely publicized studies showed that up to 30 percent of Vietnam veterans experienced some type of post traumatic stress disorder.



Today, as our nation fights two wars, in Iraq and Afghanistan, dramatic advances in field medicine are reducing casualties still further. As a result, however, an alarming number of surviving soldiers experience life-changing cognitive and physical impairments, including severe neurological disorders and the loss of limbs. The commitment of our nation to find and use medical science, biotechnology and robotics to assist these returning veterans may lead to critical advances in assistive technology for all people with disabilities. In addition, as many thousands of these veterans with disabilities return to their communities to work and contribute, they are impacting people’s perception of disability by the grace of their circumstance.

The Disability Experience Today

While the disability rights movement has grown increasingly sophisticated and influential over the last 30 years, it has shifted its focus increasingly towards self-determination and choice for people with disabilities. This emphasis may yield promising policy results in the future.

The concept of self-determination is based on the recognition that all persons, including people who have disabilities and their families, have the need to determine their futures. Interpersonal relationships, family structures, and community roles all suffer under programs that “provide for” but do not encourage self-direction in one’s own life.



Four Guiding Principles of Self-Determination

Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program.

Authority: The ability for a person with a disability (with a social support network or circle if needed) to control their own resources in order to purchase these supports.

Support: How personnel and resources - both formal and informal – are arranged to assist an individual with a disability to live a life in the community rich in community association and contribution.

Responsibility: The acceptance of a valued role in a person’s community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.

— Source: *Beyond Managed Care: Self-Determination for People with Disabilities (first edition), 1996*

If our nation can commit itself to these principles, millions of people with disabilities whose talents are now wasted might become contributing citizens with full and independent lives. If government, for a change, could flex its imagination and build policies around these four principles, then the disability experience might change entirely.

For this minor miracle to happen, the disability community and policymakers must fully understand the scope of the challenges ahead of us. Statistics show several emerging trends.

Importantly, many of the nearly 80 million aging baby boomers may soon experience age-related disabilities. Federal legislation passed in the 1990s recognized that “disability is a natural part of the human experience,” making literally every human being a candidate, and certainly age enhances that candidacy. While preventive healthcare and good management and coordination of health services may mitigate some of these emerging disabilities, it is virtually undeniable that the number and prevalence of disabilities among the US population will increase. It will be critically important for the greater disability community to acknowledge and assimilate the experiences of aging citizens in order to meet their needs and harness their political power.

Revolutionary advances in assistive technology are occurring every day. Soon it may be possible for people with severe disabilities to regain function through biotechnology, robotics and advanced neuroscience. For example, a neural implant may one day allow a person with profound physical disabilities to move a mouse on a computer screen, speak through a computer or drive an electric wheelchair. These advances must be encouraged and made more accessible to people with disabilities, regardless of their income or access to quality healthcare.

Poverty continues to be a significant risk factor for disability, which is made worse by growing income inequality throughout the country. In 2005, more than 37 million Americans lived in poverty and about 40 percent of these people experienced a disability. Additionally, some 47 million Americans do not have health insurance. Data show that children living in poverty are especially vulnerable and may experience developmental disabilities as a result of preventable malnutrition, birth defects or related environmental factors.

Finally, more than 2 million people with disabilities live in some type of rigid institutionalized setting. While this population continues to decline, it is still significant. Increasingly, state and federal policymakers are acknowledging that community-based supports and services may lead to both improved cost benefits and higher living standards. However, near-term budget constraints, the high cost of housing and collective shortsightedness may lead to a resurgence of state-supported institutionalization. The disability community and its advocates must remain vigilant and build upon the momentum of the past quarter century towards vastly reducing the number of people living in institutions.

The State of Disability in America

The following briefing document examines issues central to the disability experience including disability rights, healthcare, education, employment and housing. Through historical analyses, we take the long view of disability public policy, showing the evolution to its current state. In doing so, we find a troubling snapshot of America:

Disability Rights: In addition to bringing about broad prohibitions of discrimination on the basis of disability, the enactment of the ADA demonstrated that the disability community is capable of rallying broad grassroots and political forces to create change. However, the courts have weakened many protections contained in the ADA, particularly in private employment practices.



Healthcare: Medicaid and Medicare are critically important in providing health insurance and long-term services and supports to millions of Americans with disabilities. However, while becoming more and more supportive of community-based services, the current structures of these government programs leave most beneficiaries with disabilities without the ability to lift themselves out of poverty without losing critical benefits. Meanwhile, private health insurance is often not available or affordable to people with serious pre-existing conditions or disability, and when it is, may not cover important services such as physical or occupational therapy and assistive technology.

Education: The Individuals with Disabilities Education Act has resulted in significant gains in education whereas just 30 years ago many young people with disabilities were denied access to public schools altogether. Nevertheless, graduation, college admission and employment rates for people with disabilities remain far below national averages.

Employment: Despite the focus by federal and state governments on employment services, people with disabilities experience very high rates of unemployment. Public and private employers continue to discriminate in their hiring and employment practices. In addition, federal and state benefit programs such as Medicaid don't provide adequate incentives to enable all people with disabilities who want to work to do so.

Housing: Public-private partnerships have demonstrated great promise in developing affordable supportive housing for people with disabilities. However, limited federal and private funding for these endeavors and other accessible public housing is constantly threatened. Meanwhile, the nationwide housing boom of the last decade has dramatically aggravated the shortage of affordable accessible housing.

DISABILITY RIGHTS IN AMERICA

AT ITS CORE, THE DISABILITY RIGHTS MOVEMENT SEEKS TO EMPOWER PEOPLE WITH DISABILITIES to determine their own destiny and to undermine the widely-held perception that disability is exclusively a medical issue. It seeks to emphasize the socio-political issues that underpin the oppression of people with disabilities and de-emphasize the medical model of disability.

This philosophical foundation conflicts with common public health doctrine, which emphasizes the prevention of the initial medical impairment rather than the enablement of people with disabilities to live healthy, independent and productive lives. While the disability rights movement has achieved great success in recent years, the medical model of disability persists, and a massive shift in the current paradigm will be necessary for fundamental change.

According to disability activists, the state of disability is largely caused by a myriad of structural and attitudinal barriers that impair inclusion and participation, such as the systemic lack of wheelchair access to public services, the failure of educational institutions and employers to make materials available in alternative formats for people who are blind or have visual, cognitive or intellectual impairments, and the intricate bureaucracy that people with disabilities must navigate in order to get essential services such as income support and health insurance. Physical and architectural environments, medical and technological developments, and public policies significantly shape how people experience disability.

Like other American civil rights struggles, the disability rights movement is fragmented by the various interests it represents. While an estimated 54 million Americans have disabilities, their disabilities vary widely — from developmental disabilities such as cerebral palsy or Down syndrome to acquired disabilities such as paralysis or traumatic brain injury. Cognitive, sensory, illness-related and age-related disabilities abound as well. Each sub-population has its own politics and interests, which can dilute the movement's collective power. In addition, most people with disabilities do not actually self-identify as experiencing a disability, and just a fraction of the total disabled population show real interest or are activists in the disability rights movement.

Furthermore, the disability rights movement uniquely exists in a paternalistic environment. Most disability rights and service organizations were established by family members on behalf of people with disabilities and, to this day, are run by able-bodied peers. These groups may limit their mandate to a specific medical impairment, thereby reinforcing the medical model of disability. Additionally, some charitable organizations depend on the state for funding, resulting in an inherent conflict. Well-intentioned organizations may become more focused on maintaining revenue for services than fundamentally changing the system in which they operate.

In this chapter we examine a series of major milestones in the disability rights movement, though these examples should not be viewed as an all inclusive history. An important trend among significant events in the modern day disability rights movement includes the leadership of people with disabilities, rather than events driven entirely by advocates on their behalf.



The League for the Physically Handicapped and Jobs for People with Disabilities

More than five years after the 1929 stock market crash, the Great Depression persisted. It had brought the country to its knees by 1933, leading to widespread unemployment, growing poverty, and diminished consumer and business activity. To combat widespread unemployment, President Franklin Roosevelt championed the Works Progress Administration (WPA) in 1935 to put downtrodden Americans back to work.

At the time, it was especially difficult for people with disabilities to find employment. If they could get a job at all, people with disabilities tended to earn less than their able-bodied peers. Many businesses required applicants to take a physical examination – even for jobs that required no physical activity – in order to weed out people with disabilities.

Sylvia Flexer Bassoff, who used crutches and wore a leg brace, explained to a reporter at the time:



I wanted to teach English, or be a librarian, until I found out I couldn't get a job if I were trained for it... But not because there was a Depression. I found I couldn't get a job because I was handicapped... In my naïveté, I figured, 'I'll graduate from the Drake Business School and they're all going to grab me.' Well, nobody grabbed me... Some people who graduated got jobs who weren't, they didn't begin to be as good as I was... And finally I got a job at the Brooklyn Bureau of Charities, who only hired handicapped people... It was a great injustice. And I didn't know what to do.

— Source: *The League of the Physically Handicapped and the Great Depression: A Case Study in the New Disability History*, by Paul K. Longmore and David Goldberger

In addition to poor employment opportunities, people with disabilities experienced frequent discrimination in public services. Courts upheld the right of public transit authorities to refuse to carry people with disabilities. Some cities had “unsightly beggar” ordinances that prohibited people with disabilities from soliciting. Immigration laws banned immigrants with disabilities. Some states even sought to sterilize, prevent marriage between and incarcerate people with disabilities in order to prevent the reproduction of the “unfit.”

The nadir for people with disabilities was Roosevelt’s WPA, which categorized about 1.5 million people with disabilities, mothers with dependent children and elderly people as unemployable. Though they looked to the New Deal for help in finding jobs, people with disabilities were deemed ineligible for assistance by the WPA and passed off to local assistance programs.

Consistent with new federal policy, however, many local programs such as the New York City Emergency Relief Bureau began to automatically reject applicants with disabilities, even though jobs were available.

Demoralized and angry, five young people with disabilities – all in their 20s – decided they had

had enough. Led by Hyman Abromowitz, who used leg braces due to a childhood case of polio, the group descended on the New York City Emergency Relief Board and demanded to speak director Oswald Knauth. They were dismissed and told that Knauth might be able to meet with them in a week, but they refused to leave.

For a full day, nothing happened. But then Abromowitz's wife came to visit and she was turned away by the office's security personnel. She returned with a large angry mob of socialists who picketed on the street outside the relief board's Midtown offices. While the crowd would eventually disperse, the five unemployed people with disabilities who refused to leave the relief board's offices had captured the attention of the city and the media. They called themselves the League of the Physically Handicapped.

Without any real plan, Abromowitz and the others began to negotiate. Their demands escalated to include the immediate employment of 50 people with disabilities and jobs for 10 additional people per week thereafter. They wouldn't accept jobs with charity groups in sheltered workshops or jobs that segregated them from other workers. Fair wages were a must.

Knauth demurred and the picketers stayed put. About 25 more people with disabilities and hundreds of sympathizers rallied outside the relief board, disrupting its operations. For nine days, the protest continued inside the relief board's office and outside on the street. About a dozen were arrested leading to a highly publicized trial.

Though this first protest was ultimately unsuccessful, it triggered a grassroots movement and raised significant awareness. Less than a year later, the group returned to picket the WPA in New York and this time they had more members and money, were better organized, and had politicized their message. Acquiescing to their demands, the local WPA director, Victor Ridder, promised to hire 40 league members and within six months all of the protesters had jobs. In addition, New York established a new Bureau for the Physically Handicapped to focus on the employment of people with disabilities. Ridder conceded that just one percent of WPA employees were disabled, though at least five percent of the city's population was disabled.

Though the league eventually carried their fight to the WPA's headquarters in Washington, DC, the promise and the reality separated in the end. The federal employment policies did not change, while a broader question around the role of people with disabilities in society remained. Nevertheless, progress had been achieved through greater public awareness, a new grassroots organization and the empowerment of people with disabilities to engage the political process. At a time when people with disabilities were ostracized at every corner, the league had achieved the first great victory of the modern day disability rights movement.

The Willowbrook State School and Deinstitutionalization

During the 20th century, every state in the country passed laws that encouraged or forced the institutionalization of people with disabilities. This fervor was motivated in part by a social philosophy called eugenics, which advocated for the improvement of human hereditary traits through intervention, including relatively benign procedures such as prenatal testing and the extreme, such as forced sterilization. Eugenics gained acceptance around the globe in the late 19th century and was championed by thought leaders such as Alexander Graham Bell and Adolf Hitler, who carried the concept to an absolute extreme. Here in the United States, the eugenics movement scorned people with disabilities as menaces to society. In 1927, the U.S. Supreme Court even upheld a Virginia law compelling the sterilization of residents in state mental institutions.



Despite an environment that encouraged the institutionalization of people with disabilities from the cradle to the grave, many families still took their new born children with developmental disabilities home. Until the mid 1970s, however, these children had little or no access to community-based services and supports to help them learn and grow like their non-disabled peers. As a result, many grew to become adults dependent on their families for shelter and support. And they faced institutionalization later in life when their parents or siblings could no longer care for them.

In 1947, the state of New York opened a school for children with cognitive and developmental disabilities on Staten Island and named it the Willowbrook State School. A quarter of a century later, Willowbrook would become the most infamous large state-supported institution in the United States and home to some of the worst atrocities committed against people with disabilities in an institutionalized setting anywhere.

Though it became an Army hospital during World War II, the state resumed control after the war and continued to develop a campus for the institutionalization of people with disabilities.

Willowbrook was developed during the era when families were discouraged from keeping their children with developmental disabilities at home. At the time, people with cognitive and physical disabilities were demeaned and segregated from all facets of society including schools, jobs and communities. Institutions such as Willowbrook were supposedly created to be safe havens for people with disabilities – places where they could receive individualized care while reducing their impact on the rest of society. People with severe disabilities would be both protected and hidden from the rest of society.

The state's misguided goal easily evolved into something even more sinister. While a population boom contributed, overcrowding at Willowbrook was largely due to enthusiastic New York City officials who sent all sorts of people to live at the Staten Island campus. Though Willowbrook was originally intended to house people with cognitive impairments, its residents had all types of physical and cognitive disabilities. In addition, some didn't have disabilities at all, just no place to go. While it was designed to house 2,000 people with disabilities, Willowbrook would hold more than 6,000 during its worst days, becoming one of the largest institutions for people with disabilities in the world.

In 1963, physicians at Willowbrook began a series of highly unethical experiments. Most notably, they conducted a hepatitis medical study in 1966 and injected residents with or exposed them to the hepatitis virus.

Budget cuts also helped to create scandalous living conditions. As few as four to five attendants cared for hundreds of residents in any given ward. Some workers would later claim that the building that housed babies was completely silent because even infants had learned the futility of crying.

The average amount of time feeding children or adults who could not feed themselves was three minutes. Not surprisingly, the most common cause of death was aspiration pneumonia.

Residents were jammed into overcrowded quarters and lived in squalor. Overworked and understaffed attendants would leave some residents in their own urine and feces for hours on end and they provided little supervision. Physical and sexual abuse was rampant and often perpetrated by residents who had no one to teach them healthy behaviors.

In 1972, WABC-TV reporter Geraldo Rivera launched an Emmy-award winning investigative series on Willowbrook. Sneaking cameras onto the campus, Rivera exposed Willowbrook's dark wards and showed graphic images of its residents. One of the residents he interviewed was Bernard Carabello, who had cerebral palsy but no cognitive disability. He lived at Willowbrook for almost 20 years.



[Willowbrook] was overcrowded and there were severely mentally retarded people in the ward. There were only two attendants to take care of the people. It was impossible for them to take care of all of them...We had only two or three minutes to eat because they had fed something like 40 residents who could not feed themselves. When they fed a resident they would mix his or her food, bread, soup, or whatever else, all together on one plate...

If a patient would run out into the dining room and grab the food off somebody else's tray, then he would take that food and shove it down his throat. If an aid would not get to that patient in time, then he would automatically choke to death. I have seen it happen.

Most of the time—and I know this for a fact—the parents would ask about, "How did my child die?" They would have to say, "Natural death..." They covered this up so they would not get in trouble with the people in Albany...

The conditions were of no clothes, kids laying on the floor, and if a kid was not in an activity like a school or a program, then they would stay and mess in their own feces and urine. The attendant would get a working boy to clean up...

I live in my own apartment now but I still eat like that after 16 years. It is so hard to break out of that habit. When my friends and family come over, they tell me that the food will not run away from me. They will tell me that I have four or five hours to eat. It is hard for them to understand that after doing this for so many years, it is hard for me to break out of that habit. I do choke on my food. I have to run into the kitchen real fast to get a drink of water so I can get the food down...

— Source: 1977 testimony of Bernard Carabello before the United States Senate



Geraldo's series was a turning point in the fight against unnecessary institutionalization and it raised significant awareness of the neglect and abuse of people with disabilities in institutionalized settings.

The public exposure also resulted in a class action lawsuit in 1972, led by families and public advocates for people with disabilities. In 1975, the lawsuit ended in a consent decree that mandated reforms in the New York institution. The legal precedent was used around the country to address discrimination, neglect and abuse in other institutions.

More importantly, changes in public policy occurred. The Civil Rights of Institutionalized Persons Act (CRIPA) of 1980, though narrow in focus, was a critical step towards recognizing the rights of people with disabilities to live in the least restrictive environments possible. The passage of CRIPA was made possible in large part by the efforts of those in the mental health and developmental disability communities. Bernard Carabello and other former Willowbrook residents were critical in building political support for the law. Incremental progress in the deinstitutionalization of people with disabilities continued until 1999, when the landmark U.S. Supreme Court ruling in *Olmstead v. L.C.* found that the unnecessary institutionalization of people with disabilities was discriminatory.

The case revolved around two Georgia women with cognitive disabilities who were forced to remain in an institution for many years because health professionals believed that they could not get adequate services to enable them to live in their communities. In a 6-3 decision, the court ruled that states are "required to provide community-based treatment for persons with mental disabilities when the state's treatment professionals determine that such placement is appropriate."

Importantly, the Supreme Court upheld the 11th Circuit, which stated:

"...By definition, whereas here, the State confines an individual with a disability in an institutional setting when a community placement is appropriate, the state has violated the core principle underlying the ADA's [Americans with Disabilities Act] integration mandate."

Dr. Donna Shalala, the Secretary of Health and Human Services at the time, sent a letter to the nation's governors emphasizing the court's decision, stating that "unnecessary institutionalization of individuals with disabilities is discrimination under ADA."

While people with disabilities are still institutionalized throughout the United States, the number of people living in large congregate settings has been diminished – from a peak of nearly 200,000 residents in 1967 to about 40,000 in 2005. States and the federal government are slowly moving toward funding community-based services and supports that allow even people with the most severe disabilities to live in regular neighborhoods in regular communities and are, in many cases, less costly than large institutions. Nevertheless, true community inclusion for people with disabilities – including healthcare, education, employment and housing – remains an aspiration rather than a reality.

An Empowered Community Rallies for Section 504

In the early 1970s, Congress passed the Rehabilitation Act, a historic law that included a provision prohibiting discrimination on the basis of disability for the first time. The new federal legal protection contained in Section 504 stated that any program receiving federal funds could no longer discriminate against people with disabilities.

President Richard Nixon was not a fan, however, and he pocket vetoed the bill twice before finally signing it in 1973.

While groundbreaking, the law was no magic wand. It did not appropriate funds for education, health, housing, employment or other federal programs to adjust their activities or policies to include people with disabilities. Instead, future funding was tied to compliance.

Furthermore, the law required the government to develop and execute enforceable regulations. It would take nearly four years to complete these regulations because of the Nixon Administration's hesitancy to implement them and the law's broad mandate. With input from the disability community, however, the Nixon and Ford Administrations finally developed the regulations, but they did not execute the draft regulations before leaving office.

Meanwhile, in his campaign for president, former Democratic Georgia Governor Jimmy Carter promised to sign the regulations as they had been written. Once in office, however, Carter's Secretary of the Department of Health, Education and Welfare (HEW) Joseph Califano waffled and began to revise the regulations, watering down their impact.

Stymied at the verge of victory, the disability community was outraged and the American Coalition of Citizens with Disabilities, a national consumer-led disability rights organization out of Berkeley, California, announced that they would hold demonstrations beginning on April 6, 1976. Following through on their promise, the group and its supporters rallied outside various HEW offices around the country. In San Francisco, more than 100 people with disabilities stormed the HEW office and demanded that Secretary Califano sign the early versions of the regulations.

The protesters persisted for nearly a month while the HEW did everything it could to get them to leave. The bay area community rallied, however – the mayor provided mattresses, the Black Panthers prepared food, and the local media celebrated the protesters' cause.

Seizing the moment, two California Congressmen arrived in San Francisco to hold a special Congressional hearing on the matter, though they proved no match for the fired up protesters. Activist Judy Heumann, who experienced childhood polio, emotionally told the politicians to stop placating their grievances.



We will no longer allow the government to oppress disabled individuals. We want the law enforced. We will accept no more discussion of segregation. And I would appreciate it if you would stop shaking your head in agreement when I don't think you understand what we are talking about.

— Source: Statement by Judy Heumann at the special Congressional hearing in 1976, National Public Radio, April 28, 2002



Ten protesters flew to Washington, DC, to demand a meeting with Secretary Califano or President Carter. As the protesters lingered in the HEW's headquarters, television cameras caught security guards trying to tip over some of the wheelchairs, completing a public relations disaster for the new Carter Administration. Relenting, Secretary Califano signed the regulations and handed the disability community one of its greatest victories. Fifteen years later, the Rehabilitation Act's final regulations would become the basis for the landmark Americans with Disabilities Act.

Prior to the San Francisco sit-in, most of the protesters had little sense of community or shared history and some would later say that this watershed moment was one of the most liberating experiences in their lives and changed their perception of their own disability. Many had been isolated and demoralized, and the 504 protests gave them hope for a better future.

The Independent Living Movement

Ed Roberts, the father of the independent living movement, acquired his disability at the age of 14 due to polio. After spending a year in a hospital, Roberts returned home despondent about his future. His disability required him to spend vast amounts of time in an iron lung, and he graduated only after his high school waived physical education and drivers' training license requirements.

When the time came to go to college, Roberts applied for financial assistance from the California Department of Rehabilitation. His hopes were dashed, however, when his application was denied by the department because he was too disabled to work. Infuriated, Roberts took his case to the media and within one week, the department reversed its decision. Ironically, 15 years later he was named to lead the very same department by Governor Jerry Brown.

Roberts earned an associate degree from the College of San Mateo and later applied to attend the University of California at Berkeley. The school resisted but eventually invited Roberts to join its freshman class with conditions. Roberts had to live in the University's Cowell Hospital because the dormitories could not support his massive 800 pound iron lung. When he started classes, his attendance was considered a breakthrough because the university and the city of Berkeley were largely inaccessible to people with disabilities at the time, despite their liberal politics.

Blazing a trail, other students with severe disabilities followed Roberts to Berkeley. By 1967, 12 students lived at Cowell Hospital and the following year a formal program for students with disabilities was established and managed by the California Department of Rehabilitation.

As the students soaked up the university culture, they developed a sense of community and a political consciousness that encouraged them to look beyond their physical limitations toward new possibilities for the future. Roberts formed the Rolling Quads, a group for students with physical disabilities and began to organize.

Soon their new organization was tested when a rehabilitation counselor determined that the educational goals of two students were unfeasible and their life styles improper. The counselor further stated that the two students should be moved to nursing homes. The Rolling Quads protested, demanding that the counselor be fired and the students be reinstated. Though they eventually won their fight, they ruffled feathers at the Department of Rehabilitation, even instigating a psychiatrist to threaten to institutionalize them all.

As the protest continued, however, an official at HEW took notice. At the time, Berkeley English

professor Jean Wirth was developing peer counseling programs and supports for minority students in order to boost graduation rates. She approached Roberts and the Rolling Quads to design a similar program for students with disabilities.

The young activists rallied and developed the Physically Disabled Students Program (PDSP), which organized personal assistance services, wheelchair repairs, emergency attendant care, and financial assistance from state and federal social service and rehabilitation agencies. The program was funded by HEW in July 1970 and was up and running two months later.

The student-organized program had several key principles:

- Experts on disability are people with disabilities.
- The needs of people with disabilities can be best met with a comprehensive program, rather than fragmented programs at different agencies and offices.
- People with disabilities should be integrated into the community.

PDSP even organized a class for students with disabilities under the university's group studies program called "Strategies for Independent Living," in which they developed utopian plans for community-based communal living arrangements for students and non-students with disabilities.

The PDSP program flourished and many students with disabilities moved from Cowell Hospital into the community. Meanwhile, more and more people with disabilities sought out services from PDSP, including non-students in the Berkeley community.

In May 1971, the group began meeting with residents in the community and soon established the first Center for Independent Living (CIL) in the nation with a \$50,000 grant from the Federal Rehabilitation Services Administration. The group became instrumental in obtaining affordable accessible housing for people, working with landlords, improving accessibility in the community including curb cuts, and even working with the California legislature to boost the state add-on to federal Supplemental Security Income, a key source of income for many people with disabilities. Today, CILs run by people with disabilities for people with disabilities serve communities in every state in the nation and remain a powerful force within the disability rights movement.

The Americans with Disabilities Act

The apex of the disability rights movement in the late 20th century was the Americans with Disabilities Act of 1990 (ADA), a broad and definitive law that prohibited discrimination and mandated accessibility to all public and private accommodations. The ADA is cited as the crown jewel of disability rights and July 26, the anniversary of its enactment, is rightfully celebrated annually by the disability community throughout the country. While the ADA's journey to enactment was difficult, its genesis and development was closely tied to the evolving disability rights movement and the public perception of disability.

During the last quarter of the 20th century, the disability rights movement gained momentum and political savvy. People with disabilities, their families, and their advocates pressed for and achieved broad federal legal protections against discrimination including Section 504 of the Rehabilitation Act, the Civil Rights of Institutionalized Persons Act, the Education of all Handicapped Children Act (Public Law 94-142) and more. But discrimination against people with disabilities was still rampant.



In 1979, for example, a Supreme Court case proved that Section 504 was not sufficient on its own. In *Southeastern Community College v. Davis*, the court ruled that a woman with a hearing impairment was unqualified for nursing school thereby allowing the school to reject her application.

Throughout the 1980s, additional lawsuits weakened and watered down the mandate of Section 504. It became clear that the politically engaged disability community would have to push for greater protections against discrimination.

An early and well-known champion of the ADA was Justin Dart, Jr. who had been born into a privileged Texas family. His mother was Walgreen's heiress, Ruth Walgreen and his father, Justin Dart, Sr. was head of Dart Industries, a multinational conglomerate. Dart contracted polio in his adolescence, leading to a life-long physical disability. When he was young, Dart's father gave him a job that was a risky venture overseas: launching Japan Tupperware. Dart made good in two short years, growing the company from four employees to 25,000. He went on to other business ventures in Japan and always used his Japanese enterprises to employ people with severe disabilities who had lived in institutions. He married in Japan and he and his wife, Yoshiko, returned to the United States in 1974 as committed disability rights activists.

In 1978, he connected with the disability rights vanguard in Austin, Texas and co-founded one of the early Centers for Independent Living. In 1981, he was appointed by President Ronald Reagan to the National Council on Disability, an independent federal agency. At his own expense, he traveled the country, meeting with activists to unify community support. He and others on the National Council on Disability drafted a national policy calling for federal civil rights legislation, which would become the foundation for the ADA. In 1983, Dart was appointed by Reagan to head the Rehabilitation Services Administration (RSA). However, he was asked to resign his position when, in testimony before Congress, he said the RSA was a "vast, inflexible federal system which, like the society it represents, still contains a significant portion of individuals who have not yet overcome obsolete, paternalistic attitudes about disability."

Later, Dart chaired the Congressional Task Force on the Rights and Empowerment of Americans with Disabilities. In that role, he again traveled the country to build critical grassroots support for federal legislation.

The first draft of the ADA was developed by the National Council on Disability and in 1988; the legislation was introduced in the 100th Congress, in the Senate by Senator Lowell Weicker (R-CT) and in the House of Representatives by Congressman Tony Coelho (D-CA).

The community rallied like never before to build public and political support. Advocates in Washington, DC held regular meetings in a church close to the U.S. Capitol in order to bring together the diverse elements of the disability community to share in one common purpose. Dart and other disability rights activists held more than 60 public hearings and collected thousands of "discrimination diaries" from people with disabilities in communities across the country.

In 1988, both presidential candidates, Vice President George Bush and Governor Michael Dukakis, pledged to support national disability rights legislation. Meanwhile, Congress began a series of formal hearings where scores of people with disabilities testified regarding the discrimination they faced in their communities every day.

In May 1989, the ADA was reintroduced in the 101st Congress. Teams of lawyers and advocates worked on its complex legal issues and participated in negotiations around concerns from the

business community and other interest groups. Importantly, the disability community fought hard to make sure the legislation included protections for people with all types of disabilities. In particular, though controversy surrounded the inclusion of people with HIV/AIDS and those with psychiatric disabilities, the community fought back efforts to exclude these populations at the final hour from the bill. It would take 17 hearings, five committee markups, 63 public forums, 8,000 pages of transcripts and testimony from dozens of prominent public officials before the legislation was ready for a final vote.

The ADA was overwhelmingly passed by both houses of Congress in September 1989. The law included broad protections against discrimination in employment, as well as in public and private accommodations, and the ADA took the critical step of forcing private entities to make their businesses accessible to people with disabilities.

Since its passage, however, a series of restrictive and antagonistic Supreme Court rulings have cast a shadow on the ADA's employment provisions, despite the clear intent of Congress. The Court has inconsistently and narrowly interpreted the definition of disability, limited enforcement provisions such as the awarding of attorney fees and litigation costs to plaintiffs, allowed discrimination in employment practices in the name of worker safety, and permitted exceptions to the law's mandate for reasonable accommodations. On the whole, these limitations have drastically weakened the protections of the ADA and exposed deficiencies within the law.

Today, the disability community is working with Members of Congress to craft legislation that clarifies the law and the full intent of Congress when it passed. When successfully enacted, an ADA restoration act will be another important milestone in the history of disability rights. In mid 2007, legislation was introduced in the U.S. House of Representatives, generating broad bipartisan support.

However, it is important to note that incremental and technical changes in the law will not entirely fix the problems people with disabilities face every day – poverty, poor educational opportunities and outcomes, little access to quality healthcare, high unemployment, shortages of affordable accessible housing, and low community participation – hardly the American Dream. Thus, despite a rich and celebrated history, the disability rights movement has failed to revolutionize the public perception of disability. Perhaps, the next great disability rights battle will be in the hearts and minds of the American public, rather than in the courts, Congress or state capitols.



HEALTHCARE AND INDEPENDENCE

ONE OF THE GREATEST MISCONCEPTIONS OF DISABILITY is that a physical or cognitive impairment equates to poor health. Many Americans perceive disability as a physical symptom of disease or sickness – an unfortunate perception that helps feed fear of and discrimination against people with disabilities. But this perception of disability also informs public policy. In fact, our nation’s public health systems largely focus on the prevention of disability rather than on preventive health services for people with disabilities. As a result of this bias, limited accessible and affordable health services, cumbersome and inefficient government programs, and environmental factors, Americans with disabilities are, on the whole, in poor health. Again, systemic barriers, rather than the medical impairment itself, define the disability experience.

Many factors contribute to the poor state of health among Americans with disabilities. People with disabilities are less likely to be employed, more likely to live in poverty, less likely to participate in the social fabric of their communities, and, unless they qualify for Medicaid or Medicare benefits, less likely to have health insurance coverage. Moreover, regardless of who pays, people with disabilities have greater difficulty in accessing affordable, quality healthcare services, including preventative care.

As a result, people with disabilities are more than two and half times as likely to be diagnosed with diabetes and experience higher rates of other chronic conditions. They are less likely to engage in leisure-time physical activity and other recommended health behaviors. For example, people with disabilities are more likely to smoke and have higher rates of obesity. They are less likely to have good dental health. About 28 percent report symptoms of depression, and when asked, people with disabilities are less likely to report being satisfied with their lives.

It is important to note that the nature of disability is not the reason why Americans with disabilities are in poor health. Most can or should live long healthy lives. While it is true that people with disabilities may need more health-related services and supports than the general population, these services are often not designed to meet the needs of people with disabilities.

Access to Care

Sydney Case, a middle-aged woman who uses a power wheelchair, especially dreads visiting her gynecologist. For the magazine *New Mobility*, she wrote, “Part of the problem is the lack of proper equipment, such as lower examination tables. But by far the worst cause of dread is the lack of sensitivity.”

She recalled a recent visit to see her physician. While Case undressed herself, a task that requires more time and effort for a person with physical disabilities, a nurse told her to hurry up and then to “hop” on the examination table. When she told the nurse and physician that she could not,

they tried to lift her on to the examination table and dropped her on the floor. Clearly, the nurse and physician were not prepared or trained to lift her and the table was too high. Then, the nurse told Case, “This would be a lot easier if you lose weight.”

Case’s story received some attention because she is a well-known disability activist. But other women with disabilities may not be able or willing to advocate for themselves. A recent survey found that only 45 percent of women with disabilities reported receiving a mammogram in the past two years compared with 63 percent of women without disabilities.

Today, nearly two decades since the ADA became law, widespread problems with access to healthcare remain. Since 1994, the U.S. Department of Justice has settled at least 157 cases related to people with disabilities and access to healthcare services. Fifty-one of these cases specifically involved inaccessible healthcare environments, such as examination tables, waiting rooms, restrooms, entrances, and passageways.

As important as they are, civil rights laws like the ADA are not self-executing and public and private litigation may not be enough to improve access to healthcare. Though some cases have had a significant impact on improving healthcare for people with disabilities, litigation is costly and cases may languish in the court system for years. Meanwhile, people with disabilities continue to experience immediate access problems, especially those who have life-threatening conditions or need emergency care.

Nevertheless, one case, *Metzler v. Kaiser Permanente of California*, had a particularly notable impact on improving access to care. In 2000, three people with disabilities sued Kaiser Permanente, which operates 30 hospitals in nine states and the District of Columbia serving about 8.2 million members. The class action suit sought to resolve a range of barriers to care, including inaccessible facilities, specific problems with medical equipment such as examination tables and weight scales, and discriminatory policies. In 2001, Kaiser entered in a wide-ranging settlement agreement to correct these deficiencies, setting a critical precedent for future litigation according to legal experts.



Metzler v. Kaiser Permanente Plaintiffs Received Unequal Care

Plaintiff 1: *Hospital patient who experienced a pressure ulcer that went undetected and later required surgery.*

Plaintiff 2: *Patient was told to weigh herself on a set of truck scales because the clinic did not have a scale that was accessible.*

Plaintiff 3: *Patient stated, “This isn’t about doctors. It’s about the system. When you’re disabled you take what they hand you until you can get something better. That’s what this lawsuit is all about. Getting something better.”*

— Source: *It Takes More than Ramps*, by Dr. Judy Panko Reis, et al



Disability Rights Advocates, the California-based nonprofit legal center which pursued the Kaiser case, recently found that significant but basic access problems remain. Among Californians with disabilities:

- **17%** with mobility disabilities reported difficulty getting in the main entrance of their doctor’s office.
- **69%** of wheelchair users reported difficulty using exam tables.
- **45%** of wheelchair users reported difficulty using x-ray devices, such as mammography equipment.
- **26%** of individuals who are deaf reported difficulty in getting interpreters for medical appointments.
- **95%** of individuals who are blind or partially sighted reported not receiving medical history forms in alternative formats.
- **59%** of individuals with learning disabilities and **64%** of individuals with cognitive disabilities reported that their providers communicate with someone else in the room rather than directly with them.

Healthcare workers also suffer when health systems do not accommodate people with disabilities. In particular, nursing aides, orderlies and attendants are at high risk for work-related injuries. Among all workers, they experience the third highest number of injuries after laborers, truck drivers, and freight, stock and material movers. Often without proper training or equipment, healthcare workers are injured while providing very personal services to people with disabilities with a responsibility for maintaining their safety and dignity.

These problems exist despite the high utilization of healthcare and healthcare systems by people with disabilities. Moreover, the impact and prevalence of disability is expected to grow even further as the baby boomer generation ages. By 2030, up to 20 percent of the population will be over 65 years-old.



People with Disabilities Use Healthcare Systems More Frequently

33% of physician visits

62% of hospital stays

46% of adult-related healthcare expenditures

Source: Structural Impairments That Limit Access to Healthcare for Patients with Disabilities, Journal of the American Medical Association, by Dr. Kristi Kirschner

A lack of access to healthcare also creates vast inefficiencies in healthcare systems. By improving short-term outcomes for people with disabilities, private and public healthcare systems can significantly lower the long-term cost of care. Costs can be trimmed further when new facilities are constructed using universal design, a philosophy of design in which form follows function. While the ADA requires new and renovated buildings and facilities to be accessible, universal design extends the idea of accessibility to making environments useable by all people, to the greatest extent possible, without need for adaptation or specialized design.

Health Insurance for People with Disabilities

Medicaid

In 2003, eight million adults with disabilities relied on Medicaid as their primary health insurance at a cost of \$72.7 billion. Created in 1965, Medicaid is a health insurance program for Americans with low-income that is jointly funded by the federal government and the states. While Medicaid eligibility varies from state to state, generally people with disabilities and others whose income is equal to or less than the federal poverty level are eligible. A number of states extend Medicaid benefits to people with incomes as high as 250 to 300 percent of the poverty level, but most income eligibility is in the poverty level range. In 2007, the federal poverty level for a single individual was \$10,210 and \$20,650 for a family of four.

In addition to income, other factors may “categorically” qualify one for Medicaid benefits. People with disabilities who receive Supplemental Security Income (SSI) are “categorically” eligible for Medicaid healthcare benefits, as are children and youth in foster care systems and those who are institutionalized in facilities for people with developmental disabilities. Individuals with developmental disabilities living in the community who would otherwise be eligible for institutional care are also categorically eligible for Medicaid healthcare benefits.

Medicare

The federal Medicare program was also created in 1965 and is a health insurance program designed for retired workers over the age of 65. There are also, however, some 6.4 million people with disabilities under the age of 65 who are “dual eligibles”, low-income elderly and individuals with disabilities who are eligible for both Medicare and Medicaid benefits.

Dually eligible people with disabilities are primarily those who receive Medicare benefits as well as Social Security benefits as dependent adult children who developed a permanent and severe disability before age 22 and whose parent is/was a Medicare beneficiary. Those who become disabled after working may also become dual eligibles. Generally, these individuals must wait 29 months after the Social Security Administration affirms their disability status before Medicare benefits begin. The waiting period begins at age 18 for most adult dependents with disabilities.

For dual eligibles, while Medicare covers basic health services, including physician and hospital care, Medicaid pays Medicare premiums and cost-sharing and covers critical benefits Medicare does not cover, such as long-term care. In 2006, coverage of prescription drugs for dual eligibles shifted from Medicaid to Medicare.



Growth of Medicaid: 1995 – 2005

	1995	2005
Spending:	\$145B	\$315B
Beneficiaries:	43.3M	60.4M

Source: *Medicaid Revisited – Skirmishes over a Vast Public Enterprise*,
New England Journal of Medicine, By John K. Iglehart



In 2005, Congress passed important changes to Medicaid in order to stem the enormous growth of the program. The Deficit Reduction Act of 2005, which was signed into law by President George W. Bush, required Medicaid beneficiaries to prove U.S. citizenship, gave states greater flexibility to implement changes to the program, and included provisions to encourage states to move toward home- and community-based services for people with disabilities remaining in nursing home and institutionalized care.

In response to the Deficit Reduction Act, some states have enacted policies that promote cost-sharing and credits for healthy behaviors. Still, other states have taken aggressive steps to restrict eligibility and limit services. Tennessee, for example, attempted to reduce its Medicaid rolls by 225,000 and restricted access to prescription drugs and other services in 2005. Tennessee disability advocates staged an ultimately unsuccessful sit-in at the governor's office for months to fight the cuts. These developments indicate an ominous trend towards placing the burden for the cost and scope of healthcare on the individual, deepening the slide into poverty for many people with disabilities and further restricting access to critical services.

In addition, many private physicians and health maintenance organizations are increasingly experiencing difficulty in obtaining adequate reimbursement for services to patients with disabilities on Medicaid. Frequently, Medicaid programs place caps on reimbursement rates, forcing physicians and health organizations to struggle with providing appropriate care to patients and maintaining a profitable business. A recent national survey of solo and two-physician practices found that more than 35 percent were not accepting new Medicaid patients. Meanwhile, in 2003, 22 percent of people with disabilities reported that they were denied care because a physician would not accept Medicaid. More than a quarter of people with disabilities also reported trouble finding a doctor that “understands my disability.”

Private Insurance

Private insurance is not heavily utilized by people with disabilities, largely because people with disabilities experience substantially higher rates of unemployment and poverty than the general population. Also, people with disabilities or other health conditions often cannot buy private insurance or will be denied coverage for healthcare services related to their disability, which may be considered a “pre-existing condition” by the carrier.

Annually, private insurance contributes only about \$6 billion to the cost of healthcare for people with disabilities. Even when private insurance is available, most private insurance plans do not pay for specific services needed by people with disabilities, such as equipment and supplies, mental health services, certain home- and community-based services, and physical, occupational or speech therapies. As a result, some adults with disabilities and particularly families with children with disabilities must live in poverty to maintain eligibility for Medicaid or Medicare and thereby ensure access to comprehensive healthcare. Often they struggle to pay for these services on their own. People with disabilities and their families pay about \$34 billion in out-of-pocket healthcare costs annually.

Medicaid Buy-In Programs

For many Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) recipients, the risk of losing Medicaid healthcare coverage linked to their cash benefits is a powerful disincentive to going to work where they might earn a salary that would disqualify them from receiving Medicaid benefits any longer. To address this problem, Congress included a Medicaid “buy-in” option in the Balanced Budget Act of 1997 and enacted the Ticket to Work and Work Incentives Improvement Act (TWWIIA) in 1999. These laws authorized states to create Medicaid buy-in programs to extend Medicaid coverage to people with disabilities who go to work.

In 2006, Congress passed the Family Opportunity Act to address the dilemma many families face when they lack adequate insurance to cover much-needed healthcare services for their child. The program is optional for states, allowing states to offer Medicaid coverage to children with severe disabilities living in middle-income families through a sliding scale “buy-in” program.

Almost 47 million Americans do not have health insurance at all, including more than two million people with disabilities. And more than 13 percent of families with a member with a disability live in poverty.

Even with public or private insurance, people with disabilities struggle to afford the healthcare services they need. For example, a Kaiser Family Foundation study found that people with disabilities on Medicare alone were six times more likely than the general public to postpone care because of cost.

The 2003 Kaiser survey of non-elderly people with disabilities found that because of cost concerns:

- **46%** go without health-related equipment, such as a wheelchair, glasses or hearing aid
- **37%** postpone care needs
- **36%** skip doses or split pills
- **36%** spend less on food, heat or other staples to afford healthcare

Problems Paying for Selected Healthcare Services

■ Percent of people with disabilities reporting serious problems paying for the following services in the past 12 months



Source: Kaiser Family Foundation, 2003

With wide-ranging healthcare needs and lower income, people with disabilities bear an increasing burden in today’s healthcare environment, which is focused more and more on cost. At the federal and state levels, policymakers are scrutinizing publicly-funded health programs in order to slow the growth in healthcare-related spending. These efforts have stirred wide-ranging debates regarding the role of government in providing healthcare and the value of home-community-based services over institutionalized care for people with disabilities.

In 2006, United Cerebral Palsy released *A Case for Inclusion*, a report on state Medicaid programs for people with mental retardation and developmental disabilities, a group that accounts for just 1.3 percent of the total Medicaid population but 9.5 percent of all Medicaid spending. In ranking



all 50 states, United Cerebral Palsy found that states with Medicaid programs that prioritized home- and community-based services performed better and were more efficient. Despite this evidence, most states still allocate significant resources towards large institutions, which prevent people with disabilities from living in and interacting with their community. In addition, aggregate care facilities may be prone to inefficiencies and may cost more to operate on an average per person basis than home-based care. In 2007, the organization further updated this report and provided *A Plan for Inclusion*, a roadmap for its affiliate organizations to work with the states in reforming Medicaid.

Healthcare and Independence

Beyond basic health needs, affordable and accessible healthcare services are the foundation for living independently in the community for people with disabilities. Health care is elemental in saving a human life and essential in providing opportunity to work and contribute. As we begin a discussion about the future, the Life Without Limits Project and others must prioritize the crisis in healthcare for Americans with disabilities. While the complex task ahead involves resolving a web of intricately intersected issues, such as accessibility, poverty and unemployment, healthcare remains at the nexus of barriers and discrimination, policies and programs, people with disabilities and the public.

A FREE AND APPROPRIATE PUBLIC EDUCATION



Today, education is perhaps the most important function of state and local governments. Compulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. It is required in the performance of our most basic public responsibilities, even service in the armed forces. It is the very foundation of good citizenship. Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right which must be made available to all on equal terms.

— Source: *Brown v. Board of Education*, Supreme Court Justice Earl Warren

The seeds of “free and appropriate” public education in the United States were planted in 1643 when the first taxpayer-funded schoolhouse opened its doors in Dedham, Massachusetts. For many years following, however, education was a privilege of wealth. Even if free public schools were available, most families of modest means sent their children to school for only a few weeks or months in the winter when no farm work could be done.

At the time of our nation’s founding, public education was entirely a state and local program. The quality and curriculum of public education varied greatly by region and reflected local cultural values. In 1787, the authors of the U.S. Constitution did not specifically suggest that the country’s citizens had the right to a free education. However, even then, it was clear that an educated populace was the foundation of democratic government. After all, 32 of the 55 delegates at the Constitutional Convention were attorneys.

In 1868, however, the 14th Amendment was ratified by the states, codifying into law the foundation for equality: that no state shall “deny to any person within its jurisdiction the equal



protection of the laws.” Nevertheless, it would still take more than a century before America’s schools were opened to children with disabilities.

Throughout much of our country’s history, people with disabilities of all ages were isolated and separated from society. While institutions for people with cognitive disabilities doubled up as prisons for convicted felons, adults with all types of disabilities were involuntarily sterilized to prevent the perpetuation of their disability, and children born with severe developmental disabilities were sent away to live in large institutions for the “mentally retarded.” Given society’s negative perception of disability in general, it’s not surprising that children with disabilities were barred from public schools entirely.

Legally and culturally, the beginning of the 20th century in America was a difficult time for people with disabilities, as for many minority groups. In 1896, the Supreme Court upheld the doctrine of “separate but equal” segregation of the races in *Plessy v. Ferguson*, an unfortunate precedent used to, among other things, exclude children with disabilities from the classroom.

In 1919, the Wisconsin Supreme Court upheld a state law that forbade children with disabilities from being educated alongside students without disabilities. Citing the *Plessy* precedent, the court ruled that Merritt Beattie, a 13-year-old boy with cerebral palsy could be expelled from the regular classroom he had attended for a year.

The court stated that Merritt had “a depressing and nauseating effect upon the teachers and school children, [and] that by reason of his physical condition he takes up an undue portion of the teacher’s time and attention, distracts the attention of other pupils, and interferes generally with the discipline and progress of the school.”

The court further reasoned that Merritt’s presence would be “harmful to the best interests of the school,” saying “Individual rights must be subordinated to the general welfare.” Indeed, the Wisconsin State Supreme Court said that the local school board had the fundamental duty to decide “whether this boy should be denied a [state] constitutional right because the exercise of that right would be harmful to the school and the pupils.”

The experience of Merritt Beattie and his family was hardly the exception, but the rule. At the time, most states had statutes that barred children with disabilities from attending public schools. In Maine, for example, a state law that remained on the books until 1975 stipulated that “the school board may exclude from the public schools any child whose physical or mental condition makes it inexpedient for him to attend.” In other words, a local school board could simply refuse to teach any child that it deemed inconvenient to educate.

In 1984, Supreme Court Justice Thurgood Marshall wrote of the time:

A regime of state-mandated segregation and degradation... that in its virulence and bigotry rivaled, and indeed paralleled, the wrong excesses of Jim Crow. Massive custodial institutions were built to warehouse the retarded for life; the aim was to halt reproduction of the retarded and nearly extinguish their race. Retarded children were categorically excluded from public schools, based on the false stereotype that all were ineducable and on the purported need to protect nonretarded children from them. State laws deemed the retarded unfit for citizenship.

While it is impossible to know how many people with disabilities and their families were harmed by the prejudices of the times, it is reasonable to assume that the number is in the tens of millions if not more. But even at a time when public disdain for Americans with disabilities was rampant, a change of heart was occurring. And it was led by the very people, families and communities that these laws and prejudices offended.

Long before the Wisconsin State Supreme Court decided that Merritt Beattie was unfit to go to school with his peers, the farm boy was already attending his town's schools with his friends and neighbors through the fifth grade. Moreover, when his case was first heard by a county court, a jury decided that he should continue to go to school. Despite its decision, this was something that the Wisconsin Supreme Court could not discount or explain away.

Over time, Merritt and other children with disabilities began to chip away stereotypes and antiquated assumptions about disability, teaching communities that all children belong, all children can learn, and all children have a fundamental right to be educated in our public schools.

Parents and families who wanted their children to live full lives in their communities, began to band together to advocate for change in the public education system. One key organization, The Arc of the United States, was formed in 1950 by concerned parents of children with cognitive and developmental disabilities. At the time, there were virtually no community-based programs or services for children with cognitive or physical disabilities.

These pioneers overcame great obstacles to raise their children at home. With little or no resources, some of these parents formed their own schools to educate their children in church basements or in their homes. Meanwhile, they pushed federal, state and local governments to allow their children to access public education.

Over time, their advocacy paid off. Throughout the 1950s and 1960s, the federal government passed a series of laws that promoted the development of practices and educational services for children with disabilities. For example, the Training of Professional Personnel Act of 1959 supported the training of educators in teaching children with cognitive and developmental disabilities. The Teachers of the Deaf Act supported the use of interpreters to teach children who were deaf or hearing impaired. By 1968, the federal government had trained more than 30,000 educators, helping to open up schools across the nation to children with disabilities.

Despite the incremental progress, more than one million children with disabilities were still barred from public schools. And more than half of all children with disabilities actually attending public school were severely limited in accessing the services and settings provided for children without disabilities. For the most part, children with disabilities sat idly in regular or special classrooms until they were old enough to drop out.

Growing up amidst the civil rights movement, leading disability rights activist Bob Williams, who has cerebral palsy, led a sit-down of students in special education when he was just 13-years-old to demand inclusion in regular classrooms. Williams would be later appointed commissioner for the Administration on Developmental Disabilities in the Clinton Administration.



In 1968, I attended a “special class” in a room in a local church, which the town rented rather than make any of its schools accessible to any of my six to eight classmates and me. Some of the other kids lived in Newington, the same town in Connecticut I did. But, others came from surrounding towns. That happened a lot. Every year it seemed like you were being sent off to some other special class, very often in some other community, as if you were never really welcomed to stay in any one place very long. The worse part about it, though, was that I never got to go to any of the same schools that my brothers and sisters, or anyone from my neighborhood went to.

I had a couple of friends near where I lived. But, most of the kids in the neighborhood had no way, no real chance to get to know me, nor I them. So, unsure about what else to do, they turned to ridiculing and taunting me instead.

I began to see the parallel between going to a segregated school in Birmingham and being stuck in a church basement in an all white Connecticut suburb. The parallel between using separate drinking fountains and not being able to reach the fountain at all.

For me, like many other people with disabilities coming of age in the late 1960s, the civil rights struggles of the day gave me hope. I knew that the dignity, freedom and civil rights which black people, women and others were beginning to win were exactly those things I wanted and would have to work hardest for in life.

— Source: Bob Williams

Parents and advocates began to address systemic inequities through more hospitable courts. In the early 1970s, parents in Pennsylvania and the District of Columbia filed separate law suits challenging state laws that barred children with intellectual and other disabilities from receiving any public education. In striking down these policies, the federal courts directed state and local school authorities to cease denying children with disabilities a free public education and to start providing education appropriate to the capacities of the child.

Applying the same principles as the Supreme Court had in *Brown v. The Board of Education*, the Pennsylvania and DC federal district courts cited the equal protection clause of the 14th Amendment as guaranteeing equal access to public services.

Responding to these decisions and the growing advocacy movement, Congress acted in 1975 and passed the Education for All Handicapped Children Act, commonly known as Public Law 94-142.

The law, which revolutionized the educational environment for children with disabilities, mandated that children with disabilities were guaranteed a “free and appropriate public education” in the least restrictive environment and tailored to their own unique needs. It protected the rights of children and families against discrimination in educational services and assisted states and localities implement integrated educational environments with federal funding.

Public Law 94-142 was amended in 1986, 1990 and 1997 to include, among other things, early intervention services beginning at birth and transition services to assist teenagers with disabilities in high school transition to productive adult living. In 1990, the law’s name was changed to the Individuals with Disabilities Education Act (IDEA).

The law specified that each student with a disability should receive an Individual Education Program (IEP), or a specific plan tailored to the student’s unique needs. The law and its amendments empowered parents to challenge school districts to provide adequate education programs, giving them the right to appeal decisions by school systems through mediation, due process hearings and the courts.

Education Today

Since the mid-1970s, tremendous progress has been made. More than six million students with disabilities receive special education services in the United States today, and the majority are educated in neighborhood schools in regular classrooms with non-disabled peers. High school graduation rates for students with disabilities have dramatically increased, though they remain significantly lower than rates for students without disabilities. More importantly, employment rates for youth served under IDEA are twice those of older adults with similar disabilities and the percentage of college freshman reporting disabilities has more than tripled since 1978.

From early intervention to transition services, today’s special education programs for children with disabilities can begin at birth and continue through to adulthood.

Early Childhood

Since 1988, the number of children receiving early intervention services through IDEA has increased six-fold. In 2001, a little more than 230,000 infants and toddlers received early intervention services through IDEA’s Part C. In addition to IDEA, a variety of early intervention programs are funded through federal, state and local sources and all can have a profound impact on the lives of children and their families. Effective early intervention programs can enhance a child’s development, provide support and assistance to families, and maximize a child’s and family’s benefit to society.

Early intervention services may include evaluations of a child’s strengths and needs, individualized educational experiences, special therapies such as physical, occupational, or speech and language therapy, family supports such as home visits, service coordination, and transition supports to facilitate a smooth change from early intervention to preschool programs. These services may be provided in homes, child care centers, Early Head Start programs, or other early childhood settings.

Research has shown early intervention to be a sound investment. During early childhood, children experience a critical period of development when they are most malleable to learning skills and adapting to their environments. Proper intervention can prevent or ameliorate disabilities which left unattended might require costly supports and services later in life. Investment in intervention may also decrease the burden on special education programs by



maximizing the possibility to participate in mainstream classrooms.

Additionally, families of children with disabilities may feel disappointment, social isolation, added stress, or helplessness. Early intervention can provide families with the knowledge and tools to properly address the needs of their children. Research has also shown that children with disabilities are more often victims of emotional, physical and sexual abuse. Appropriate early intervention may help families prevent these abusive situations from occurring.

All states currently participate in IDEA's Part C, which is a discretionary program that provides federal funding for state-run early intervention programs. Eight states also provide optional services to specific at risk populations, such as low birth weight babies and children whose parents have substance abuse problems.

About 600,000 children with disabilities age three to five are in some kind of special education program, a 30 percent increase from just a decade ago. Most of this increase is due to a rise in early intervention services that have identified developmental disabilities and delays at an earlier age.

Because public school education for most children begins at kindergarten, preschool years are difficult for families of children with disabilities. Frequently, private and community preschool and child care services may not accept children with disabilities, leaving families with deeply inadequate supports. For example, a survey of child care providers in Maine found that only about one-third of the state's child-care providers served children with medical, physical or behavioral disabilities.

In addition, families with low incomes are most acutely affected. Without adequate resources, including appropriate child care, stressful family situations may become all but unavoidable and can contribute to abuse or neglect.

Primary Education

Today, more than six million children with disabilities are enrolled in special education in the United States. Once children with disabilities reach school age, they are entitled by law to special education services that meet their unique needs. The cornerstone of special education is the Individualized Education Program, or IEP. Under IDEA, school districts are required to provide eligible children with an IEP. Though the IEP's specific format may differ from state to state, it is designed to evaluate a student's unique needs and plan specific services required to meet annual performance goals.

The IEP process begins when a child is referred by educators or a request is received from a parent. The child is then evaluated and eligibility is determined using IDEA's definition of disability. (It is important to note that there is no common definition of disability in federal law. Many statutes applying to health, housing, employment, education and civil rights may have varied definitions of disability).

Once the child's eligibility is verified, an IEP meeting is convened with educators, parents, school administration officials and others with knowledge of the child, such as counselors, therapists and case workers.

The IEP is then written taking into account the input of all involved. Generally, the IEP details the child's current performance, annual performance goals, specific special education services, modifications or training required, integration with regular classrooms and participation in state-wide tests.

When students reach age 14, their IEPs must begin to include transition services. And at 16 years of age, these services must begin to be implemented. Transition services aim to assist teens with disabilities become productive and independent adults. They may address higher education, technical training, employment and/or independent living services.

Once set, the IEP is implemented by educators and reviewed at least annually. When parents disagree, they have the right to challenge education plans written for their children through third-party mediation, due process hearings, complaints to state education agencies and the courts. However, this right was weakened in 2005 by the U.S. Supreme Court in *Schaffer v. Weast*, in which the court placed the burden on parents to prove that schools are not properly educating their children with disabilities rather than on schools to prove that they are meeting the terms of the student's IEP and the law. As a result, low and middle income families who cannot afford an attorney may be unable to challenge inappropriate education plans.

Continuing Barriers to Excellence in Education

While IDEA forever changed the possibilities for children and youth with disabilities, they still face serious obstacles to living productive, independent lives as adults. Even today, 22 percent of students with disabilities fail to graduate high school compared with 9 percent of students without disabilities. While continuing to ensure access to education, America must begin to look at global issues affecting children with disabilities and their families in order to further level the playing field.

Poverty

Poverty remains a significant risk factor for disability. About 13 million children live in poverty in United States and about 1.9 million of these children have disabilities. This means that more than one out of every 10 children living in poverty has a disability. From 1983 to 1996, the prevalence of disability among children and young people under 21 increased from 5.8 to 6.8 percent, and experts link virtually all of this increase to poverty.

Even more stunning, about 48 percent of all children with disabilities are members of families living in poverty or part of the working poor. In addition:

- One million children with disabilities are on Supplemental Security Income (SSI)
- Poor families are twice as likely to have a child with a disability and 50 percent more likely to have a child with a severe disability
- More than 25% of families with children with disabilities are led by single parents

Families living in poverty often have difficulty providing basic care for their children with disabilities. Many do not have health insurance and rely on public programs such as Medicaid to provide services and supports for their children. In most states, however, Medicaid eligibility requires families to live at or below the federal poverty level. So, families seeking to lift themselves up out of poverty through hard work and ambition may be stymied by inadequate and unavailable private insurance. The lack of adequate healthcare can result in or aggravate disabling conditions throughout the course of child's life - from conception to 18 years.

While the federal government has played an increasingly significant role in public education, states and local school boards still largely determine the quality of public school curriculum, facilities and programs. Most public schools still receive the majority of their funding from local



sources, especially from local property taxes and state government. Despite significant investment by the federal government, services provided by schools in less affluent communities can vary greatly from others. This reality maintains a historic bias in American public schools towards children from wealthy families.

Further, families living in poverty are less likely to be able to effectively advocate for the best possible education for their children with disabilities. Many are not informed about the rights afforded to their children by law and are unable to afford an attorney to protect these rights when they are violated.

Race

Minority children are more likely to have disabilities. African American children, for example are nearly three times as likely to be labeled with intellectual disabilities. Native American children in six states are more than twice as likely to have learning disabilities. While these increased rates of disability may originate from socioeconomic inequalities, they contribute to further difficulties within the education system.



Minority children with disabilities all too often experience inadequate services, low-quality curriculum and instruction, and unnecessary isolation from their nondisabled peers. Moreover, inappropriate practices in both general and special education classrooms have resulted in overrepresentation, misclassification, and hardship for minority students, particularly black children.

— Source: *Racial Inequality in Special Education*, Harvard Civil Rights Project, 2002

Graduation rates among minority children continue to lag behind white children more than 50 years after the landmark case *Brown v. The Board of Education*. Notably, about one-third of students receiving special education services belong to a racial minority group.

Broken Families

Almost one-third of the more than 500,000 children living in foster care have disabilities, and the majority of those waiting to be adopted are children with disabilities. Most likely, these children have been exposed to conditions that undermine their chances for healthy development. A 2006 report from United Cerebral Palsy and Children's Rights found that children and youth in foster care are in worse health than those who are homeless or those living in the poorest sections of our inner cities. They have a higher likelihood of chronic medical problems, lifelong psychiatric and behavior issues, as well as permanent physical, cognitive and developmental disabilities than children in the general population.



Children with disabilities in foster care have poorer education experiences and outcomes, including higher rates of school transfer, absenteeism, tardiness, grade retention, achieving poor grades, dropping out, performing below grade level, receiving low state testing scores, exemption from state testing, suspension and expulsion, enrollment in vocational training, placement in more restrictive classrooms, and lower rates of doing homework, receiving help with school work from caregivers, being enrolled in college preparatory courses, receiving a high school diploma, or participating in postsecondary education.

— Source: *Forgotten Children, United Cerebral Palsy and Children's Rights*, 2006

While up to 40 percent of children in foster care may qualify for special education, just 16 percent actually receive services. In addition, children with disabilities in foster care lack consistent advocates and suffer from frequent placement changes. While input from parents is critical in the creation of an Individual Education Program (IEP), case workers, foster parents and birth parents are often poorly equipped to properly inform the process. Birth parents are often excluded, foster parents frequently do not understand their role, and caseworkers are too busy to dedicate significant time to a client's IEP. Meanwhile, frequent placement changes create havoc as each school may develop an independent IEP.

Public Perception and Tight Budgets

A dramatic increase in students enrolled in special education in recent years has fueled a growing debate regarding the burden special education places on the education system as a whole. Since 1977, the percent of students enrolled in special education has increased more than 5 percent to 13.7 percent in 2004. At the same time, the average annual cost for a student enrolled in special education is about \$17,000, while it costs about \$8,000 annually to teach a child without a disability. From 1977 to 2003 the cost of special education doubled to about \$34.3 billion.

Vocal critics of this growth in spending have particularly attacked parents whose children with disabilities attend private school paid for by public funds because the local public school system lacked the facilities or expertise to educate them. Outlandish stories of extravagant private education were called out by *The New York Times* and other high-profile publications, further encouraging a backlash against special education laws and funding. In reality, however, less than 90,000 children with disabilities, among more than 6 million total, attended private schools in this manner in 2004. In fact, public school systems are more likely to request placement in private schools than parents themselves.

Another common criticism cites the high cost of educating children with significant physical, cognitive or developmental disabilities. While students with severe disabilities are in fact far more expensive to educate, the growth in special education spending has little to do with this population. For example, some media outlets have cited growing numbers of students with



autism, but their numbers remain less than 0.3 percent of student enrollment and account for less than 0.45 percent of all spending. Rather, the majority of special education cost increases comes from exponential growth among students with learning disabilities, who are among the least costly to serve. According to the Hoover Institution, students in this category grew from 796,000 in 1977 to 2,848,000 in 2003.

The Hoover Institution report also makes clear that special education is not taking away more resources from general education. Like special education, total revenue for general public education also nearly doubled between 1977 and 2003, adjusted for inflation. Special education costs constituted roughly the same share of total public school revenue (8.3 percent) in 2003 as in 1977. While special education does consume more money over time, the relative financial burden of special education on public education has not increased because public schools are also receiving significantly more money.

That said, when Congress passed the Education of All Handicapped Children Act in 1975, it promised that the federal government would pay for 40 percent of all special education-related costs. This has never come close to happening. In the 2006 fiscal year, Congress funded just 18 percent of special education programs, continuing to burden states and communities with funding special education services mandated by federal law.

FULFILLING EMPLOYMENT

By Seth D. Harris

WORKING-AGE AMERICANS WITH DISABILITIES FACE THE SAME BILLS AS EVERY OTHER AMERICAN: rent or a mortgage, groceries, utilities, and medical bills. Yet, they have a great deal less money, on average, than working-age Americans without disabilities.

In 2005, the median annual household income of working-age Americans without disabilities was \$61,500. The median annual household income of working-age Americans with disabilities was \$35,000 – a deficit of more than \$26,000. These adult workers with disabilities were almost three times as likely to live in poverty as people without disabilities. And while many American workers are struggling to keep their financial heads above water, workers with disabilities are drowning in rough economic seas.

Adults with disabilities are drowning, in large part, because they can't find jobs to keep them afloat. They want to work. Sixty-three percent told the Harris Poll in 2005 that they want a paying job. Despite their eagerness to work, to secure the dignity that comes from holding a job, and to earn the money they need to pay their bills, adults with disabilities have been deprived of equal opportunity in the American labor market and the American workplace.

A Grim Numbers Game: Adults with Disabilities Can't Find Jobs

The federal government's statistical agencies have not yet perfected a way of measuring which workers have both a "disability" and a job. But every measure tells the same distressing story: adults with disabilities are employed at a much lower rate than adults without disabilities:

- **22% vs. 76%:** According to the U.S. Census Bureau's Current Population Survey (CPS), the 2005 employment rate for working-age Americans with a "work disability" was 22% while the employment rate for working-age Americans without a disability was 76%. Other CPS data found men with disabilities working about one-third as many weeks during 2002 as men without disabilities, while women with disabilities worked about one-quarter as many weeks as women without disabilities.
- **38% vs. 78%:** The Census Bureau's American Community Survey found that 38% of working-age Americans with disabilities and 78% of working-age Americans without disabilities were employed in 2005.
- **45% vs. 88%:** The Census Bureau's Survey of Income and Program Participation (SIPP) found that 45% of working-age Americans with "severe disabilities" were employed in 2002 compared with 88% of working-age Americans without disabilities.



In sum, the best case scenario is a 40 percent gap between the employment rate of adults with disabilities and those without disabilities. By any measure, adults with disabilities are employed at a significantly lower rate than their non-disabled friends and neighbors.

Even more troubling, these data offer only a recent snapshot at the end of a long, slow decline in the employment rate of adults with disabilities. Government statistics and academic studies consistently show that employment rates for men and women with disabilities have declined steadily since the recession of 1991 and 1992. Despite the Americans with Disabilities Act (ADA), a growing and activist disability rights movement, and rising awareness of their talents and abilities, adults with disabilities do not have equal opportunities in the labor market and the workplace.

How are adults with disabilities paying their bills? The unfortunate answer is that they have been forced to rely more and more on government assistance.

The two largest federal programs providing cash assistance to working-age adults with disabilities are the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. During 2004, the Social Security Administration paid a total of \$78 billion in SSDI benefits to adults with disabilities for the year and another \$2 billion each month in SSI benefits to adults with disabilities or blindness. Workers' compensation and unemployment insurance programs, state and private temporary and long-term disability insurance programs, food stamps, veterans' disability compensation programs, and Temporary Assistance for Needy Families also provide income support to some adults with disabilities depending upon their circumstances.

SSDI provides cash support to people with substantial work histories who cannot engage in "substantial gainful activity" anywhere in the national economy because of a physical or mental impairment that is expected to either last one year or longer or cause death. Nearly 6.8 million workers with disabilities received SSDI payments in 2006. Almost 4 million people with disabilities or blindness who do not have substantial work histories received SSI payments. Again, these data offer only a recent snapshot of these two programs. The larger picture shows explosive growth in the SSDI program both with respect to the number of people receiving benefits and the total amount of money being paid.

Despite the growth in these programs, benefit amounts have remained small, and neither SSDI benefits nor SSI benefits provide adequate sustenance for adults with disabilities and their families. Male SSDI beneficiaries received an average monthly payment of \$1,128.32 in December 2005. Female SSDI beneficiaries received only \$846.26. Payments to adults with disabilities or blindness from SSI were even smaller: only \$446.55 per month, on average, at the end of 2004.

The fortunes of adults with disabilities in the labor market affect them and their families most, but they also place burdens on other Americans. Employees, employers, and self-employed individuals pay taxes to the federal government's Disability Insurance Trust Fund – more than \$86 billion in 2005 – to support the SSDI program. Everyone who pays federal income taxes or other taxes to the federal treasury supports the SSI program. At the same time, many adults with disabilities do not pay payroll taxes, or pay a full share of income taxes, because they do not have a job, so the tax burden falls more fully on others.

More importantly, our society squanders the creativity, energy, and productivity of many adults with disabilities who are forced to be passengers in the economic ship when they would rather pick up a laboring oar and help row. Whether adults with disabilities will be able to pay their bills

is not the only question. We should also ask whether all of American society will be able to sail across the rough seas of global competition without the help of a sizable portion of America's working-age population.

The Supply Side of Unequal Job Opportunities: Because Sometimes the Rational Choice is Not to Work

Most workers would take a good job if it were offered to them. The decision might depend upon how much the job pays or how many hours of work the job requires. The length of the commute from home to the job might be a factor, along with other working conditions, like the office or factory environment and the number of vacation days. The worker's sense of whether s/he can succeed in the job and whether there will be opportunities or advancement may also play a role in the worker's decision. Generally speaking, workers decide which job offer they will accept based on whether the job is a good fit for their lives and whether their skills and knowledge are a good fit for the job.

For adults with disabilities, employment decisions are much more complicated. Certainly, all of the factors that are relevant to their non-disabled friends and neighbors also matter to adults with disabilities. But some of these factors affect them differently. Health insurance looms larger. The fit between jobs and skills and knowledge is more complicated. And adults with disabilities face the added barrier of discrimination. Discrimination haunts many workers in the American labor market and workplace. But people of color, women, religious Americans, and workers from varied national origins can look to broadly effective federal anti-discrimination laws to protect them. Workers with disabilities cannot.

Supply Factor #1: Health Insurance

Approximately 47 million Americans do not have health insurance – an increase of 6.8 million since 2000. The single largest contributor to the rising number of uninsured Americans is the decline in the percentage of workers getting health insurance from their employers.

- In 1987, 70% of Americans had employer-provided health insurance. In 2004, only 59.8% of Americans got health insurance from their employers.
- 40% of all employers provide no health insurance coverage at all. The coverage rate has declined since 2000 because smaller employers are increasingly unlikely to offer insurance.
- Employees who have kept their employer-provided health insurance saw their share of the costs of that insurance nearly double between 2000 and 2006.

The lack of health insurance is a serious problem for any working family. For adults with disabilities, having no health insurance can mean irrevocable deterioration in their physical and mental health. Many people with disabilities need regular care and supervision of their conditions by doctors and specialists. The requisite care may range from routine blood work to rehabilitation services, to electrocardiograms, to filling prescriptions, to regularly scheduled visits with a psychiatrist. Without health insurance, patients with disabilities must pay for these services out of pocket and, as a result, may have to forego or delay seeking the medical care they need. The effects on their health can be dire.

But a complete lack of health insurance is not the only potential danger adults with disabilities must take into account when deciding whether to pursue a job. Even if they can find a job with health benefits despite the shrinking number of employers that provide them, two other risks remain.



The first risk is that the employer will not provide health insurance that addresses the particular needs of an employee with a disability. People with disabilities are more likely to need specialized healthcare and to have chronic medical conditions requiring more services, like more frequent doctors visits or hospitalizations and larger amounts of prescription drugs. But private health insurance plans are structured around providing insurance to relatively healthy people and, as a result, do not take the needs of people with disabilities into account. Services like prescription drugs, mental health services, rehabilitation services, and personal care services that are essential to many adults with disabilities can be subject to annual lifetime limits or may not be covered by private insurance at all. By contrast, Medicaid pays for disability-related services like case management, rehabilitation, and personal care services that private insurance carriers typically do not.

The second risk is that an employee with a disability could lose his job and his health insurance along with it. Studies show that losing a job or changing jobs is a leading explanation for workers' lack of health insurance. The COBRA system which allows some laid off workers to buy into their former employer's health insurance plan has proven to be too limited and too expensive. In addition, an employee with a disability might find his job transformed from full-time with benefits to part-time without benefits. COBRA offers no protection, and no health insurance, to these workers.

In light of these substantial risks associated with employer-provided health insurance – the risk of no health insurance, the risk of losing health insurance, and the risk of inadequate health insurance – adults with disabilities should be expected to look elsewhere for the reliable, comprehensive health insurance they need. How can they find it? Once again, by relying on government assistance.

SSDI and SSI beneficiaries are entitled to health insurance coverage from the government. SSDI beneficiaries are eligible for Medicare beginning 29 months after they begin receiving their benefits. SSI beneficiaries are a “mandatory eligibility group” for Medicaid – that is, states are required to provide them with health insurance under the Medicaid program. As long as an adult with a disability remains eligible for SSDI or SSI benefits, government provides guaranteed health insurance. Thus, adults with disabilities have a substantial incentive to remain on SSDI or SSI rather than seeking a job: health insurance that cannot be lost or taken away.

Some help with this issue has been provided by Congress' passage of the Medicaid “buy-in” option in the Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act (TWWIIA) in 1999. These programs, and others instituted by a number of states, provide workers with disabilities a mechanism to pay, on a sliding scale, reasonable premiums for their Medicaid healthcare benefits for a period of time after they become ineligible for Medicaid benefits due to the rise in their income.

Supply Factor #2: Workplace Discrimination

The ADA uses a definition of “disability” drawn from the Rehabilitation Act of 1973 which had proved both broad and inclusive: “a mental or physical impairment that substantially limits one or more of the major life activities [of an individual.]” This definition reflected the ADA's authors' belief that “disability” is not inherent in the individual. Rather, “disability” arises only when some human condition comes into contact with an environment – a workplace, for example – that will not accommodate it. The problem is that human variation is endless and workplaces take many, varied physical and organizational forms. So, the ADA's authors used a flexible definition of “disability” that left courts with room to adapt the law to the facts of particular cases.

For the same reason, the ADA does not codify a particular approach to how each worker with a disability should be fitted into any particular workplace. Rather, the ADA requires employers to make “reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability... , unless [the employer] can demonstrate that the accommodation would impose an undue hardship on the operation of the business of [the employer].” Again, this is a flexible standard which vested courts with broad discretion to achieve the goal of integrating adults with disabilities into the workplace and the workforce.

Rather than using the discretion Congress gave it to advance the goal of equal opportunity, the Supreme Court has sharply curtailed the number of adults with disabilities who are protected by the ADA, in general, and its employment provisions, in particular:

- **Corrective Measures:** In *Sutton v. United Airlines*, *Albertson’s, Inc. v. Kirkingburg*, and *Murphy v. United Parcel Service*, the Court held that “corrective measures” undertaken to address an impairment’s effects – for example, people with epilepsy who take phenobarbital to arrest their seizures, people with hearing impairments who use hearing aids – must be taken into account when determining whether that impairment “substantially limits” a “major life activity.” As a result, the choice to correct an impairment’s effects can mean exclusion from the ADA’s protections against discrimination.
- **“Working”:** The Sutton Court also held that adults with disabilities are not substantially limited in the major life activity of “working” unless they have been excluded from a “broad class of jobs” – essentially, any job they are able to perform in their local labor market. Workers whose impairments substantially limit their ability to perform their own jobs and similar jobs may not have a “disability” and, therefore, may be excluded from the ADA’s protections.
- **“Tasks Central to Most People’s Lives”:** In *Toyota Motor Manufacturing v. Williams*, the Supreme Court held that the central inquiry when determining whether an individual’s impairment substantially limits a major life activity “must be whether the claimant is unable to perform the variety of tasks central to most people’s daily lives, not whether the claimant is unable to perform the tasks associated with her specific job.” Thus, a worker whose severe carpal tunnel syndrome and tendonitis starkly limited her functioning both at work and at home did not have a “disability” and could not sue under the ADA. Why? Because she could brush her teeth, tend her garden, and fix her breakfast.

As a consequence of these Supreme Court decisions, lower federal courts have consistently declared that people with epilepsy, heart disease, diabetes, and other serious impairments do not have a “disability” for ADA purposes. The Supreme Court also categorically excluded all state employees with disabilities from the ADA’s protections in *Trustees of the University of Alabama v. Garrett*. So, after *Garrett*, it is entirely legal under federal law for state employers to discriminate against workers with disabilities even if those workers fit within the ADA’s whittled down definition of “disability.”

Workers excluded from the ADA’s protections are not merely deprived of a legal basis for requesting workplace accommodations. Rather, as former Congressman and chief House sponsor of the ADA in 1990, Tony Coelho suggested, the Supreme Court has legalized all forms of discrimination against these workers with disabilities under federal law. It is entirely legal to fire, demote, or harass a worker with heart disease, epilepsy, asthma, carpal tunnel syndrome, diabetes or any other impairment simply because the worker has that impairment, as long as a court finds that the worker does not have a “disability.”



The discriminatory conduct might be outrageous, egregious, and offensive to any American's sense of decency. It would not matter. These workers simply cannot seek justice from the law Congress enacted to protect them. Nonetheless, in every year since 1994 when the ADA was fully implemented, the U.S. Equal Employment Opportunity Commission and its state counterparts have received more than 30,000 charges from workers with disabilities that employers had discriminated against them.



James Todd was forty-two years old. He had epilepsy from the time he was five years old. James also began taking medication at the age of five which controlled - but did not cure - his epilepsy. Even with the medication, he had "light" seizures approximately once per week. Three or four seizures came while he was working as a "stocker" for Academy earning about \$5 per hour.

James suffered his first seizure at work a few weeks after being hired. He met with two supervisors and explained that he suffered from epilepsy. He asked if his condition would be a problem. His supervisor stated that it would not be a problem if James informed the other supervisor were there to be another seizure.

James missed a week of work due to a stomach flu. When he returned to work the following Monday, he was fired. The reason given was that James violated a policy requiring termination of any employee who failed to report to work for three consecutive days without notifying his supervisors. The problem was, this reason was not true. James had placed a phone call to his supervisor every morning of his illness and left a voice mail message informing the supervisor that he was sick and would be forced to miss work.

The general rule in employment discrimination cases is that disproving an employer's reason for firing an employee offers enough evidence to allow a jury to decide if the employer illegally discriminated. But James Todd's case - his argument that his employer discriminated against him because he has epilepsy - never made it to a jury. The judge in the case ruled that James did not have a "disability" and, therefore, could not sue under the ADA. James was thrown out of court even before he could prove that he suffered discrimination.

— Source: *Todd v. Academy Corp.*, 57 F. Supp. 2d 448 (SD Tex.1999).

Supply Factor #3: Poor Educational Opportunities

The American economy has undergone and continues to undergo a significant restructuring. The kinds of jobs that are and will be most readily available for the foreseeable future have changed from the jobs our parents knew. The United States had been a goods-producing economy. Now, it is increasingly a service-providing economy. The number of goods-producing jobs in manufacturing, agriculture, mining, and other similar or related industries has been stagnant or declining for more than 20 years. The U.S. Department of Labor's Bureau of Labor Statistics (BLS) expects these jobs to decline further by 2014. By contrast, service-provision industries have generated and are expected to generate the greatest jobs growth through 2014.

Will adults with disabilities – already struggling to find jobs and avoid reliance on government assistance – be left behind even further by our economy's transition from goods production to service provision? The answer depends, in part, on educational opportunities.

The college degree is the new high school diploma. In 2005, workers with high school diplomas had an 80 percent higher unemployment rate than workers with bachelor's degrees. The unemployment rate for workers who dropped out of high school was nearly triple that of workers with bachelor's degrees. More education means a much greater likelihood of getting and keeping a job. In addition, a worker's education drives earnings.

Twelve of the 20 occupations expected to grow fastest by 2014 require a bachelor's degree or an associate degree. The average hourly wage in these twelve occupations is currently \$26.58.

The average hourly wage in the eight fastest-growing occupations that do not require a bachelor's or associate degree is \$16.37 – more than \$10 per hour less – and ranges as low as \$8.34.

While success in the schoolhouse is essential to success in the workplace and the labor market, there is powerful evidence that students with disabilities are being left behind. Adults with disabilities have less education than adults without disabilities. In 2005, adults with disabilities were more than twice as likely to have less education than a high-school degree than were adults without disabilities. On the other hand, adults with disabilities were only one-third as likely to have a bachelor's degree or more education. Even if they can overcome the problems associated with health insurance, discrimination, transportation, and other issues, many adults with disabilities do not have the education they need to compete for good jobs in the American labor market.

As we have previously discussed, Congress enacted the Education of All Handicapped Children Act in 1975, and subsequently re-tooled and re-named it the Individuals with Disabilities Education Act (IDEA), to address these education deficits. The IDEA's purpose is to assure students with disabilities a free and appropriate public education.

Since 1976-77, the number and percentage of public school students receiving services under the IDEA has grown steadily. There is also evidence that IDEA has produced better outcomes for students with disabilities. Since 1992, both the number and percentage of IDEA-served students who have graduated from high school with a diploma or a certificate has grown modestly. While the number of these students who dropped out of high school has risen and fallen with the times, the percentage of dropouts among IDEA-served students has declined modestly in recent years.

But these high school graduates with disabilities compete against their non-disabled classmates when they enter the labor market. The percentage of high school dropouts among Americans between the ages of 16 and 24 has also declined slightly. And, more important, a far smaller percentage of high school students without disabilities drop out. In 2004-05, 10 percent of



students without disabilities dropped out of high school. In that same year, even after a long and substantial decline in dropout rates, 28 percent of students exiting an IDEA program dropped out of high school. So, students with disabilities have been doing better, in part due to the IDEA, but they are still much more likely to have less than a high school diploma and, as a result, face better educated, better credentialed competition in the labor market.

High school graduation rates are only the beginning. When they finish high school, these graduates with disabilities compete against their non-disabled classmates when they enter the labor market. Competing for more and better jobs, particularly as the United States continues its transition to a service provision economy, calls for at least some college education or, better yet, a bachelor's degree. The good news is that students with disabilities who earn a bachelor's degree find roughly the same success as their non-disabled labor market competitors. Baccalaureates with and without disabilities had generally comparable employment rates and salaries and they enrolled in graduate school at similar rates, at least within the first year after earning a bachelor's degree. Thus, clearly workers with disabilities can compete successfully in the labor market if they have a post-secondary education. The bad news is that students with disabilities are much less likely to earn a college degree than students without disabilities.

The Demand Side of Unequal Job Opportunities: Because You Can't Work if Employers Won't Give You a Job

The low employment rate among adults with disabilities is not merely a function of whether they are ready and able to work. Supply is only one half of the equation. Demand is the other half. Adults with disabilities cannot find jobs if employers will not hire them.

Even the federal government has not lived up to its promise to hire workers with disabilities, and the private-sector has followed its example. Instead of providing abundant jobs, employers offer excuses for not hiring large numbers of workers with disabilities. Perhaps the most commonly heard excuse is that hiring workers with disabilities is too expensive because they need expensive accommodations. Certainly, some workplaces, work schedules, and work organizations need to be modified to make room for workers with disabilities. Some do not. But even where accommodations are needed, the evidence strongly suggests that, on average, they are inexpensive. The evidence also suggests that, in many circumstances, employers can benefit from accommodating their employees with disabilities.

Demand Factor #1: The Federal Government's Broken Promise

In March 1961, President John F. Kennedy issued Executive Order No. 10925 requiring federal contractors to "take affirmative action to ensure that applicants are employed, and that employees are treated during employment, without regard to their race, creed, color, or national origin." This "affirmative action" mandate was not understood to require any special measures to diversify the American workforce. It merely required racially neutral hiring and employment practices. But merely banning race-conscious employer decision-making proved to be an inadequate solution to the problem of unequal employment opportunity for African-Americans. As President Lyndon Johnson proclaimed at Howard University in his 1965 commencement address, "We seek not just freedom but opportunity. We seek not just legal equity but human ability, not just equality as a right and a theory but equality as a fact and as a result... [E]qual opportunity is essential, but not enough, not enough."

So, in September 1965, President Johnson issued Executive Order No. 11246 to reaffirm President

Kennedy's "affirmative action" mandate, but also to re-define the phrase to require federal contractors to undertake "reasonable efforts within a reasonable time" that would increase the representation of African-Americans among their employees. But President Johnson did not stop at signing a piece of paper. In 1968, he summoned fifteen top business leaders to the White House for a steak lunch and a classic Johnsonian arm-twisting session. President Johnson pledged federal funds to employers that would train disadvantaged African-Americans to work. In return, he demanded "your commitment to make taxpayers out of these tax-eaters." The result was the National Alliance of Businessmen (later the National Alliance of Business), billions of dollars in federal job-training money, and a nationwide effort to recruit employers to the task of increasing the employment rate among African-Americans.

Although the low employment rate among adults with disabilities at the start of the 21st Century harkens back to the labor-market problems faced by African Americans during the civil rights era, the federal government has not yet forged a Johnson-style, large-scale effort combining cash, cajoling, and creative use of the presidential pulpit to expand employment opportunities for adults with disabilities. Some efforts have been made. In March 1998, President Bill Clinton signed Executive Order No. 13078 creating the National Task Force on the Employment of Adults with Disabilities (PTFEAD). Chaired by then Secretary of Labor Alexis Herman, the Task Force's charge was to make sense of a confused web of often contradictory federal programs relating to adults with disabilities with the goal of "bring[ing] adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population." Unfortunately, the PTFEAD did not survive the 2000 presidential election and could not, as a result, achieve all of its goals. Instead, President George W. Bush replaced it with his own interdepartmental effort, the New Freedom Initiative.

But the unmet promise of better coordinated federal disabilities programs has not been the only failure. President Clinton also issued Executive Order No. 13173 in July 2000 to require federal executive branch agencies and departments to hire an additional 100,000 workers with disabilities over the following five years. His idea was that the federal government should set the standard for more hiring by private-sector employers. Instead, the executive order had no real effect, even though it remained in force after President Bush took office in January 2001. In 2004, the number of federal employees with disabilities had increased by less than 5,000 from the historically very low level to which it had fallen in 2000. Looking only at this narrow time frame, the federal government fell short of its promise by 95,000 federal employees with disabilities. But broadening the time frame, the story gets much worse. The number of federal employees with disabilities had declined by almost 20,000 between 1994 – when it hit its historic high-water mark – and 2004. The federal government has set a standard for private-sector employers – that is, indifference and broken promises to workers with disabilities.

Even if the federal government's word could be trusted, the federal executive branch's departments and agencies could not possibly hire enough adults with disabilities on their own to dramatically improve their overall employment rate. The private sector is a much larger reservoir of potential jobs. But the federal government has an important role to play in encouraging the private sector to change its behavior, as well.

Demand Factor #2: Workplace Accommodations

The ADA requires employers to provide "reasonable accommodations" to job applicants and employees with disabilities as long as the accommodations will not cause the employers "undue hardship." An accommodation can be any change to a physical environment, work schedule, or job responsibilities that allows a worker with a disability to perform the essential functions of his job or to enjoy the same privileges and benefits as his co-workers. Accommodations range from a



ramp for wheelchair users to a flexible work schedule that facilitates doctors appointments to an ergonomic keyboard that ameliorates carpal tunnel syndrome to periodic breaks that allow a diabetic to take her insulin.

Human beings experience a wide variety of impairments that interact differently with different kinds of jobs and workplaces. As a result, accommodations differ from employee to employee and from workplace to workplace. An employee with Tourette's Syndrome who occasionally shouts or screams, but who works in a private office or a loud manufacturing facility, presents a different accommodation challenge than the same employee working in a library. Workplace accommodation is a case-by-case endeavor.

In order to be "reasonable," and not impose an "undue hardship," the accommodation must be effective and its costs must not be substantially disproportionate to its benefits. But the accommodation's costs and benefits are not the only consideration. The ADA also takes the employer's financial resources, the nature of its operations, and the impact of the accommodation on the business into account. Wealthy corporations like Microsoft might be required to provide accommodations that a neighborhood electronics store would not.

Some economists argue that the ADA's accommodation mandate makes hiring workers with disabilities more expensive and, therefore, less rational for employers. Employers choose to hire workers without disabilities, rather than workers with disabilities, because workers without disabilities do not need costly accommodations, according to this argument. Some economists have used this argument to suggest that the ADA is partly to blame for the low employment rate among adults with disabilities.

This argument has several flaws. As a starting place, many questions regarding accommodations do not arise in the context of choosing between equally qualified entry-level workers with and without disabilities. A large majority of the ADA charges filed with the EEOC come from incumbent employees, not applicants for jobs. Further, data drawn from the 1992 Health and Retirement Study, a survey of Americans between the ages of 51 and 61, found that 36 percent of people in that age range with work-limiting impairments acquired those impairments because of an accident, injury, or illness at work. Thirty-seven percent (37%) of SSDI recipients in the same age group were disabled because of an accident, injury, or illness at work. The accommodations questions presented by these employees involved staying in their current job or, at least, working for their current employer rather than acquiring a first-time, entry-level job. Keeping a skilled, knowledgeable, and valued incumbent employee is quite different, and much more valuable to an employer, when compared with choosing new employees from the entry-level job market.



Jean Shortall, an independent contractor in Arlington, remembers when she worked in garment design and needed a special chair. Shortall had polio as a child and now walks with crutches or rides an electric scooter. As a clothing designer, she had to drape material high and low on mannequins, and she did not have an easy time constantly shifting positions.

The solution? A simple drafting chair that has a control to raise and lower the seat. "That

cost my employer \$100, but it meant the difference between my working or not," she said.

— Source: *The Thought Counts – But Does it Fit? The Washington Post*, August 25, 2002

In addition, employers have free access to information about workplace accommodations. The Job Accommodation Network (JAN) is a free service sponsored by the U.S. Department of Labor's Office of Disability Employment Policy providing individual telephone consultations about workplace accommodations to employers and employees. JAN currently fields about 32,000 inquiries per year. A team of researchers from Syracuse University, the University of Iowa, and West Virginia University surveyed employers that contacted JAN between January 2004 and June 2005. The survey's goal was to learn more about accommodations' costs and benefits.

Nearly 85 percent of employers contacted JAN in search of information about accommodating an incumbent employee, not a new hire. The survey of these employers found:

- **No Costs:** Approximately half of accommodations had no cost.
- **Low Costs:** Of those accommodations that had costs, almost three-quarters had a first-year cost of \$500 or less. The median first-year cost was \$500.
- **Likely Benefits:** More than 90% of employers reported that providing the accommodation benefited the company by allowing it to retain and/or promote a qualified employee.
- **Long List of Benefits:** Employers that provided accommodations also reported other direct benefits: no costs of training a new employee (59.5%); saving on workers compensation or insurance costs (43.0%); increasing the accommodated worker's productivity (76.7%); improving the accommodated worker's attendance (53.3%); increasing the diversity of the company (41.4%), and "other" direct benefits (20.1%).
- **Large Benefits:** Of the employers that provided economic estimates, more than half reported their company benefited by more than \$1,000 from providing the accommodation. The median direct benefit to the company was \$1,800.
- **Net Benefits in Most Cases:** Of the employers who provided economic estimates, an overwhelming majority (81.3%) estimated that the accommodation's benefits offset the accommodation's costs. Over half (61.3%) reported that benefits outweighed costs. One-fifth (20.0%) reported benefits equal to costs. Only 18.7% reported accommodation costs exceeding accommodation benefits.

This recent study's findings are consistent with a 1996 study of JAN's clients, as well as a study of one employer's use of accommodations both before and after the ADA became law.

Demand Factor #3: Paid Leave

The Family and Medical Leave Act (FMLA) provides eligible employees of larger employers (i.e., 50 or more employees) with 12 weeks of unpaid leave to care for a newborn or newly adopted child (or a newly placed foster child), or a seriously ill child, spouse, or parent, or to care for their own serious health condition. During leave periods, employers must continue to provide health insurance. They must also assure that the leave-taking employee can return to his job or a substantially equivalent job.



Even though it arrived on the heels of the ADA, the FMLA was principally focused on solving the problem of parents struggling to balance their work and family lives. When President Clinton signed the FMLA into law on February 5, 1993, he did not mention how people with disabilities might benefit. He stood alongside a working mother and announced that “[n]ever again will parents have to fear losing their jobs because of their families.”

Equal attention was not paid to the requirement that employers provide leave to allow their employees with disabilities to take a few hours off every week for physical therapy, chemotherapy sessions or other medical care for physical or mental impairments.

But employees with disabilities understood the FMLA’s importance to their working lives. According to a 2000 study for the U.S. Department of Labor, about 16 percent of all American employees have taken leave pursuant to the FMLA. Fully 52 percent of these leaves from work allowed employees to care for their own health, rather than to care for a child or a sick relative. These data suggest that the FMLA assures some employees with disabilities have access to a useful workplace accommodation: leave from work. And, once again, this accommodation is not expensive. A large majority of employers reported that compliance with the FMLA was either “very easy” or “somewhat easy.”

The problem is that the FMLA’s assurances are limited. The FMLA does not cover everyone. Only about 11 percent of private-sector establishments employing about 58 percent of all employees were covered by the FMLA in 2000. Also, many employees working for covered employers also are not eligible to take protected leave. The FMLA requires that an employee work one year, and a minimum of 1,250 work hours, before taking leave. Between 18.5 and 24.4 million employees worked for covered establishments in 2000, but were not eligible, according to the Labor Department study. For a very large number of employees, the FMLA does not assure they will get time off from work to attend to their physical or mental health needs.

The FMLA’s gaping coverage holes are not the only problem. The FMLA requires only unpaid leave, not paid leave. As a result, many employees who are covered by the law cannot use their legally protected leave because of family economics. Roughly 3.5 million employees needed leave during the 18-month period of the Labor Department survey and could not take it. Nearly half of these employees needed leave to care for their own serious health condition and could not take it. More than three-quarters of the employees who needed but did not take leave reported that they could not afford to take unpaid time off from work. More than half of employees who took FMLA leave worried about not having enough money to pay their bills.

Employees are often forced to spend their limited sick, vacation, or personal leave benefits for reasons covered by the FMLA. Yet, according to a Bureau of Labor Statistics study looking at the period from 1996 to 1998, nearly 59 million workers did not have access to designated, paid sick leave days. As a result, employees who live from paycheck to paycheck cannot take time off from work, or may be forced to take less time off from work than they need, regardless of what the FMLA says.

As with government-assured healthcare, the United States lags far behind the rest of the developed world in guaranteeing that workers get paid leave to care for their own serious health conditions. Only five states – California, Hawaii, New Jersey, New York, and Rhode Island – currently provide a system of paid leave for short-term disability. By contrast, nearly every other industrialized country in the world provides paid leave for family and medical purposes, particularly taking time off from work to attend to the employee’s own impairment. A national paid leave policy would help many employees with disabilities keep their jobs while taking the leave they need to care for their impairments.

In 2007, Senators Chris Dodd (D-CT) and Ted Stevens (R-AK) introduced legislation that would provide up to 8 weeks of paid leave to workers needing time off due to the birth or adoption of a child, to care for a child, spouse or parent with a serious illness or to care for their own serious illness. The Family Leave Insurance Act of 2007 would establish a Family Leave Insurance Fund, through which employees, employers and the federal government share the cost of providing compensation during times of family crisis.



A HOME OF YOUR OWN



Anthony White is just 26, and in the past year has lived in two hospitals and now a nursing home in Washington, D.C. He came to the nursing home because he needed medical care, but he stays — largely because he has no other place to go.

White was born with spina bifida and uses crutches, leg braces and a wheelchair to move his large and heavy body. He was just 16 when his mother died, and White moved to his grandmother's house.

Living conditions there were far from ideal — he slept on a blanket on the floor, and had to drag himself up the narrow stairwell to the second-floor bedroom. That opened up sores on his feet, landing White first in the hospital and later in the nursing home where he still lives.

"His situation is unfortunately very common," says Marjorie Rifkin of University Legal Services, a public law firm that represents the disabled. She tells Shapiro there are many clients in desperate need of housing — but there's too little government-subsidized housing available.

"And as a result, they end up spending years on the waiting list for public housing or subsidized Section 8 housing, and we're seeing fewer and fewer of those units available to people living on extremely low incomes," she says.

— Source: Report by Joe Shapiro, National Public Radio, June 17, 2003

For millions of Americans, the place we call home, whatever and wherever it may be, is a defining characteristic of life. It is where we build our most cherished relationships, store our most prized possessions, and invest our hard earned wealth. Bricks and mortar, however, are just a small part of the larger community where we work, live, learn, socialize and contribute. For decades, even centuries, Americans with disabilities have been denied inclusion in communities. And the place people with disabilities call home can be the point of debarkation, where they are separated from society for life.

Since the mid 19th century, millions of Americans with disabilities have been sent to live in large institutionalized settings without their consent - warehoused in substandard living conditions, denied educational and employment opportunities, and subjected to neglect and abuse. In many cases, this institutionalization was sanctioned by physicians and state governments. Since the 1970's when the Willowbrook story was exposed, public awareness of appalling conditions in large institutions has been raised, over time, has led to significant victories in public policy and the courts, and the shift from institutional to community living has been ongoing.

During the last century, every state in the country passed laws that encouraged or forced the institutionalization of people with disabilities. This fervor was motivated in part by a social philosophy called eugenics, which advocated for the improvement of human hereditary traits through intervention, including relatively benign procedures such as prenatal testing and the extreme, such as forced sterilization. Eugenics gained acceptance around the globe in the late 19th century and was championed by thought leaders such as Alexander Graham Bell and Adolf Hitler, who carried the concept to an absolute extreme. Here in the United States, the eugenics movement scorned people with disabilities as menaces to society. In 1927, the U.S. Supreme Court even upheld a Virginia law compelling the sterilization of residents in state mental institutions.

During the last century, despite an environment that encouraged the institutionalization of people with disabilities from the cradle to the grave, many families still took their new born children with developmental disabilities home. Until the mid 1970s, however, these children had little or no access to community-based services and supports to help them learn and grow like their non-disabled peers and, even today, shortfalls in services continue. As a result, many grew to become adults dependent on their families for shelter and support. And they faced institutionalization later in life when their parents or siblings could no longer care for them. This remains a major challenge within the disability community as parents die or become unable to provide care or financial support for their adult children with disabilities. Many leave little or no support structure for their children to remain independent participants in their communities.

People with disabilities and their families initiated a movement against institutionalization in the 1970s. Supported by the media, they raised public awareness of appalling conditions in large institutions such as the Willowbrook State School in New York. Over time, such exposure led to significant victories in public policy and the courts.

Today, while people with disabilities have more opportunity than ever to live independent and productive lives in their communities, they face growing challenges that may lead to a resurgence of state-supported institutionalization. Poor educational opportunities and outcomes, rampant poverty, high unemployment and dependence on public benefits continue to prevent many people with disabilities from achieving independent and productive lives. Complicating matters, property values and average rent prices have skyrocketed in recent years, deepening the shortage of affordable, accessible housing in the United States.



Therefore, access to affordable, accessible leased housing, including units subsidized by government or private organizations, is critical to people with disabilities seeking to live and work in their communities. While only a fraction of the 54 million Americans with disabilities depend on public housing, they are among the most at risk to become institutionalized or homeless. Accordingly, a discussion around housing for people with disabilities must begin with public housing in the United States, including its history, inclusion of people with disabilities and outlook for the future.

Public Housing in the United States

In 1937, the United States government began a program to assist millions of poor Americans living in substandard housing because of the Great Depression. The economic collapse led to an epic housing crisis that was compounded by years of inadequate and substandard urban housing for poor and middle class families. With unchecked unemployment and poverty, the population living in slums and tent cities surged throughout the 1930s, and the living conditions were often dangerous and unsanitary. In addition to programs to support homeownership and rural housing, Congress empowered the new Federal Housing Administration to give loans to local housing agencies to construct new low-rent and safe housing. This led to widespread urban renewal efforts over the next decade.

Though the country's commitment in World War II slowed the construction of affordable urban housing, a revival occurred in the 1950s. Funding was allocated not only for the construction of new public housing, but for the rehabilitation and conservation of deteriorating areas. In addition, the Housing Act of 1956 added special provisions to give preference to the elderly and authorized relocation payments to people, mostly very poor, who were displaced by urban renewal efforts.

In 1961, the Section 23 Leased Housing Program was implemented as an amendment to the U.S. Housing Act of 1937. The predecessor to Section 8, Section 23 provided funding to local housing authorities to subsidize rent for people with low income. The housing authority selected eligible families from a waiting list, determined appropriate rent payments, and signed a lease on behalf of the tenant. Local housing authorities paid the difference between what the family could afford and the total rent due.

On April 4, 1968, Dr. Martin Luther King was assassinated in Memphis, triggering race riots across the country. Almost immediately, President Lyndon Johnson pushed Congress to take action on housing legislation that had languished before lawmakers since 1966. Part of Johnson's Great Society, the Fair Housing Act prohibited discrimination on the basis of race, religion and gender in the sale, financing and leasing of public and private housing. Johnson saw the law as a tribute to King, as African Americans had long experienced discrimination in housing. The U.S. House of Representatives acted quickly, as did the Senate, which passed the bill without debate. Just a week after King's death, Johnson signed the legislation into law. Despite its groundbreaking protections, however, this new law did not prohibit discrimination on the basis of disability.

In the early 1970s, a new housing crisis emerged as costs rose sharply. While the inventory of housing had improved, the poor and middle class were spending a significant percentage of their income on housing. The Housing and Community Development Act of 1974 began to address the growing inequity by transforming the Section 23 program into the broader Section 8 program, which calculated that residents should pay no more than 30 percent of their income on housing. Importantly, this standard remains today.

The Section 8 program is divided into two equally important components, project-based and tenant-based vouchers. The project-based program applies to 25 percent of all Section 8 vouchers and corresponds to specific housing units, meaning that the benefit stays with unit rather than the tenant. The tenant-based program, on the other hand, provides a voucher directly to eligible families and it is portable from unit to unit, and theoretically from state to state. Once a voucher is issued, an eligible family is responsible for finding housing that accepts Section 8 vouchers and landlords cannot charge more than Fair Market Rent, which is determined annually by the Department of Housing and Urban Development in each metropolitan area. The voucher pays for the cost of rent over 30 percent of the family's gross income.

All housing supported by the Section 8 program must meet federal housing quality standards. In addition, federal benefits are distributed and managed through local housing agencies.

Importantly, landlords are not required to accept Section 8 vouchers, which may contribute to a shortage of available units and the segregation of low-income housing. While some landlords may perceive Section 8 tenants as more likely to damage property or cause disturbances, others may welcome Section 8 tenants because of the guaranteed revenue.

Today, Section 8 supports about 1.4 million households nationwide. However, thousands of people are on waiting lists because the number of available vouchers is capped based on available funding, not need. It is not uncommon for families to wait three to five years and some housing authorities will periodically close their waiting lists to new applications because of the backlog.

In 1973, Congress passed the Rehabilitation Act and, for the first time, prohibited discrimination on the basis of disability. Section 504 banned the discrimination of people with disabilities by any program or entity receiving federal funding, including federally-funded public housing programs.



No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

— Source: Section 504 of the 1973 Rehabilitation Act

The purpose of the law was to encourage participation and equal access in public accommodations. Its profound applications included federally-funded public housing programs, which had denied the participation of some people with disabilities through inaccessible housing units and unsupportive policies. However, the law provided no new funding to implement change and really applied in principle only. In addition, federal regulations that forced compliance with this new anti-discrimination policy weren't executed until 1977.

It would take another 15 years for the federal government to provide more explicit protections for people with disabilities in housing. In the fall of 1988, President Ronald Reagan signed the Fair



Housing Amendments Act, which expanded upon the 1968 law to explicitly prohibit discrimination based on disability. The result was an important shift that protected the rights of people with disabilities to obtain accessible housing.

Consistent with the spirit of Section 504, this new law prohibited discrimination and the refusal of landlords or property owners to make reasonable accommodations. Providers, both public and private, could no longer refuse or place conditions on residency for people with disabilities. In addition, providers had to allow reasonable accommodations, including changes in rules, policies, practices or services that were necessary for a person with a disability to use and enjoy a dwelling.

In 1990, the Cranston-Gonzalez National Affordable Housing Act created Section 811 Supportive Housing for Persons with Disabilities. The new program recognized the right of people with disabilities to live in the less restrictive environments possible and the role of mission-driven non-governmental organizations in developing, owning and operating supportive housing.

Like Section 8, Section 811 was also divided into tenant-based and project-based components. The tenant-based component included some 14,000 rental vouchers specifically for people with disabilities, paid through Section 811 funding but administered through Section 8. While increasing the voucher preference for people with disabilities with low incomes, a still greater need for additional vouchers has continually existed.

The project-based component was an exciting program that encouraged the entrepreneurship of nonprofit advocates for people with disabilities. By providing interest-free capital, the program enabled nonprofits to develop, rehabilitate and operate new affordable accessible supportive housing. Importantly, this allowed some nonprofits to design all-encompassing community-based living environments, with highly accessible features and corresponding services, such as home health supports, employment training and recreation programs. Section 811 funding was used to pay for new construction, rehabilitation or acquisition of property, and the federal loan could be forgiven as long as the property is dedicated to providing supportive housing for people with disabilities for at least 40 years.

While the need for affordable, accessible housing has increased, Section 811 has been extremely successful. For example, United Cerebral Palsy of Los Angeles (UCPLA) is now the largest developer of affordable, accessible housing in Southern California. Section 811 along with private capital has helped the nonprofit develop 10 apartment buildings throughout Southern California. UCPLA's Casa de la Providencia in Burbank includes 18 apartments outfitted with wide doorways for wheelchairs, automated door openers, emergency pull cords in bedrooms and bathrooms, and wheel-in showers.

Meanwhile, its tenants, most of whom depend on supplemental security income (SSI), receive housing vouchers and pay just \$250 per month or less in one of the most expensive housing markets in the country. These residents, who might otherwise be forced to live in institutionalized settings, live comfortably in their community. Successful nonprofit developers include many affiliates of United Cerebral Palsy as well as chapters of The Arc of the United States.

Limitations of Public Housing

Despite the success of Section 811, the rising cost of housing and the growing need among people with disabilities with low income, support for the program has faltered in Washington as budget constraints abound. The Bush Administration's initial budgets for several years of the

administration stripped nearly 50 percent of Section 811 funding and entirely eliminated project-based capital for the development of new affordable, accessible housing. While appropriations were restored by Congress, an ominous shadow was cast over the program's future. Further, Congress has not fully supported funding in recent years for the 2.1 million Section 8 vouchers administered by local public housing authorities. In 2004, about 80,000 housing vouchers could not be issued despite growing need.

In addition, the tentative support for subsidized housing for people with disabilities is especially troubling as property values and rental costs have skyrocketed in recent years. While the housing boom has created great wealth for some, it has also deepened the divide between the rich and the poor. People with disabilities with very low incomes are at even greater risk for institutionalization and homelessness today than they were in the past.

Priced Out in 2006: The Housing Crisis for People with Disabilities, a 2006 report by the Technical Assistance Collaborative and the Consortium for Citizens with Disabilities (CCD) found that people with disabilities on SSI had to pay an average of about 113 percent of their monthly income to afford a modest one-bedroom apartment. Demonstrating a dramatic increase in costs, the report states that the same people paid an average 69 percent of their monthly income in 1998.

Some metropolitan areas have seen even greater inequity. For example, a modest one-bedroom in the District of Columbia cost about 188 percent of monthly SSI income in 2006. In addition, less urban areas have seen significant increases in housing costs. From 2002 to 2006, the cost of a one-bedroom apartment in Rhode Island increased more than 30 percent. Even Alabama and Kansas, states not known for their high housing costs, saw rents increase more than 10 percent during the same period.

Approximately four million people with disabilities between the ages of 18 and 64 rely on SSI income to pay for their basic needs – including housing. They are among the poorest citizens in America, earning just 18.4 percent of the nation's median income in 2004. In 2007, SSI rates are just \$632 per month for an individual and \$1,114 for a couple.

Importantly, cost of living increases to SSI have not matched the pace of the housing market. And while home prices are stagnant or declining in many major metropolitan areas today, rent prices are either increasing or holding steady.

The National Low Income Housing Coalition has long advocated for a so-called "housing wage," a common sense minimum wage that ensures workers earn at least enough to afford modest housing. The housing wage takes into consideration the average cost of a rental unit and that residents should allocate no more than 30 percent of their income to housing. According to the group, the housing wage should have been \$13.00 per hour in 2004, though the federal minimum wage was only \$5.15 per hour and monthly SSI income equated to just \$3.56 per hour.

In many respects, the nation has failed to articulate a clear national policy on housing for people with disabilities, though advancements have been made through the years. Despite a growing acceptance that the institutionalization of people with disabilities is discriminatory, rising housing costs, dwindling inventory and poorly funded programs have prevented many from living independent and productive lives in their communities. It hasn't mattered that some large institutions have been found to be more costly than federal and local investments in community-based services and supports.



HOYO: A Model for the Future

In the future, tactics used to address the housing crisis for people with disabilities may include more revolutionary means than simply increasing funding for public housing vouchers.

One model being replicated around the country is the Texas Home of Your Own Coalition (HOYO), a public-private initiative that helps people with disabilities purchase their own home. While homeownership may be the height of independence, it is telling that in 2005, only seven percent of people with disabilities owned their own home compared to 69 percent of the general population.

The HOYO coalition, which includes United Cerebral Palsy of Texas, has revolutionized housing for people with disabilities in the state, many of whom are sustained by low income. The state coalition brings together nonprofits, private businesses including mortgage lenders, developers and realtors, and government. Together, they provide a range of services, from financial counseling to accessibility renovations.

Housing counseling organizations provide pre-purchase homebuyer counseling and education, budget preparation, early delinquency intervention, credit repair counseling, and post-purchase follow-up and support. Realtors locate appropriate and accessible homes and property inspectors. Lenders play a key role with specially designed mortgage products, which may include down payment and closing cost assistance, as well as financial assistance for property rehabilitation and maintenance. Disability nonprofits are involved in home assessments for accessibility, grant writing and marketing services. Finally, government may provide funds for new construction.

Leveraging at least \$9 million to date, the Texas HOYO coalition has helped 200 people with disabilities purchase their own home, 58 percent of whom have mobility impairments. Importantly, many HOYO participants have low income, demonstrating the program's potential to address the housing needs of a wide range of people. In fact, 69 percent of new homeowners earned incomes at or below 50 percent of their community's median income. In addition, none of the new homeowners have defaulted on their mortgages.

While homeownership may not be an option for everyone, HOYO sets a positive example of how community integration can expand the concept of what is possible.

THE LIFE WITHOUT LIMITS PROJECT: ORGANIZING FOR CHANGE

OUR DISCUSSION OF CORE DISABILITY POLICY ISSUES – disability rights, healthcare, education, employment and housing – has shown that much remains to be done. The social and economic power of millions of Americans with disabilities remains untapped. Our community is not short on ideas, creativity or imagination. The question is whether our nation is willing to commit to fundamental social and political change. We have to be able to look at the world differently in order to be able to see it accurately. If we do, an exciting new world will open up for all people.

Through rigid government and charity programs and societal stereotypes, we have promulgated an era of victimhood. As we have shown, various public and private programs, initiatives and laws, while helpful and important, can actually prevent people with disabilities from living full lives. For example, strict eligibility requirements may require people with disabilities to remain unemployed and to live in poverty so that they can keep their Medicaid health insurance. We must work to end this era of victimhood and empower people with disabilities to be independent and productive members of their communities.

Such structural and attitudinal change will not happen overnight. Our society will not wake up one day with the collective wisdom to say, “Oh my, we have to change this!” It is going to take aggressive public education and powerful grassroots organization to insist that these changes occur as rapidly as possible.

Renewing the Grassroots Community

As the disability community fought for the ADA and other protections against discrimination on the basis of disability, it demonstrated a capacity to build a broad-based grassroots movement and unify diverse individuals and organizations to achieve a common purpose. In order to create radical social and political change, the community will need to renew this grassroots structure and expand upon it. It will be a Herculean effort, but its success will be critical to the future of the disability rights movement.

The first step will be to change perceptions and reinforce support within the disability community itself. People with disabilities must look at the world through a different lens – to dream of possibilities and to insist that those dreams be translated into realities. In addition, people with disabilities cannot expect others to carry their call. Although they will have many allies, it is their unique experience that will be the most important educational tool. While our community campaigns for community-based supports and services that allow people with disabilities more control over their lives, we must also support and celebrate self advocates.



Further, we must continue to educate our own. Through outreach within the disability community, we must rally support around the concepts of self-determination and community-based services and supports. People with disabilities will need tools to advocate for themselves. Families and friends must learn how to support their loved ones with disabilities to live full and independent lives. Long-standing community organizations need to understand how they and their constituents will benefit from change.

It will be essential to change the community's mindset in order to achieve success in essential policy areas. Community members must believe passionately that change is needed before we can enlist others in the battle. It is not as easy as it sounds. Many people with disabilities, families and advocates have worked hard to create daily living routines that work for them. And it is easy to grow weary of situations that we must confront every day. Let's not forget the simple fact that dramatic change can lead to rational fear. Some may persist in saying, "Let's not rock the boat."

Patience, education and empowerment are essential tools in building a powerful unified drive to improve quality of life for all. To create the dream of self-determination is one thing, but to make it a real possibility in people's mind is another. This work is critical to the success of the disability rights movement. '

Mobilizing Allies

We also need to mobilize investors in the disability rights movement. Investors are individuals, organizations, institutions and corporations that either profit from consumers with disabilities or have built powerful institutions around them. This would include powerful national nonprofit organizations, hospitals and managed care organizations, the medical establishment, corporations that serve the community with products, health insurance companies and others. Many of these investors may have considerable political and financial strength and at minimum, they must be convinced that change will complement their business or organizational objectives.

It is essential that these investors be on our side and not driven by fear to resist the change we are advocating. With them by our side, many resources will be available. If they remain silent or oppose us outright, those same resources could be used against us. Once we understand this simple equation, it should be easy to spend the necessary time and resources to make investors allies.

In addition, we must build strong alliances with traditional civil rights groups, labor unions, educational organizations, corporate institutions and other national and state associations. Our community should not be afraid to call upon established leaders in the civil rights establishment. While the disability rights struggle is unique among civil rights movements, lessons may be learned and partnerships forged through collaboration with those who have also fought for freedom. However, it is important to remember that simply because someone has experienced a civil rights struggle, they may not automatically be an ally of the disability rights movement. While some may be territorial, others may cling to learned stereotypes of disability. Everyone has to be educated.

By reaching out and bringing together a vast network of internal and external influencers, we can build a broad grassroots network of foot soldiers. Advances in accessible communications and technology – including the Internet – will aid in keeping this new network united and focused.

Building Political Power

With our renewed grassroots network, we must build broad-based public support for change by deconstructing negative perceptions of disability and reinforcing positive messages and examples of people with disabilities living independently in their communities. A critical first step will be to address lingering stereotypes of disability through news and entertainment media. Too often, the portrayal of people with disabilities in the media (with some notable exceptions) has been appalling and extremely damaging. Rarely, if ever, do we see positive portrayals of people with disabilities.

Clearly an organization like the Anti-Defamation League or the Gay and Lesbian Alliance Against Defamation is badly needed in the disability community. Entertainment industry executives and artists, news reporters and editors, and Internet companies must be called upon to stop the proliferation of damaging disability stereotypes. When media firms insist on using negative images and messages, the community should fight back hard. Conversely, we must call upon our champions in these communities to incorporate positive messages about disability in their work.

At times, our community's approach to the American political system may contribute to the paternalistic and outdated dynamic between the political elite and the disability rights movement. We will need to fundamentally change the equation in order to exert greater influence and power within existing political structures. While the power of pity may be persuasive to some, it will take far more to mobilize a broad-based bipartisan political coalition. Creative policy development, political fundraising and networking will be necessary.

Whether we like it or not, power comes from being politically active. Those who participate in raising money and mobilizing blocs of voters are the first to have their agendas heard in the corridors of power. While this might not seem fair, it is the reality of our nation's form of democratic government.

That said, the law clearly states that most tax exempt organizations cannot explicitly participate in the political process. But these organizations can educate the public and policymakers about our issues and needed policy changes. Once agreement is reached within the community, individuals and organizations should explore possibilities for a large-scale collaborative public education program. This might include a targeted focus on specific media organizations, particular population groups or geographic areas.

Given the limited ability of nonprofit organizations to engage the political process, individuals within the community should consider creating a national political action committee (PAC) to raise funds for political candidates with disabilities or candidates that strongly support our policy goals. This new PAC might also recruit and train candidates for elective office from within the disability community. Workshops might train community members in grassroots organizing and techniques in political action or help able-bodied political leaders fully understand disability issues.



Developing Clear and Consistent Messages

As demonstrated by advances in public policy over the last 30 years, the disability community has an agenda and committed advocates. Their work must continue unabated with the community's full support. No benefit, protection or program should be dropped or ignored as we look into changing the future. As people with disabilities and advocates talk about the Life Without Limits Project and changing the future, we should celebrate our rich history and build upon the successes of the past. We need not reinvent the wheel, but use what currently exists to drive us forward.

What should fundamentally change, however, is how we define and talk about our objectives. Simple and consistent messages are critical to changing attitudes towards disability and building broader public and political support for change. We must better define:

- **Who we are**
- **What we stand for**
- **How we will achieve our goals**
- **Why we deserve support**

These messages must move beyond the medical model of disability. As we have previously discussed, too many associate the disability experience with the underlying medical condition. This physiological association segments the community into corners – cognitive versus physical, acquired versus developmental. While there are significant interests unique to each faction, they should be addressed within a common framework. Additionally, messaging that reinforces the medical model deemphasizes the environmental and structural barriers that define the disability experience, such as discrimination and inaccessibility. As a result, paternalistic and uninformed perceptions of disability persist.

Our messages should also serve as rallying points that reinforce the ideological and philosophical foundation of the disability rights movement. One example might be the principles of self-determination:

- **Freedom to live my life how I choose**
- **Authority to control my own body, resources, dreams and destiny**
- **Support from professionals, family, friends and my community**
- **Responsibility to achieve and contribute to my full potential**

Change is Freedom

For people with disabilities, change will be true freedom to choose a life path and to control the supports needed to achieve it. Change will include being responsible for individual decisions and contributions to society. Change will mean full participation in communities.

Ed Roberts, one of the first pioneers of the independent living movement had a vision in the 1970s that led to many reforms in his home town of Berkeley, California and beyond. The philosophy developed by Roberts and his fellow students still serves as an important foundation for today's movement.



The student program was radical. The medical model of disability measured independence by how far one could walk after an illness or how far one could bend his legs after an accident. But Roberts redefined independence as the control a disabled person had over his life. Independence was measured not by the tasks one could perform without assistance but by the quality of one's life with help. The healthcare system offered only custodial help. Roberts rejected this in favor of innovative self-help and group organizing. Disabled people themselves, the newly christened "independent living movement" assumed, knew better than doctors and professionals what they needed for daily living. And what disabled people wanted most of all was to be fully integrated in their communities, from school to work.

— Source: *No Pity*, by Joseph Shapiro

So, without constraints, what should this independence look like? What kind of change are we talking about? Let us make this a reality by imagining a model of what is possible:

Joe lives in Charlotte and he is a quadriplegic as a result of a diving accident when he was 12-years-old. He uses an electric wheelchair and other assistive technology for mobility and communication.

After his accident, Joe received quality special education services that allowed him to attend regular public school classes. Critical assistive technology such as an electric wheelchair and special computers were reimbursed by his family's health insurance. Joe's high school welcomed and encouraged his participation in extracurricular activities. As a result, Joe did well enough in high school to easily get into college.

His university campus was highly accessible and throughout his college career he lived with his fellow students in housing developed with universal design. The university provided accommodations such as a note taker and helped him find a direct support professional to assist with daily tasks. While a student, he joined a business academic fraternity and met his future wife, Jane. After Joe earned a bachelors degree in business, he applied for several marketing jobs in consumer electronics.

After five interviews, Joe received three job offers. In the end, he chose a job that offered the best long-term career opportunities. He had no trouble finding an affordable, accessible apartment near his new workplace and he started heading to work each day via his community's highly accessible public transportation system. His employers voluntarily made modest accommodations including raising his desk height to fit his wheelchair and purchasing special computer equipment so he can do his job. His benefits included comprehensive health insurance that covered home-based direct support and assistive technology. He also felt secure that if he were to



lose his job he could rely on and afford reformed government programs such as Medicaid to sustain his needed supports.

Living on his own, Joe still needed support to complete daily tasks such as getting dressed, performing personal hygiene and cleaning up around his apartment. Joe is an early riser and because he was able to hire his own direct support staff, he was able to find an affable morning person to help him get ready for work each day.

Joe and Jane were married a few years after college. Today, they are planning a family and a life together without limits. Disability is part of Joe's life but it does not define it.

Joe is in control of his own destiny. He makes his own life decisions. He designs supports unique to his own needs and as a result, he's an active participant in his community and enjoys an enriched life.

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