

**NCIL : MEETING
WITH PRESIDENT
OBAMA**

**MENTAL HEALTH
ADVOCATE WANTS
END ON HER TERMS**

**PEOPLE WITH
DISABILITIES AT
HIGHER RISK FOR
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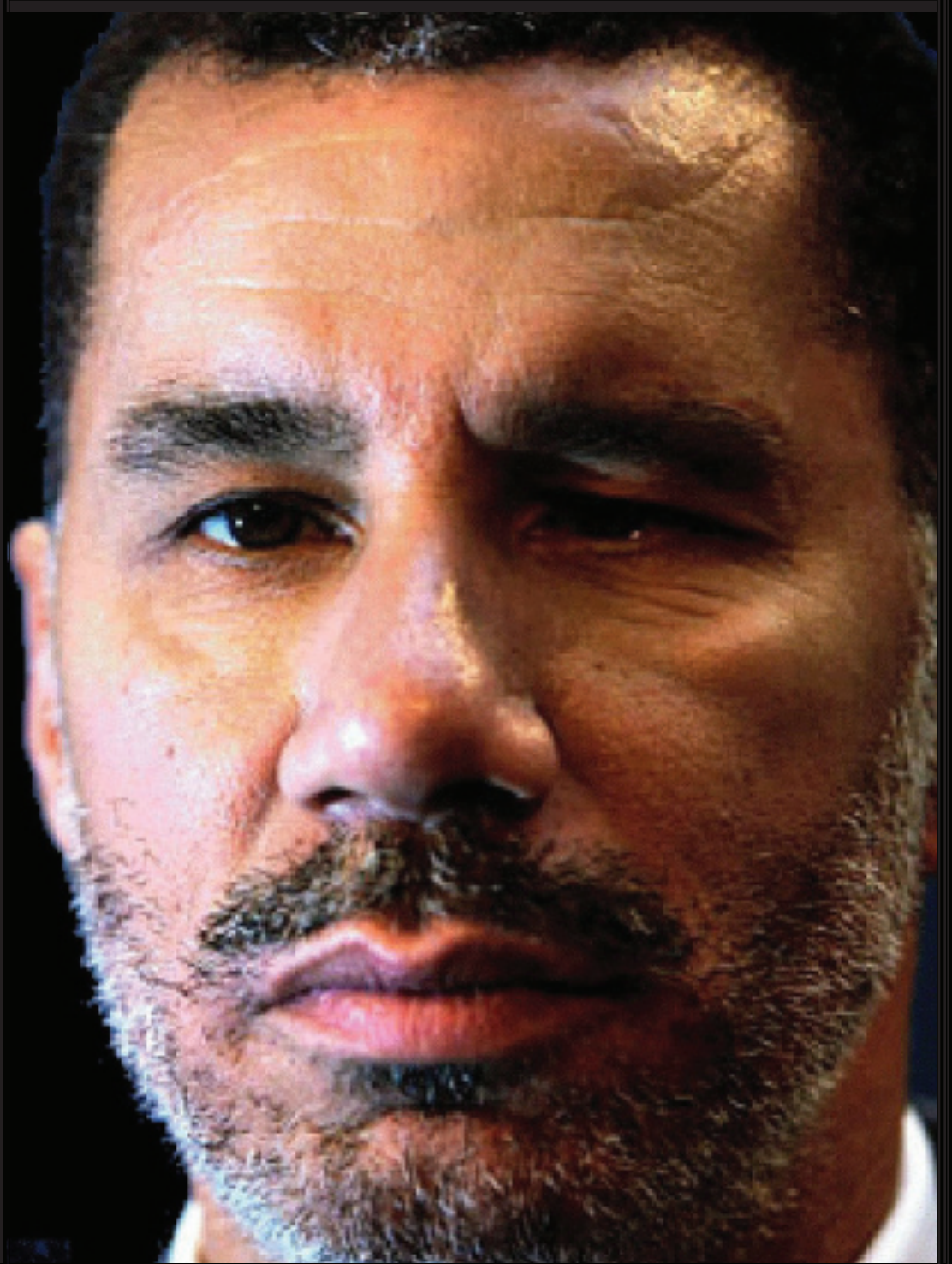
independence today

Volume 3

Issue 4

NYS GOV. DAVID PATERSON:

**He's No
FDR....
But Does He
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Spanish Disability Organization Proving that ONCE is Enough

By William Loughborough

When ONCE (Organización Nacional de Ciegos Españoles, the National Organization of the Spanish Blind) was founded in 1938 during Francisco Franco's rule, the blind of Spain and the world were largely unemployed and many were beggars. Now, almost entirely because of ONCE, the blind of Spain are essentially 100% employed.

ONCE, Spain's organization of and for the blind, has taken on two institutions that have been accused of exploiting the poor: lotteries and "rehabilitation agencies." By running the lottery efficiently, the organization has acquired capital that has been successfully invested in commercial ventures through its own entity, Corporación Empresarial ONCE, S.A. Those ventures include service companies, hotels, food businesses and Servimedia, a news agency that specializes in providing information on issues of social interest, such as disability, integration, corporate social responsibility and leisure.

ONCE is given a share of gross lottery revenues and uses it for the social benefit of its members, who must be blind and Spanish. It is one of the largest enterprises in Spain, with more than 40,000 employees.

Although the jobs, many as lottery ticket salespeople may seem like "make-work", it is far from the usual lot of blind people who in the U.S.A. are often relegated to really demeaning tasks like winding brooms or stuffing envelopes - the Spaniards get to experience social interactions with "normal" people rather than slaving away in "sheltered workshops", so-

called because they are "sheltered" from minimum wage laws. In fact ONCE has been so successful that the unemployment rate among its members is zero, compared with a rate of 70% for people with disabilities in so-called "advanced countries."

Though many of the jobs, such sellers, may not seem exceptional, the employees get to interact socially with sighted members of society. In the U.S., that is not always the case. The unemployment rate among ONCE members is zero, compared with a rate of 70% for people with disabilities in so-called "advanced" countries.

A spin-off company, Fundación ONCE, provides professional training and employment to eliminate architectural, urban and communication barriers and to promote "digital solidarity," that is, Web-based services for people with disabilities. An organization founded to enhance the lives of people with disabilities is called Grupo Fundosa.

Many observers cite ONCE as an example of a private-sector organization doing a better job at improving the lives of others than that of most governmental organizations in other countries.

William Loughborough, a frequent contributor to Independence Today, is moving to Madrid, Spain. He has been involved in the Web Accessibility Initiative since its inception and has been an advocate for universal accessibility. He has 50 years' experience in providing devices for blind orientation.

William Loughborough's blog is available on the home page of <http://www.ilusa.com>.

THIS DAY IN DISABILITY HISTORY

September 13th, 1956

-- Geri Jewell, the first person with a disability (cerebral palsy) to have a regular role on a prime-time television series, is born. She is best known as Cousin Geri on the NBC sitcom "The Facts of Life." She began her career doing standup comedy at the Comedy Store in California in 1978. In 1980 she performed at the 2nd annual Media Access Awards, when she was introduced to Norman Lear by producer Fern Field. After her groundbreaking role on "Facts," she appeared on such shows as "The Great Space Coaster," "Sesame Street," "21 Jump Street," "The Young and the Restless," "Strong Medicine," the HBO hit series "Deadwood" and the Emmy Award-winning movie "Two of a Kind." In January 2009 she was the main entertainment, alongside dancer Bill Shannon, at the Disability Power & Pride Ball, part of the inaugural activities for President Barack Obama.

September 16th, 2008

-- The U.S. Paralympic wheelchair rugby team wins the gold medal in Beijing. The U.S. team defeated Australia 53-44 in the championship match. The victory eased the sting of a loss to Canada in the semifinals in Athens, Greece, in 2004, a story documented in the movie "Murderball." The 2005 film was nominated for Best Documentary Feature at the 78th Academy Awards.

October 6th, 2000 --

"CSI" debuts on the CBS television network featuring disabled actor Robert David Hall, starring as coroner Dr. Albert Robbins. Hall made his usage of Canadian crutches a key feature of his portrayal. In 1978, Hall

had to have both of his legs amputated as a result of an accident in which an 18-wheel truck crushed his car. The accident also caused the gasoline tank of the car to explode, causing burns over 65% of his body. He now uses prosthetic limbs. He is a prominent advocate for disabled Americans and is on the board of directors of the National Organization on Disability.

October 18th, 1932 --

Hugh Gregory Gallagher, "grandfather of the disability rights movement," is born. In late adolescence, Gallagher developed polio and would rely on a wheelchair for mobility. He wrote the definitive biography of Franklin Delano Roosevelt, titled "FDR's Splendid Deception," which chronicled the disabled life FDR hid with help from the press during his time as president. He was a strong advocate for the statue of FDR in a wheelchair that was eventually displayed in Washington, D.C. He was instrumental in the passage of the 1968 Architectural Barriers Act.

October 24th, 2008 --

The Fred Fay Advanced Leadership Forum holds its first meeting, hosted by the Boston Center for Independent Living. The purpose of the forum, named after one of BCIL's founders and a longtime leader in national disability advocacy, was to bring current leaders of the disability rights movement together with the emerging generation of leaders to plan the movement's future direction. The forum's goal was to give participants the background, training, information and expertise that they could use in advocating for disability rights. A position letter summarizing the participants' thoughts was distributed to

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CoverStory

N.Y. Governor Paterson Blind to Tools of Success

By Deborah Kendrick

Several years ago, when I received some mystifyingly bad treatment at the hands of other people who shared my disability, a friend who was both black and blind comforted me with her insight. "Blind people can sometimes be like a basket of crabs," she told me. "When one of them makes it to the top, the others scramble to pull him down." Folks I thought to be my peers, in other words, were attacking me out of envy.

I vowed I would never do that. I would fervently support anyone with any disability who achieved success in any field. We should all be one happy family, right?

Then, following the 2006 elections, alarms went off that challenged that personal pledge. The good news was that New York state had elected a lieutenant governor who was both black and blind. The more troubling news was that David Paterson, that newly elected official, by declaring that he didn't use any of those blindness tools – Braille, assistive technology, a white cane – indicated to those who don't have disabilities that he was too

cool for all that nonsense. Those of us who proudly use the tools of blindness, who depend on them to give us a competitive edge in a host of professional and educational environments, tried to be tolerant. I wanted to be first and foremost proud. A blind guy – a sort of brother to me in the disability family – was rising to the top, and it was cause for serious celebration.

Of course, when Eliot Spitzer was caught with his pants down, so to speak, and Paterson rose to the very top of his state, sworn in as New York governor on March 17th, 2008, the media made even more noise about how this brilliant guy didn't need Braille or talking computers or any of that blind nonsense. He had a superhuman memory, we were told, and relied heavily on staff. His staff read important memos and documents into voicemail messages that he listened to at all hours.

Voicemail messages? What?

He's governor of one of our most important states, and he doesn't use a computer? Still, I reminded myself to be tolerant. Each of us has different techniques, different ways to accomplish the same goal. One deaf person reads lips. Another uses American Sign Language. Another uses Signed English. And on it goes. The man was governor, after all. He didn't have to do things the way other blind people do them to earn our support. He was one of us, and we should stand behind him.

Then Paterson started doing really dumb things. He didn't always know the facts. He made decisions and then, under pressure of one kind or another, reversed them. He appointed a lieutenant governor when nobody was sure he was even allowed to do that and who, to add insult to injury, had trampled with dirty boots on transportation prospects

for New Yorkers with disabilities.

He seemed to "get it" when he responded with disdain to the "Saturday Night Live" skit that ridiculed his blindness. And yet, he didn't hesitate to grab a few laughs himself at the possible expense of people with disabilities when he appeared in a wheelchair for a charity gig.

More recently, he has vetoed one bill that would prevent discrimination against people with disabilities in public facilities in his state and another that would require all polling places to be made physically accessible.

OK, we could argue, just because he has a disability doesn't mean he has to always agree with us, supporting every bill that comes down the political pike to improve the quality of life for New Yorkers with disabilities. Shouldn't we still support him? He's both black and blind, after all.

The proverbial "last straw" in struggling to hang on as a cheerleader for this New York governor came when I started seeing references in the press linking his failures to his blindness. One New York state senator, Diane Savino, was widely quoted as saying, in effect, that hey, even though the guy is brilliant, he's blind, after all, and being blind means he can't use the same digital tools -- such as e-mail or a Blackberry -- as his peers.

Wait a New York minute! And let me do some deep breathing so as not to do anything undignified like spew bad words in my own e-mail or Smartphone messages!

One headline read: "It's not his race, it's his blindness." Let me set the record straight: "It" -- his failure to lead -- is not because of his race or

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Denise A. Figueroa, Executive Director
Patricio Figueroa, Jr., Publisher/ Editor
Mike Piekarski, Associate Editor
Eleanor Cantor, NCIL Editor

For editorial matters, please call
(518) 274-0701 or Fax: (518) 274-7944
Via e-mail: itodaynews@ilchv.org

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his blindness. It's the man himself. But blindness is something I know well and know more than a little bit about with regard to tools and techniques, so let me tell you now what I was suppressing all along.

His avoidance – since childhood – of tools related to blindness, don't make him superior to other blind people, but rather inferior. He can't read print but refused to learn Braille. That's denial to the point of masochism. In other words, he's illiterate by choice! Why, I wonder, if he's so "brilliant" did it take him 12 years to get two advanced degrees, when lots of "ordinary" blind people have obtained those same two degrees in six? And even though the second of those two degrees is a law degree, he never went into practice as a lawyer because he couldn't pass the bar exam. Why was that? Was it because he couldn't read Braille or use a computer? Now, in all fairness, I don't know the answer to that question, but his explanation is that he didn't receive adequate accommodations. But what would those accommodations be, anyway, for a man who is blind but doesn't know how to use any of the tools that similarly educated blind people avail themselves of daily?

You could say it's not his fault. When he was a child, New York City schools couldn't promise that he wouldn't receive any special education, and his parents moved to a suburb where he could go to public school "unhindered" by special ed. Now, maybe that was a good thing. I wasn't there. But it sounds to me like being perceived as sighted was more important to the family than getting the best education possible.

And so, here we have a

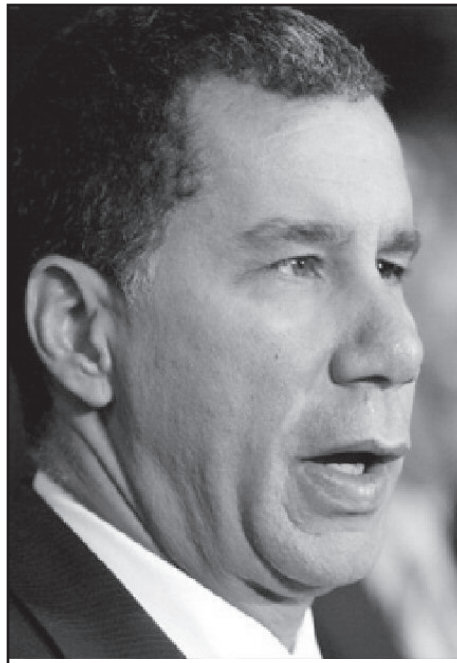
21st-century governor – the first legally blind governor to serve in any state longer than 11 days – and he's using 1960s or '70s tools to do his job. Staffers read materials onto tapes and into voicemail for him. He has no means of prompting himself with notes, which would be effortless had he taken the time to learn to read and write Braille.

Had he been governor in 1975, the tools he now uses would have been adequate because sighted people at the time were using them at the same level of sophistication. But those tools now are inadequate.

Why doesn't Paterson use a computer with one of the popular screen-reading programs, such as JAWS or Window-Eyes or System Access? If he did, 99 percent of all documents generated by other computers could then simply be e-mailed to him. If he wanted to travel light, he could carry a netbook (a small laptop computer) or a thumb drive, into which staffers could pop anything he needed to read. With practice, he could do what blind professionals all over the world do – crank their reading speed up to several hundred words a minute and get through material as quickly as any sighted politician. Add that to his amazing memory, and he could have been a governor to make us proud.

Why does he have staffers read newspapers to him? For free, he could sign up for the National Federation of the Blind's NEWSLINE, a telephone service that would enable him to read any of 220 newspapers around the country, from any phone anywhere, at any speed he chose. He could zip through articles at his own speed as quickly or even quicker than his sighted peers.

Now, this "brilliant" guy is using tools that were state of the art when Jimmy Carter was president, has an approval rating that has



NYS Governor
David Paterson

dropped at a staggering rate, and against even the advice of President Obama, said he'll run again in 2010. It's pitiable, really, but I'm not feeling sorry for him. How can I when, along with his own failure, he's pulling the overall acceptance of and employment opportunities for other blind people down with him?

I'm not saying I could do his job. I don't think I could. But I am saying that lots of people who are blind could and do it brilliantly. He wanted so much to hide his blindness that now, in his appalling unpopularity, it's the one thing that outsiders are interpreting as his weakness. It hasn't been. His weakness has been his own arrogance and denial of reality. It's a shame. With proper training, he might have done a good job.

But he isn't doing one, and I'm OK with having broken my promise to myself. I know now that just because he has a disability doesn't mean I have to like him. And if he's going to fall headlong into the basket, I don't want him to kick the rest of us down to the bottom as well.

Deborah Kendrick is a newspaper columnist, editor and poet. She is currently working on a biography of Dr. Abraham Nemeth.

Commentary
Paterson Says
Equal Rights Too
Expensive

By Peter S. Kahrman

New York Governor David Paterson this week put a value on equal rights – too expensive.

With the slash of his hard-hearted veto pen, Paterson killed bills that would have required polling places to meet federal accessibility guidelines for people with disabilities within six months, another that would have protected people with disabilities from missing out on services from state and local governments, and another that would have made it a felony for caregivers to endanger the welfare of an incompetent or physically disabled person. On reflection, his vetoes represent the very kind of felonies the latter bill sought to address.

For 15 years now Timothy J. Feeney has headed up the Neurobehavioral Resource Project for New York State's Traumatic Brain Injury Waiver. The NRB is arguably the most powerful influence over the TBI Waiver, a Medicaid program designed to provide services to brain injury survivors across the state. What's the problem? Feeney runs around the state, country and world claiming he is Dr. Timothy Feeney or Timothy Feeney Ph. D. when he is neither. His masters and Ph.D. were obtained through a now defunct diploma mill called Greenwich University. It seems the DOH accurately reflects the mindset of its governor.

A New York State Department of Health official for the Division of Home and Community Based Services, said that the contract signed by Feeney does not require him, as director of the NRB,

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Disability Rights Group: 30 Years as a Force for Change

By Kathi Wolfe

Having breast cancer is no picnic.

It wasn't a day at the beach five years ago, when Disability Rights Education and Defense Fund (DREDF) co-founder and senior policy advisor Mary Lou Breslin began outpatient chemotherapy for it. Breslin, who has polio and uses a wheelchair, was told that she had to lie down on a table to receive the treatment. The table, though, wasn't wheelchair-accessible, so she asked to be given a portable wheelchair lift. The clinic staff told her that, to comply with her request, she would have to be admitted as an inpatient to the hospital.

"The problem was that the (hospital) floor nurses didn't know how to administer the chemo," Breslin said. Finally, after four DREDF attorneys contacted the outpatient clinic, Breslin said, a lift was brought in and she was able to get the chemo that she needed. "What would somebody have done if they hadn't had access to four lawyers?" Breslin asked.

DREDF, a leading national civil rights law and policy center, marks its 30th anniversary this year. The disability rights group, headquartered in Berkeley, Calif., was co-founded in 1979 by Robert ("Bob") J. Funk and Patricia A. Wright. (Currently, Funk is executive director of Paraquad, a St. Louis center for independent living, and Wright is a DREDF consultant on special projects.)

The Disability Rights Education and Defense Fund's groundbreaking work propelled many of the advances in disability civil rights policy and law over the last three decades, from

the well-known Americans with Disabilities Act to the more obscure Fair Housing Amendments Act.

Many people with disabilities currently experience instances of discrimination and inaccessibility in schools, their places of employment or other facets of society, Breslin said. "Yet, today, there are civil rights laws and (disability rights) legal resources, and there (usually) aren't written prohibitions against hiring people with disabilities."

When Breslin came to the San Francisco Bay Area in 1972, she wasn't involved in disability issues. "I was politically active on a lot of progressive issues, but I didn't have a way to analyze disability in the context of civil rights," she said. "It was a period when some city and county governments had written policies saying they wouldn't hire people with disabilities. Even if they didn't have this in writing, they wouldn't hire anyone (with a disability) because they couldn't see or imagine how they could be productive. Accommodation (in the workplace) was a new idea in those days."

In the 1970s, the idea of people with disabilities living independently in apartments or houses was almost unheard of and frightening to most non-disabled people, Breslin said. Accessible housing wasn't on the radar screen then. "There was real concern about blind people living alone or whether people in wheelchairs would wreck the house," she said.

Like others with disabilities during that period, Breslin wasn't yet connected with the disability rights



Mary Lou Breslin, a co-founder of DREDF, at the group's offices in the mid- to late-1980s.

movement then just emerging in California, St. Louis, New York and other parts of the United States. She grew up believing that people with disabilities should pull themselves up by "their bootstraps," Breslin said. The mind-set at the time was: "Don't ask for accommodation. Fall down the stairs if you need to. Pretend that you're not disabled. Eschew everyone with a disability."

Breslin's attitude changed when she worked in the disabled students placement office at the University of California at Berkeley from 1975 to 1978.

"I became politicized about disability in what felt like five minutes," she said. "There was an outpouring of federal (disability rights) legislation. The Education for All Handicapped Children Act (the predecessor to the Individuals with Disabilities Education Act) was enacted in 1975. The Developmental Disabilities Assistance and Bill of Rights Act became law, also in 1975. Section 504 of the Rehabilitation Act was passed in 1973."

The regulations implementing "Section 504" weren't signed into law until 1977 after people with disabilities demonstrated in San Francisco (by

staging a monthlong sit-in that city's offices of the then-U.S. Department of Health, Education and Welfare) and in Washington, D.C. Section 504 prohibits entities such as hospitals and schools that receive federal funds from discriminating against people with disabilities.

Becoming a foot soldier in the Section 504 demonstrations gave her "a political context for my experience," Breslin said. "The demonstrations made it clear that it was possible to effect change (on disability issues) using traditional civil rights tactics. It coalesced around cross-disability issues."

The late George Musconi, then mayor of San Francisco, sent portable shower stalls to the HEW building for the demonstrators, and "labor unions and other political groups supported us," Breslin said.

The environment for people with disabilities at that time, when the first disability civil rights laws were passed, was "very volatile, in a good sense," she said. "It was a period of revolutionary change across the country." Despite

Disability Rights
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First of two parts**Assistive Technology a Big Help to People Who Stutter***By John M. Williams*

The 10-year-old pupil stands next to his desk. He is a normal-looking boy and is alert, energetic and full of dreams. Before he speaks, he weighs his words. In the past when he spoke, his speech was characterized by repetitions (li-li-like this), prolongations (lllllike this), or abnormal stoppages (no sound) between syllables. Besides facial and body movements associated with the effort to speak, he experiences subconscious, automatic behaviors that include rapid and shallow breathing, rapid heart rate, elevated blood pressure, sweaty palms, flushing of the skin, eye blinking and pupil dilation. He also feels fear, anger, relief, embarrassment, frustration and guilt.

Today, Ben Kordsmeier, a resident of High Point, N.C., is changing his old speaking patterns. In his left ear, he is wearing what looks like a hearing aid. In fact, when he started wearing the SpeechEasy (www.speecheasy.com), people asked him, "Are you wearing a hearing aid?"

After using the SpeechEasy for two years, Kordsmeier speaks fluently and appears confident. When he finishes, displaying a broad smile, he sits down. He is not as fatigued as he had been in the past when he stuttered nearly all the time. "I am no longer afraid to stutter," he says fluently in a telephone conversation.

Kordsmeier is not alone in the pride he relishes in being fluent. Thirteen-year-old Dane Stephens of Overland Park, Kansas, and 15-year-old Austin White of Houston, Texas, have identical feelings. They also use the SpeechEasy. For most of their lives, the three boys have stuttered.

The American Speech-Language-Hearing Association (www.asha.org) defines stuttering as "a disorder of speech fluency that interrupts the forward flow of speech." ASHA is the professional, scientific, and credentialing association for more than 120,000 members and affiliates who are audiologists, speech-language pathologists, and speech, language and hearing scientists.

"There is power in fluency," says Stephens, who asserts that his life has changed since he started using the SpeechEasy. His peers no longer tease him and, because stuttering tires the speaker, he is less tired. He is less angry about his stuttering, is making more friends and feels more positive about his abilities.

All individuals lack fluency of speech at times, but what differentiates the person who stutters from someone who doesn't are the kind and amount of disfluencies.

The SpeechEasy is a portable and inconspicuous fluency-enhancing prosthetic device that fits in or behind the ear. The product is designed to emulate choral speech -- a phenomenon that has been found to induce fluency among people who stutter. For years, it has been known that when people who stutter speak the same material in unison with another speaker, they become fluent. This is known as "choral speech." By allowing the user to hear his or her own voice with a pitch shift and a slight time delay, SpeechEasy creates the illusion of another speaker speaking at the same time, thereby emulating choral speech. The device creates this

choral speech pattern through altered auditory feedback (AAF) that consists of a combination of delayed auditory feedback (DAF) and frequency altered feedback (FAF).

Altered auditory feedback (AAF) means hearing your own voice in a manner that is slightly different from the way you normally hear it. It allows the SpeechEasy user to listen to his or her own voice with a combination of delayed auditory feedback (DAF) and frequency altered feedback (FAF). Using DAF allows the user to hear his or her own voice with a slight delay, similar to an echo. FAF allows the user to hear his or her own voice with a shift in the pitch, so the signal heard is either at a slightly higher or slightly lower pitch than the user's own voice.

Four factors contribute to the development of stuttering: genetics (approximately 60% of those who stutter have a family member who does so); child development (children with other speech and language problems or developmental delays are more likely to stutter); neurophysiology (recent research has shown that people who stutter process speech and language in different areas of the brain than those who do not); and family dynamics (high expectations and fast-paced lifestyles can contribute to stuttering). Stuttering may occur through a combination of factors and may have different causes in different people. It is probable that what causes stuttering differs from what makes it continue or worsen.

According to the Stuttering Foundation of America (www.sfa.org), stuttering affects four times as many males as females, and about 3 million people in the United States, approximately 1 percent of the population, stutter.

Among the many famous people who have stuttered are the Greek orator

Demosthenes; Aesop, the author of children's fables; Roman emperor Claudius; scientists Aristotle and Sir Isaac Newton; nurse Clara Barton; author Lewis Carroll; Bishop Thomas Becket; Senator Joseph Biden; Congressman Frank Wolf; naturalist Charles Darwin; the Reverend Cotton Mather; statesman Winston Churchill; Olympic diving champion Greg Louganis; professional football players Lester Hayes and Bo Jackson; novelist John Updike; short-story writer Washington Irving; Annie Glenn (wife of astronaut and former Ohio senator John Glenn); singers Mel Tillis, Carly Simon and Robert Merrill; former General Electric CEO Jack Welch; actors Jimmy Stewart, Marilyn Monroe, Peggy Lipton, Dean Jagger, James Earl Jones, Bruce Willis and Anthony Quinn; President Thomas Jefferson; former basketball great Bill Walton; and ABC's John Stoessel.

"It makes me feel proud to be among these famous individuals," Stephens says.

Laura Doty, in an article titled "Famous People Who Stutter" (<http://www.d.umn.edu/~cspiller/stutteringpage/famous.htm>), mentions a number of techniques tried by people who stuttered to gain fluency. She wrote: "Cotton Mather was an author, a leader of the Puritans, and a prosecutor of the Salem witch trails. The first book he wrote was on stuttering in America. Mr. Mather tried many methods to treat his stuttering, some successful, such as speaking in a drawling or singsong fashion, and some unsuccessful, such as fasting and prayers.

On the effects of stuttering on Marilyn Monroe, Day wrote: "(Her) signature breathy way of speaking may have been her way of treating her stuttering. She seems to have been

Assistive Technology
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Mental Health Advocate Wants End on Her Terms

By Mike Reynolds

When Judi Chamberlin was born on October 30th, 1940, no one could have predicted how much she would revolutionize the nature of mental health care and treatment and the ways in which it would be delivered in the United States and throughout much of the world.

Chamberlin, who is currently writing about the last days of her life in her blog "Life as a Hospice Patient," has been a strong voice for decades for the rights of people with mental illness to have control over their treatment.

She was first hospitalized for depression in 1961, but by 1966, she stopped getting traditional mental health treatment in hospitals.

"After my last hospitalization I felt very angry (and) upset over the way in which I was treated," she said in a recent interview. But it was not until 1971, when she discovered the Mental Patients' Liberation Project in New York City, that she connected with others who shared her concerns. "The group was run by this man called 'Howie the Harp' (Howard Geld), a man who died far too early for his time," Chamberlin recalled.

Her basic idea, that people with mental illnesses should have alternatives to a medical system in which hospitalization is seen as the only option for people with psychiatric disabilities, has won her praise across the United States and across the world. "We live in a society where the drug companies want to 'medicalize' everything," she said.

Although Chamberlin believes drugs can be an effective tool, it must be a

person's choice whether to use them, she said. Asked why mental health care has been noticeably absent from the current health care debate, she said, "It will be a long time until any elected official will be advocating for the ability for people with mental illness to refuse medication."

A committed activist, she attracted media attention after she had a letter to the editor published in The Boston Globe in which she deflected discussion of the controversial health care reform by inviting the media to chronicle her end-of-life situation. Chamberlin has been diagnosed with fatal chronic obstructive pulmonary disease, and her blog is featured in The Boston Globe.

Writing about being a hospice patient has been rewarding, she said, noting that focusing on patients and their wishes is the guiding principle of the hospice movement. "I may not be able to go give speeches all over the place, but I can still write," she said.

Her book, "On Our Own: Patient-Controlled Alternatives to the Mental Health System," was published in 1978 and is considered a vital text for the patients' rights movement. In addition to the U.S., the book has been published in Britain and Italy.

Chamberlin has received numerous awards and commendations for her activism. In 1992, she was honored with the Distinguished Service Award of the President of the United States by the President's Committee on Employment of People with Disabilities. She also received the David J. Vail National Advocacy Award



Judi Chamberlin is dying. Her only wish is to die at home.

and the 1995 Pike Prize, which honors those who have given outstanding service to people with disabilities.

Chamberlin has spoken at conferences and meetings throughout the U.S. and has appeared on many radio and television programs such as "Oprah," "The Sally Jessy Raphael Show" and "Geraldo," discussing self-help and patients' rights. Her appearances have included stops in Canada, England, Scotland, Ireland, Iceland, Sweden, Holland, Portugal, Italy, Australia, New Zealand and Japan.

Asked about her biggest accomplishments, she pointed to several, most notably the U.N. Convention on the Rights of People with Disabilities. "If that was ever enforced, and the United States has signed on to it, it would give all people with disabilities solid legal rights throughout the world," she said.

Asked what organizations an individual with psychiatric disabilities could turn to for support, Chamberlin mentioned the National Empowerment Center (which can be reached by calling at 1-800-POWER2U) and the National Mental Health Consumers' Self-Help Clearinghouse in Philadelphia. She served

on the staff of the National Empowerment Center for a number of years.

Mike Reynolds is a freelance writer and short movies producer.

Obama Proposes an Extra \$250 for Social Security Recipients

To compensate for the loss of a cost of living adjustment in January 2010, President Obama has proposed a one-time payment of \$250 for senior citizens, veterans, and people with disabilities on Social Security benefits, calling it an addition to his stimulus bill "on behalf of those hardest hit by this recession."

"These payments will provide aid to more than 50 million people in the coming year, relief that will not only make a difference for them, but for our economy as a whole, complementing the tax cuts we've provided working families and small businesses through the Recovery Act," Obama said in a statement.

Congress must approve the payments, which would cost \$13 billion, according to a White House statement. Many members of the Democratic majorities in the House and Senate have endorsed such a step. The Republican caucus said it would support the payments if the money came out of already authorized stimulus funds.

The fact sheet said 57 million Americans would benefit from the proposal: "These include 49 million Social Security and 5 million Supplemental Security Income beneficiaries, 2 million veterans benefit recipients, 0.5 million railroad retirement and disability beneficiaries, and also about 1 million public-employee retirees not entitled to any of the previous benefits."

Source AP

From Hearing Loss to Sound Outlook

Living With a Cochlear Implant

By Amy Halloran

After Melissa Enslin got her first cochlear implant, on March 19th of this year, "I can hear voices very faintly for the first time," she said.

The device was surgically installed behind her right ear, which has no hearing capacity. The implant, which works to create new neural pathways in her brain rather than amplify sound like a hearing aid, allows her to use the telephone, and although she feels frustrated that her progress has reached a plateau, she is hopeful she will gain more function over time. Function should increase with the help of an audiologist, whom she meets with regularly to determine her range of hearing and tune the implant. In addition to improving her hearing, Enslin seeks to perfect pronunciation of certain consonant combinations with the help of a speech therapist.

Enslin's hearing loss can be traced to her birth, which occurred prematurely at six and a half months. She weighed 1 pound, 11 ounces and was on the operating table for 30 hours as a newborn.

"They can do a lot with preemies nowadays, but back then, I made the history books," she said, half-joking.

Enslin's words mostly come across loud and clear thanks to her hard work with a speech pathologist as a child, though her voice does indicate signs of hearing impairment. That impairment was initially misdiagnosed as autism when she was 4 years old; she had her hearing tested and got her first hearing aids when she was 6. The youngest of three children, Enslin was mainstreamed in public schools and was often the only child with

hearing difficulties in her classes in rural Bus County, Penn.

"Kids were mean," she said. "They made fun of me. Socially, it was the pits, especially in middle school." Enslin grew a thick skin that served her well as she faced other major challenges, including domestic violence and another misdiagnosed medical issue.

"I was diagnosed with bipolar disorder when I was 32, in 1996," she said. "I had it for a while, but they didn't pick up on it. They thought my mood swings were related to my hearing trouble. They thought I was frustrated."

Unfortunately, her misdiagnosis is not rare. Symptoms of bipolar or manic-depressive disorder don't appear until late adolescence or early adulthood and can be overlooked or attributed to other causes. Because it encompasses mania and depression, the disorder requires multiple treatments, which for Enslin means a variety of therapy and medications, including lithium, respiradal, Abilify and Wellbutrin. She's happy with the medications, except for weight gain; she's trying to address that side effect by walking daily for two miles with her dog through a nearby cemetery.

The 13 years since her bipolar disorder diagnosis have held a lot of dramatic ups and downs. Positives included applying for and receiving funding from the New York state Vocational and Educational Services for Individuals with Disabilities (VESID) to study massage at the Center for Natural Wellness. The nearly two-year program is known for its academic and physical

demands but was tough for Enslin on another level, too. She couldn't look at her notebook while taking notes because she had to read lips, but she found the many reading assignments very helpful. She completed her studies and has her license to practice; she worked in a few massage groups but now works with clients on her own.

Another positive has been her mother's recent move. Enslin described her relationship with her mother as very close, and she was thrilled when her stepfather, an Episcopal priest, was placed in a church in the upstate New York city of Troy, where Enslin lives.

Setbacks related to her struggles with mental health, including many hospitalizations, are on the list of negatives.

"I am determined that this last hospitalization was my last," Enslin said. "I was in the hospital for two months in 2005. I was influenced by the wrong type of people, (who were involved in) shamanic healing. I don't know what happened. They said they could get me off my meds with nutritional healing and other kinds of alternative medicine. I lost my apartment, my car, almost lost my dog. He was in the shelter for a month. I lost my job. Anybody who has this illness, I tell them, 'Don't go off your meds; it's not worth it.' It took about two years to get my life back together."

A big part of Enslin's recovery and stability is her connection to art. A potter since she was 15, she has a studio and teaches occasional classes. "My favorite thing to make is bowls," she said. "I love to make coil pots."

She made one of her coil projects, which won first prize at the county fair, at the Roarke Center, a drop-in center that provides many community services, from a food bank and other

social-support systems to art workshops in a variety of media. Enslin began attending the center in December 2005 and was teaching there the following year. Currently, she's teaching a four-week class to four students.

"I did watercolors for a while, and pottery and writing," she said of her participation in the art program. "I had a hard time with watercolors because I couldn't touch what I was doing."

Contact and connection are important to Enslin, not just with clay but also with people. She has a dream of doing face pots with other people. Massage is another route for human connection, and she has just begun exploring writing with the goal of reaching people.

"I'm writing about my life story," she said. "I want to be a role model to other people who are going through things I've gone through: domestic violence, cochlear implants and bipolar disorder. My mother's a good storyteller, and she told me to tell the story in third person. That way I don't have to say 'I,' 'I,' 'I' all the time."

This process, she thinks, will also help her tell her story to herself, to see her experiences as a narrative dotted by highs and lows, and marked by progress. The writing, she hopes, will help her realize how far she's come, including being in a stable, loving relationship.

Her advice to others? "I would like to say, 'Don't feel like you can't do anything.' There's always something to do within your different ability. I don't like the word 'disability' because it makes you think there's something you can't do."

Amy Halloran, a writer, lives in upstate New York with her sons and husband.

Living with Hemophilia: A Personal Story

By Kevin Irvine

I am a bleeder and have been for all of my 40 years. Please don't be alarmed: It isn't nearly as messy or freaky as it sounds. If it were, I probably wouldn't have been married for eight years with a 3-year-old daughter.

Technically, I have severe Hemophilia B, but it really comes down to bleeding and clotting. Apparently, the most common mental image for the average person who learns about hemophilia is of a minor cut that won't stop bleeding. In reality, those are as insignificant for us as for anybody else. What we really worry about are more serious injuries or trauma, both external and internal (such as in joints or muscles). People living with most forms of hemophilia bleed for longer periods of time (not harder or faster) than someone without a bleeding disorder. Granted, I do tend to bruise easily, but that comes with the territory.

As with many disabilities and medical conditions, treatments have changed radically over the last 50 years, and those have greatly improved the quality of life for many people with hemophilia. In the United States, medical treatment of hemophilia is very expensive but often subsidized by the government and, therefore, readily available. One of the arguably preventable hazards of the advancement in treatment was contamination of our blood-based products by viruses, especially HIV and hepatitis. I did not escape unscathed. My experiences with blood, both mine and that of others, have been as complex as any significant long-term relationship.

My hemophilia experience began shortly after my birth

in 1969, when my parents had me circumcised. I bled for a prolonged period of time, which turned a routine procedure into a scramble for a diagnosis. Hemophilia is usually an inherited disorder, but I was one of the 30% to experience a spontaneous gene mutation. In the U.S., hemophilia occurs in about one in 5,000 males. In rare cases, females are diagnosed with hemophilia (von Willebrand disease is a different bleeding disorder that affects men and women equally).

As with joke-telling, timing is everything, and I greatly benefited from being born at the end of a decade in which a revolutionary discovery completely changed the treatment landscape. To understand the evolution of treatment, it helps to understand why people with hemophilia have such difficulty forming clots. In the 1940s, researchers discovered that the bodies of people with hemophilia failed to produce adequate amounts of a protein necessary for blood to clot. These are called "clotting factors," and most people with hemophilia are missing "factor VIII." I belong to the group of 10% of people with hemophilia that doesn't produce "factor IX." In the 1940s, the standard treatment involved icing joints and transfusions with whole blood, neither of which was very effective. Most people with severe forms of hemophilia didn't live past 30.

In 1965, Dr. Judith Graham Pool discovered a process to extract clotting proteins from plasma through a form of freeze-drying. Beyond being able to effectively treat bleeding episodes, this discovery meant that people with hemophilia could have

emergency surgery and elective procedures that had been avoided before. It also meant that kids like me would not wind up spending the majority of our lives shuttling in and out of hospitals. In many ways, my childhood unfolded in a manner not too dissimilar from those of my peers, although I did get involved in a few public blood-drive campaigns. My parents were advised to keep me out of contact sports, which wasn't a big deal for me because I was more of an artsy type anyway. When I had a bleeding episode (we just called it "a bleed"), my mom took me to the local children's hospital for treatment, and then we went home. Eventually, my mom was trained to give me an intravenous injection, and I was able to remain at home in many cases.

As the experiences of people with hemophilia started shifting from just surviving to living, in the 1970s, joint damage became our biggest problem. Guys with hemophilia typically have problems from repeated bleeding into high-usage joints, such as knees, ankles, shoulders and elbows. When I first met other people with hemophilia, a lot of guys used wheelchairs or crutches at least some of the time. My life changed when I had a major bleed in my left knee as a toddler. Being a typically adaptive and creative kid, I wasn't fazed when I couldn't walk one day. I just wriggled into the other room and announced to my parents that I was "a snake!"

Following that episode, I got into a cycle of bleeding into my left knee, which gradually began destroying the joint. I wore a leg brace for a year, but it didn't help much. As I got older, I began using my right leg more, and the muscles around my left knee atrophied. That left it more vulnerable to bleeds, a truly vicious cycle. Besides my left knee, or "target joint"

in the medical parlance, I bleed into various joints and muscles throughout my body. Sometimes it happens spontaneously and sometimes because I bang into a table or chair. Blood flows into the affected area, which swells and quickly becomes painful. Injecting clotting factor into my vein allows my blood to clot, and the blood is gradually reabsorbed into my body. In a day or two, the clotting factor has cycled out of my body, and I'm a bleeder again.

I have always had an abundance of confidence and self-esteem, so I was out and proud as a kid with hemophilia in elementary school. The law that became the Individuals with Disabilities Education Act went into effect just as I began kindergarten, so I was never segregated from non-disabled peers. I experienced some mild teasing but recall general acceptance, although I'm sure I fielded the usual questions that anyone would have about something unusual like hemophilia. I also had a fantastic experience when I attended a camp for kids with bleeding disorders at the age of 11. Many of the counselors were also guys with hemophilia who had gone to camp themselves. A standard experience for many kids at camp was learning how to self-infuse with clotting factor for the first time, with the guidance and support of the medical staff plus the encouragement of older peers. I didn't have the courage at that time but did learn a couple of years later, when my dad volunteered his own arm for my first practice jab into a vein with a butterfly needle!

My relationship with openness experienced a seismic shift when two events hit me like a landslide in the early 1980s:

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Title I of the ADA : Job-Discrimination Protection

By Cindy Powell

Title I of the Americans with Disabilities Act (ADA) protects persons with disabilities (PWDs) from employment discrimination. Private employers with 15 or more employees, including part-timers; employment agencies; labor unions; and state and local governments, regardless of the number of employees, must comply with Title I of the ADA.

Covered entities must ensure that their employment practices and policies do not discriminate against qualified individuals with disabilities. Every aspect of employment is covered, including recruitment, hiring, promotion, demotion, layoff and return from layoff, compensation, job assignments, job classifications, paid or unpaid leave, fringe benefits, training and employer-sponsored

activities, including recreational or social programs.

Private employers with fewer than 15 employees, corporations owned by the federal government, Native American tribes and private-membership clubs that are not labor organizations are exempt from Title I. Federal government agencies are covered by nondiscrimination and affirmative employment requirements under Section 501 of the Rehabilitation Act of 1973.

The U.S. Equal Employment Opportunity Commission (EEOC) enforces Title I of the ADA. The employment provisions for state and local governments with fewer than 15 employees are enforced by the Department of Justice.

The ADA is applied on a

“case-by-case” basis. An employer is not required to provide an accommodation if it will impose an undue hardship on the operation of his business. As defined by the ADA, an undue hardship is an action that is unduly costly, extensive, substantial, or disruptive or would fundamentally alter the nature or operation of the business. In determining undue hardship, factors to be considered include the nature and cost of the accommodation, overall financial resources and number of persons employed.

An employer may require that an individual not pose a “direct threat” to the health or safety of self or others. A health or safety risk can only be considered if it is a significant risk of substantial harm. The risk must be based on valid medical analyses or other objective evidence, rather than speculation.

Employers cannot deny an employment opportunity to a qualified applicant with a disability merely

because of a slightly increased health or safety risk to self or others. If an individual appears to pose a direct threat because of a disability, the employer must first try to eliminate or reduce the risk with reasonable accommodation. If an effective accommodation cannot be found, the employer may refuse to hire an applicant or discharge an employee who poses a direct threat.

If an applicant or employee believes that he or she has experienced employment discrimination because of a disability, he or she may file a charge related to that claim with the EEOC within 180 days of the alleged act. When charges or complaints are filed after 180 days, individuals may not be able to obtain resolution.

Cindy Powell is an information specialist for the Disability and Business Technical Assistance Center of the Rocky Mountain ADA Center in Colorado.

People with Disabilities at Higher Risk for Swine Flu

By Barbara Bobbi Linn

People with disabilities (PWDs), especially children, are at high risk for the H1N1 virus and should be among the first groups to have both the seasonal flu vaccination as well as the H1N1 immunization.

The Centers for Disease Control and Prevention (CDC) recommends that people first have the seasonal flu shot, which is currently available, and then be immunized for the H1N1 virus, also known as the swine flu.

Since April 2009, when the H1N1 infection was initially identified, the number of children with disabilities who have died from this strain of the virus

has doubled. According to a report from the U.S. Centers for Disease Control and Prevention, of the first 36 U.S. children to die of the swine flu, almost two-thirds had epilepsy, cerebral palsy or other neurodevelopmental conditions. The Associated Press reported that, in a previous flu season, only a third of the children who died of the flu had underlying conditions. The term “underlying conditions” usually refers to PWDs.

Individuals unable to produce a cough hard enough to clear their airways are at greatest risk from this newest flu strain. According to a September

report by HealthDay News, researchers have confirmed previous reports that the H1N1 virus goes deeper into the lungs than ordinary seasonal flu, a possible explanation for why its effects are often more severe in people with disabilities.

People over age 24 may have some immunity to the H1N1 virus. Thus far, information analyzed by CDC supports the conclusion that 2009 H1N1 flu has caused a greater disease burden in people younger than 25 years of age than in older people. Pregnancy and other previously recognized high-risk medical conditions from seasonal influenza appear to be associated with the increased risk of complications from the strain. The Centers for Disease Control and Prevention identify these groups as “people at high risk”: pregnant, adults

with HIV infection, people with diabetes, people with cardiovascular disease, people with asthma and people with other medical conditions during flu season.

The CDC Web site, www.cdc.gov, has up-to-date information not only about the H1N1 virus, but many other medical issues. The site refers deaf and hard-of-hearing individuals to www.deafmd.org, a signed Web site whose mission is to provide clear and concise health education in American Sign Language to promote the overall wellness of the deaf and hard-of-hearing community. This site has information about the H1N1 virus.

Current key indicators show that influenza activity has increased in the United

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NCIL

A Message from the Executive Director

"Opportunity is missed by most people because it is dressed in overalls and looks like work." -- Thomas Edison

Dear Advocates and Friends,

The past year has been a whirlwind for our community. We barely had time to celebrate the enactment of the ADA Amendments Act and the Mental Health Parity and Addiction Equity Act before the election and inauguration. The NCIL annual conference brought hundreds of people with disabilities to the front lawn of the Capitol to demand civil and human rights. The health care debate took center stage and provided an opening to bring disability issues to the forefront of cultural consciousness. The President has begun to open doors to our community, providing the possibility that the independent living philosophy may one day reach the highest levels of American government.

Our community has been grounded on the sidelines of American politics for far too long, our voices falling on indifferent, apathetic ears. There is a perception by the American people that the highly anticipated transformation of the political atmosphere, the change that President Obama promised, has not materialized quickly enough. But change has come. It has come in the form of the invisible: opportunity. The NCIL articles in this edition of Independence Today highlight just a few of the ways our community is beginning to seize control of the dialogue and the course of our future.

Now, more than ever, is the time to get involved in the national independent living movement. NCIL's strength lies in the power of the voice of each member. The coming year will be difficult, filled with failures and small successes eclipsed by the magnitude of our mission. But we will persevere, remaining united in our goal to make independent living a right for every American. We will be stalwart in pursuit of freedom for our brothers and sisters still unjustly detained in nursing homes and other institutions. We will not rest until people with disabilities achieve true political, social and economic equality. And together we shall achieve it.

It's time to get our hands dirty. Join us at: www.ncil.org.

Sincerely,

Kelly Buckland,
NCIL executive director

The column For Directors Only will return in the next issue.

President Obama Meets Privately with Disability Representatives, Promises to Continue the Dialogue

On July 24th, President Obama invited NCIL Executive Director Kelly Buckland, along with 11 other representatives of the disability community, to meet privately with him, Attorney General Eric Holder, Secretary of Labor Hilda Solis and nine other senior White House officials in advance of the 19th anniversary of the Americans with Disabilities Act and the President's announcement of his intent to sign and seek Senate ratification of the U.N. Convention on the Rights of Persons with Disabilities.

Attending the meeting for the disability community were representatives from the U.S. International Council on Disabilities, Access Living of Metropolitan Chicago, the National Alliance on Mental Illness, the Consortium for Citizens with Disabilities, Arc and the UCP Disability Policy Collaboration, AAPD, the Global Partnership for Disability and Development, and several other businesses, organizations and individuals.

The disability community representatives engaged in a productive dialogue with Holder and Solis before the President arrived, discussing our priorities for civil rights enforcement at both departments, including but not limited to Internet accessibility, Olmstead enforcement, reducing the waiting period for ADA complaints to be resolved, using OFCCP to enforce the affirmative action provisions in the Rehabilitation Act, protecting children from the use of aversives and restraints, and implementing a governmentwide strategy to improve the representation of people with significant disabilities in the federal workforce.

When the President

arrived, he noted that the team had a wide-ranging agenda that included employment, education, technology, health care and civil rights policy, and he indicated his interest in using this first meeting as a listening session. The team emphasized the importance of seeing disability policy issues as fundamentally about fairness, civil rights and human rights. They shared personal discrimination stories and expressed a desire to work with the White House and agencies across the administration on a broad-based strategy to make progress between now and 20th anniversary of the ADA. A significant portion of time was devoted to health care reform and the need to end the institutional bias in Medicaid.

The disability community representatives came away believing that the President, his cabinet representatives and his senior White House staff are committed to working with the disability community to achieve the goals of the Americans with Disabilities Act. NCIL looks forward to following up on all of the issues discussed at the historic meeting, which represented a very important step forward for our community and for the country.

(Two weeks after that meeting, Attorney General Holder met again with the team, this time to discuss his leadership role, enforcement priorities and access to justice issues.)

Opportunities for the Independent Living Agenda in Health Care Reform

Following the health care debate in Congress the past six months has been a challenge, to say the least. With the last of five different bills finally passed out of committee, there

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is so much information and conjecture to process that many Americans feel completely lost on how to feel about the not-yet-written final legislation. NCIL supports universal health care, based on the belief that health care is a right, and we are looking forward to seeing the progress Congress can make on this front. But the massive bills that will eventually be merged into a single piece of legislation have provided us with the opportunity to advance some of our most basic and long-standing goals: ending the institutional bias and passage of the CLASS Act.

NCIL continues to vigorously support the Community Choice Act (CCA) as a stand-alone bill. It has been our unwavering goal to have the language of the CCA in the final reform bill; our policy is to pursue a compromise only if it becomes very clear that the CCA would not be a part of the reform legislation. Over the course of the last few months, that fact has been made very clear to disability advocates in Washington and throughout the nation.

NCIL is pursuing a compromise known as the Community First Choice option (CFC option). The CFC option would encourage states to provide Medicaid home- and community-based attendant services, rather than require them, as the Community Choice Act would. The cost of the CFC option is estimated to be \$1 billion over five years. It includes a "sunset provision," which means that, after five years, Congress would need to approve keeping the CFC option in place.

The core elements of the Community Choice Act (found in Section 101 of the bill) would be structured as an option for states to include in

their Medicaid state plans. The CFC option would provide individuals with disabilities who are eligible for nursing homes and other institutional settings with options to receive community-based services. CFC would support the Olmstead decision by giving people the choice to leave facilities and institutions for their own homes and communities with appropriate, cost-effective services and supports. It would also help address state waiting lists for services by providing access to a community-based benefit within Medicaid. The option would not allow caps on the number of individuals served, nor allow waiting lists for those services. Another important feature is that the Money Follows the Person program would be modified to move the basic eligibility requirement of six months of institutionalization to 90 days.

The CFC option is included in the bill passed out of the Senate Finance Committee; the CLASS Act, another important priority for our community, was included in the bill approved by the Senate Health, Education, Labor, and Pensions (HELP) Committee. The CLASS Act would assist people with disabilities who are employed and in need of long-term assistance or supports by providing a flexible cash insurance benefit that could be used creatively to purchase services, supports and technology.

(By press time, the issue of whether the CLASS Act or the CFC option would remain in health care reform legislation was not settled.)

Compiled by NCIL Staff

Get daily disability news, national news, advocacy alerts, and more at Independent Living-USA. Com or <http://www.ilusa.com>

Holiday Toy Ideas for Children with Disabilities

By John M. Williams

Elizabeth Johnson wrote: "I have a 7-year-old child with two disabilities. She is speech challenged and not very well physically coordinated. What would you recommend for me to buy her for Christmas?"

Joseph Meyers asked: "What can I buy my grandson for the holidays? He is nearly blind and has one leg shorter than the other."

Phyllis Thomas inquired: "I have twin sons, age 10, with CP. Their speech is sometimes not clear and they are challenged walking. They wrestle with each other and me. They laugh a lot. They are not challenged intellectually. They love building things. They are physically strong. My wife and I want to buy them unique gifts for the season. What would you suggest?"

Every year around the winter holidays I receive scores and scores of e-mails from people seeking to buy gifts for a family member with a disability. I love responding. Here are some of my suggestions.

VTree™ LLC (<http://www.vtreellc.com/>) develops special-needs software and assistive technology. The company designs video games that promote confidence and enhance social interaction. It designs customizable games especially for those who are challenged by cognitive or physical disabilities. VTree's games are adaptable and accessible. Its games can be manipulated to match the player's level of competency. As certain skills are mastered, the games become more challenging, allowing the player to experience success at each level.

Toys and gifts for muscle-

sensory integration include softballs with a textured surface, punching balls, squeezable stress balls, Play-Doh and vibrating toys.

Other toys include touch-and-read books, swings, ball pits, bouncing balls, rocking horses, inside play tents, bean-bag chairs, large golf clubs, tricycles or bikes with large wheels, trampolines, scooter boards, spin-and-move toys, large trains, crawling tunnels, record players, basketball hoops, switches that move animals and large dolls.

There also are Braille playing cards, large-print playing cards, audible balls, and a variety of tactile board games.

Each year, Exceptional Parent magazine reports on games and toys that could be fun and helpful for children with special needs. The site features several toys that stand out as fun products that could foster creativity, coordination, self-discovery and social interaction.

For information about choosing toys for specific impairments, go to the National Lekotek Center's Web site.

The Toys "R" Us Guide for Differently Abled Kids evaluates the listed toys and helps millions of people choose just the right toy for the children in their lives with disabilities.

The 2010 Learning Calendar from Fat Brain Toy Co. features 365 days of historical, biographical, little-known and amazing facts from the world of Spectacular Science. Every month in 2010 includes

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Assistive Technology
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taught by a speech coach to use exaggerated mouth movements and a breathy and affected speaking style to control her stuttering.”

On Churchill’s method of obtaining fluency, she wrote: “(He) was considered the best orator in Parliament despite the fact that he was a stutterer. He went to great lengths to hide and avoid stuttering. A great deal of preparation went into all his speeches. Churchill wrote them out well in advance, often weeks, of when he would have to give them. He memorized them forward and backward so he could practice them. Before beginning to give a speech, Churchill would hum discreetly to himself to get his vocal folds vibrating.”

Using technology to control stuttering or gain fluency does not happen overnight. Some people have found that a combination of speech therapy and assistive-technology products can produce fluency. (Assistive-technology products are mechanical aids that substitute for or enhance the function of some physical or mental ability that is impaired.) The earlier that stuttering is recognized and treated by a speech-language therapist, the more effective that intervention will be. Parents or guardians who notice their child stuttering should seek advice from the Special Education Services (SES) as soon as possible.

A person growing up with a stutter may feel discrimination, rejection, failure and ridicule. Those feelings can lead to a lack of self-esteem and less confidence. A person who stutters might appear shy, unintelligent or non-assertive, even if that is not the case. People who believe that stuttering is shameful or wrong or makes them different from others may harbor feelings

of isolation, loneliness and humiliation.

Stuttering was one of reasons that Lewis Carroll, who wrote “Alice in Wonderland,” was not accepted into the Catholic priesthood. Frustrated and deeply pained about his stuttering, he wrote this poem:

“Learn well your grammar,
And never stammer,
Write well and neatly,
And sing soft sweetly,
Drink tea, not coffee;
Never eat toffy.
Eat bread with butter.
Once more don’t stutter.”

(Part 2 of this article will appear in the next issue of Independence Today.)

John M. Williams, a stutterer for 56 years, has written many articles on stuttering. He can be reached at jmmaw@verizon.net.

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what had been achieved by the demonstrations, “we could see (then) how much needed to be done down the road.”

Having disability rights laws on the books is one thing. Ensuring that they’re implemented and that people with disabilities know what the legislation means and how to access it is equally important, Breslin said. At the time, “there were a few excellent lawyers and groups, but there was no national legal organization focused on disability rights law and policy.”

The modern disability rights movement took off during that period, Breslin said, because federal laws were passed that banned disability-based discrimination. “But to make laws productive, they must be implemented,” she said.

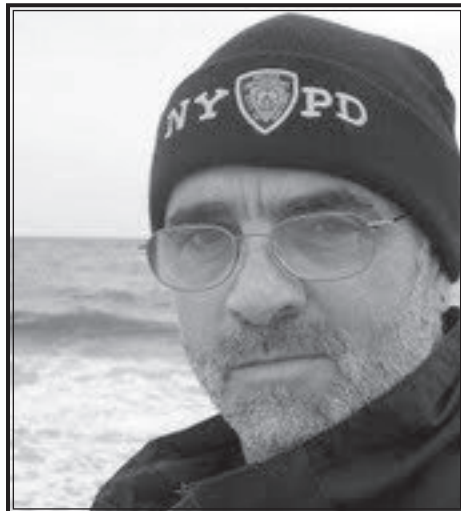
In 1978, Breslin began working with the Center

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to have a Ph.D. or master’s degree.

This is the second time this week components of the New York State Government have displayed despicable and unconscionable behavior. In actions that reek of narcissism, arrogance and greed, the New State’s Department of Health issued a letter blatantly ignoring the fact a state contract employee who has headed up a multi-million dollar project over the past 15 years isn’t who he says he is, and now the governor decides equal rights cost too much.



Peter S. Kahrman

People like Paterson and Feeney need to remember a few things; the willpower of the human spirit and the innate drive for independence and equality is far greater and far more powerful than any one person, and the damage they have done and continue to do is temporary.

We shall overcome. We’ve done it before, and we’ll do it again.

Peter Kahrman an advocate for people with disabilities and writes a blog on disability issues. He resides in New York state..

THE KAHRMANN BLOG is available on the home page of Independent Living-USA. Com or www.ilusa.com.

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States compared to prior weeks. At press time, 26 states reported widespread influenza activity, an unusual trend for the month of September.

According to the CDC, there are everyday actions that can help prevent the spread of germs that cause respiratory illnesses such as influenza. To protect your health:

- Cover your nose and mouth with a tissue when you cough or sneeze. Throw the tissue in the trash after you use it.
- Wash your hands often with soap and water. If soap and water are not available, use an alcohol-based hand rub.
- Avoid touching your eyes, nose or mouth. Germs spread this way.
- Try to avoid close contact with sick people.

If you are sick with flulike illness, CDC recommends that you stay home for at least 24 hours after your fever is gone except to get medical care or for other necessities. (Your fever should be gone without the use of a fever-reducing medicine.) Keep away from others as much as possible to keep from making others sick.

People with disabilities are advised to protect themselves as much as possible and to be in touch with a competent doctor, one who understands the ramifications of the flu on their disabilities. PWDs who experience any flu symptoms, such as fever, body aches, runny or stuffy nose, sore throat, nausea, vomiting or diarrhea, are advised to immediately call their health care provider.

Barbara Bobbi Linn is the founding executive director of the Bronx Independent Living Services and served as chairwoman of the New York State Independent Living Council. She is the author of "Ode to a Diet Coke: Disability, Choices and Control."

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middle school and AIDS. In many ways, my experience with middle school was the universal one in that it was bad for everyone but in a unique way. As I entered adolescence, I wanted to fit in, be cool and be different, but it soon dawned on me that my “difference” wasn’t cool (or at least that’s how it felt at the time). My decision to stop talking about hemophilia was strongly reinforced when doctors began diagnosing cases of AIDS among people with hemophilia. Because of our dependence on a treatment made with blood, people with hemophilia had already accepted exposure to blood-borne hepatitis as a cost-of-living expense – I had a bout with hepatitis B as an infant. But hepatitis didn’t ignite a community’s fears in the same way that AIDS would. A Time magazine cover story from July 1983 sealed the deal by bringing the link between AIDS and hemophilia into living rooms and waiting rooms all over the country. I went underground, and by high school I had begun developing an arsenal of excuses to explain why I was limping, using crutches or missing school.

My “official” HIV diagnosis came on January 20th, 1987, during my senior year of high school, but I had already concluded that I had it because the odds were not in my favor. From the late-1970s until the mid-1980s, when a process to kill viruses in blood products was developed, I injected clotting factor into my veins about once a week. A compounding factor was the fact that the blood-products industry pooled the plasma from thousands of people together while making our product. More than 50% of people with hemophilia would eventually acquire HIV through blood products, while more than 90% of people with severe hemophilia did. My

experiences with HIV/AIDS, and later, hepatitis C, have had profound effects on my life, but they are quite complex. It will suffice to say that I’m neither dead nor dying, am extremely fortunate and have many reasons to expect to be around for a long time to come.

Having survived high school, I moved from California to New York to attend college. By 1990, I came to terms with the reality of my situation and began living openly as a person with hemophilia again (and as a person with HIV for the first time.) Coming out in college by writing an article in the school newspaper was a daunting but ultimately fantastic experience because it allowed me to better define the way in which my disabilities were perceived by others. I also began developing my disability rights perspective and understanding of disability culture by getting involved in both the HIV/AIDS and hemophilia communities, including returning to hemophilia camp, this time as a counselor.

I returned to California after college and got a job teaching community-living skills to adults with developmental disabilities. Fortunately, my new (low-paying) job had an HMO plan because I couldn’t remain on my stepmom’s health insurance as I was no longer a full-time student. After a year of working that included many hours on my feet every day, the pain in my knee increased significantly. A visit with an orthopedic surgeon led me to conclude that I needed to schedule a total knee replacement, shortly before my 23rd birthday. The surgery was possible with large-scale infusions of clotting factor before, during and after surgery. I was very fortunate to have an employer that was very supportive: I got medical leave and short-term disability benefits, and I

was back at work full time three months following surgery.

One of the most eye-opening experiences of my surgery was when I received a copy of the bill and realized how much the blood industry charged for its products: nearly \$200,000 for the week of my surgery just for clotting factor. The HMO paid for it all. The clotting factor is still expensive: about \$1 per unit. I use 2,000 to 3,000 units for each infusion, every four to six days. It is not uncommon for people with severe hemophilia to reach lifetime insurance benefit caps of \$1,000,000 when blood products are counted as medical care and not as pharmaceuticals. It is one of the reasons that the hemophilia community has pushed for the elimination of lifetime caps as part of health care reform. On the flip side of this issue, however, is that pharmaceutical home care companies serving the hemophilia community compete for our business. I get birthday and holiday cards from both my current and former home care providers.

From 1994 to 1997, when I worked at a center for independent living in Albuquerque, N.M., -- the only time I had a job that did not provide health insurance -- I was able to convert my insurance from my previous job into an individual plan and pay for it out of pocket. My monthly payment of \$325 was a drop in the bucket compared to what I received in benefits. In 2009, such an arrangement might still be possible, but it is unlikely that the monthly payment would be affordable. Luckily for me, my move to Chicago in 1997 followed by only six months the effective date of the Health Insurance Portability and Accountability Act

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national disability rights organizations with the goals of generating dialogue on relevant issues and broadening the scope and impact of the disability rights movement.

October 28th, 1914 -- Jonas Salk, best known for his discovery and development of the first safe and effective polio vaccine, is born in New York City. After Salk, a medical researcher and virologist, developed his vaccine, mass trials held in 1953 on 1,830,000 children proved its efficacy. The vaccine was introduced in 1955. Salk received many honors, including a Congressional gold medal for his “great achievement in the field of medicine.”

-- **Compiled from various sources by Mike Reynolds**

Do you know of an important date in disability history?

Send it to Mike

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(HIPAA), which allowed me to circumvent a one-year pre-existing condition exclusion policy on my new employer's health insurance plan.

Since then, life as a bleeder has been relatively smooth, with a few problems along the way, such as the week that I was bleeding into my gastrointestinal system and didn't realize it until I was passing out from blood loss. I also had to get my knee replaced again in 2004 when the cement holding the first one in place came loose.

I met my wife, Karen, through our work in the disability rights movement, and we adopted our daughter, Dominika, in 2006. At that time, I left my job as a disability rights trainer and transportation advocate to be a full-time, stay-at-home dad. Dominika doesn't really understand about hemophilia, but she is fascinated by my self-infusing (and all the paraphernalia that goes with that) and always claps for me when I'm done.

For more information about hemophilia and other bleeding disorders, go to: <http://www.hemophilia.org/NHFWeb/MainPgs/>

Kevin Irvine is a freelance writer, and first time contributor to Independence Today. He lives with his family in Chicago, Ill.

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a science experiment that can be done at home or in the classroom with everyday items.

A specialty toy store owner is likely to be a resource for parents seeking appropriate materials for their children. For information on store locations, go to www.astratoy.org or contact the American Specialty Toy Retailing Association (ASTRA).

Here is what to keep in mind when toy shopping:

For multisensory appeal: Does the toy respond with lights, sounds or movement? Are there contrasting colors? Does it have a scent? Is there texture?

For activation: Will the toy provide a challenge without causing frustration? What is the force required to activate it? What are the number and complexity of steps required?

Regarding adjustability: Does it have adjustable height, sound, volume, speed, level of difficulty?

Opportunities for success: Can play be open-ended with no definite right or wrong way? Is it adaptable to a child's individual style, ability and pace?

For the child's individual characteristics: Does the toy provide activities that reflect both developmental and chronological ages? Does it reflect the child's interests?

John Williams can be reached at jmmaw@verizon.net. His Web site is www.technews.com.

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for Independent Living in Berkeley. The CIL had started a program called the Disability Law Resource Center (DLRC) to provide legal services for people with disabilities in the Bay Area. "Nobody was convinced then that people with disabilities needed legal services," Breslin said. "After '504' was signed, the DLRC provided training (in the regulations)."

DREDF was established in 1979 after it was spun off from the DLRC. From the get-go, the group's mission was to "shape and form the evolution nationally of disability rights law and policy," Breslin said.

From its inception, the Disability Rights and Defense Fund has represented clients, Breslin said. "DREDF devotes about 10 percent of its time to direct client services," she said. For the other 90 percent, DREDF "tries to pick cases that would open a new door (around disability rights legislation) or advance a new (policy) issue," Breslin said.

An early example of DREDF's influence on the legislative landscape occurred during the first term of Ronald Reagan's presidency. A task force of then-Vice President George H. W. Bush wanted to rescind the 504 regulations, Breslin said. "They argued that (they) were too extensive," she said. "DREDF threw its resources into preserving the '504.' Before faxes

and e-mail, DREDF ran a serious grass-roots campaign in support of (the regulations)."

DREDF worked with its Washington, D.C., contacts to protect the regulations. "C. Boyden Gray, then-White House counsel to Vice President Bush, played bridge with (the late Equal Employment Opportunity Commission chairman) Evan Kemp Jr.," Breslin said. "Eventually, the review of the 504 regs was halted." (Gray is now a member of the board of directors of the Atlantic Council.)

"This was a critical political accomplishment," Breslin said. "Saving 504 set the stage for passage of the Americans with Disabilities Act. The ADA is based on 504."

The Disability Rights and Education Defense Fund also has had a profound effect on the U.S. Supreme Court's understanding of disability. Historically, Breslin said, the Supreme Court "has seen disability as part of the 'medical model' -- it viewed disability in terms of sickness and benefits. The court hasn't viewed disability as a civil rights issue. DREDF has played a key role in educating the court in getting (it) to view disability in terms of civil rights."

Susan Henderson has been executive director of DREDF since 1997. Though she had a leg amputated in 1977, "I didn't identify with the disability community or have a disability consciousness," she said. "I thought of myself as an amputee."

Henderson, who had studied anthropology, was managing a small progressive law firm and studying at night for an M.B.A. degree. As she moved forward in her career, she realized that she didn't want to practice law in the private sector

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anymore. After seeing an ad in a legal newspaper, she applied for a position at DREDF.

"I came in (to DREDF) for an interview, and I knew it was the place where I wanted to be for the rest of my life," Henderson said. "I'd grown up during the civil rights era, during a time of gay rights, women's rights, African-American, and other kinds of civil rights activism. I knew that human resources people were always trying to circumvent the ADA. It was upsetting to me."

When she interviewed at DREDF, Henderson didn't disclose her disability. "It seemed like an unfair advantage. So I never said anything."

One day, Henderson, who wears a prosthetic leg, was sitting at her desk. "It was really funny," she said. "I popped my left leg off and started rubbing a spot where it was hurting. Kitty (Cone, who has worked with DREDF off and on for years and is now a development consultant for the organization) started screaming to everyone in the office, 'She has a disability! She has a disability!'"

"It's been an honor to work for DREDF," Henderson said. "I've learned a lot delving into our history during our 30th anniversary. You forget how involved we were in (securing passage) of the ADA."

Today, DREDF continues to work on many fronts of disability law and policy.

In September, DREDF went to trial with co-counsel Howrey LLP to represent the American Council of the Blind in a class-action lawsuit. The trial took place before Judge William Alsup at the U.S. District Court for the Northern District of California. According to a statement on the DREDF

Web site, the suit was filed on behalf of ACB and 3 million blind and visually impaired plaintiffs because the Social Security Administration has failed to provide its communications in alternative format. At press time, the judge had not yet issued a ruling.

DREDF took the lead in the writing and research of a National Council on Disability report titled "The Current State of Health Care for People with Disabilities" that was released in September. "Getting a disability rights perspective in health care is a big issue," Breslin said. "It hasn't changed in 20 years. We're trying to tweak disability rights issues into the current health reform debate."

Other items on DREDF's busy docket include working to ensure that children with disabilities receive an appropriate education, working with foster children with disabilities, and working with the media, Henderson said.

Foster children with disabilities live with "the double stigma of having a disability and being in foster care," Henderson said. "Because of this, it's a tough sell to get foster kids to embrace their disability."

DREDF works to bridge the gap between foster care and the disability community, Henderson said. "Many social workers in the child welfare system don't know about what it means to have a disability, and many people in independent living centers don't understand about life in foster care."

The law can go a long way toward changing societal attitudes toward people with disabilities, but to truly create change, the media must be involved, Henderson said. "Just like GLAAD (the Gay and Lesbian Alliance Against Defamation) and the women's movement, we have to address the media



The late Senator Edward Kennedy (rear row, center) poses with DREDF's staff and other advocates on the day the Americans with Disabilities Act legislation was signed in 1990. (Photo provided by Julia Epstein.)

as another arm of what we're doing."

People at DREDF work hard, Henderson said, "but they do it because they like it. They want to right wrongs."

The work of the Disability Rights Education and Defense Fund is known and felt widely. Millions have been trained in the 504 regulations, the ADA and other legislation by its staff. A few years ago, Henderson was at

a conference in Dallas. "Mary Lou (Breslin) had taught some of the people there about (Section) 504," she said. "Our reputation precedes us."

For more information about DREDF, go to www.dredf.org.

Kathi Wolfe is a writer and poet. She writes frequently on disability issues. Her recent book, "Helen Takes the Stage: The Helen Keller Poems," was published by Pudding House Press.



American Foundation for the Blind President and Chief Executive Officer Carl Augusto, right, accompanied by Senate Majority Leader Harry Reid of Nevada, inspect the statue of Helen Keller during an unveiling ceremony in the Capitol Rotunda on Capitol Hill in Washington, Wednesday, Oct. 7, 2009. (AP Photo/Vucci)