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DISABILITY RIGHTS JOURNALIST SHAPIRO GETS IT 'WRITE'

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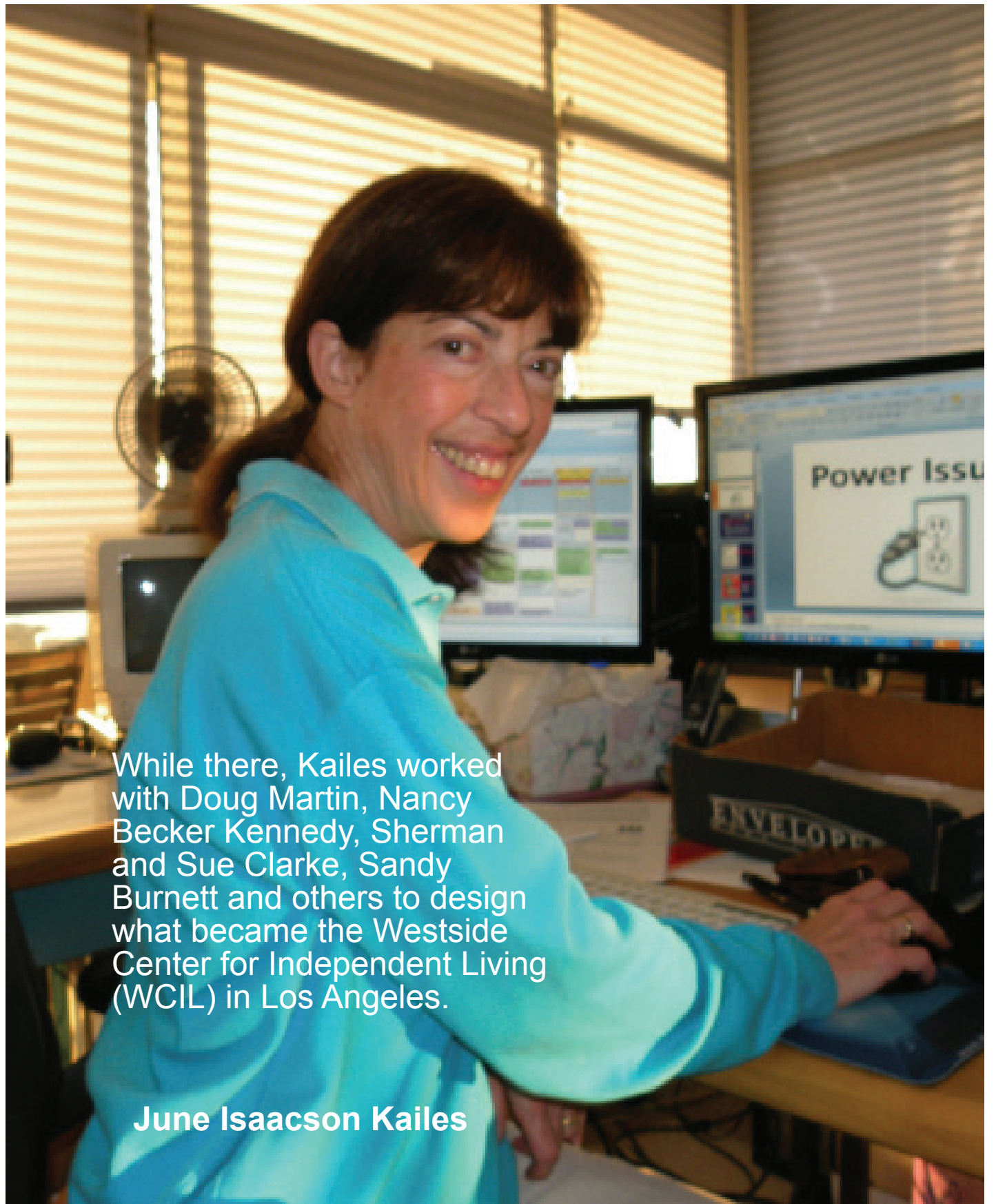
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While there, Kailes worked with Doug Martin, Nancy Becker Kennedy, Sherman and Sue Clarke, Sandy Burnett and others to design what became the Westside Center for Independent Living (WCIL) in Los Angeles.

June Isaacson Kailes

Judge to SSA: Make Notices Accessible to People with Blindness

By Penny Reeder

On October 20th, William Alsup, United States district judge for the Northern District of California, ruled in favor of the American Council of the Blind (ACB) and the class of blind and visually impaired Social Security recipients it represented in its lawsuit against the Social Security Administration (SSA).

The ruling requires the Social Security Administration to communicate with blind and visually impaired benefits recipients in an effective and accessible manner. That means that SSA can no longer simply send printed notices to blind beneficiaries through the mail, and that blind and visually impaired Social Security benefits recipients won't have to hope they locate a reader for their personal mail before they find themselves out of compliance with some unexpected SSA demand. Because the class represented by the ACB includes people who cannot read standard print due to blindness or visual impairments, SSA will be required to communicate with them in Braille or via a file in Microsoft Word on a computer compact disc (which a blind recipient can presumably read via his or her screen reader or screen magnification software).

SSA sends out more than 100 million notices each year to more than 60 million recipients. About 250,000 people receive benefits because of blindness, and another 2.7 million blind or visually impaired Americans receive Social Security for other reasons. Notices may alert recipients about pending hearings, new tax rulings, possible cuts in benefits, program changes or scheduled appointments.



The Social Security Administration emblem

Before the recent ruling, when blind and visually impaired people had asked SSA to provide notices in accessible formats, their requests had repeatedly been denied. Until now, a person who is blind could request only that SSA send notices via regular or certified mail and provide a follow-up phone call. SSA, however, consistently maintained that it was not required to provide any other kinds of formats or delivery mechanisms.

There have been reports that blind and visually impaired Social Security recipients have had benefits denied and penalties levied because they had no knowledge of a pending hearing or weren't aware that the agency was disputing some aspect of a filing or case. The ACB convinced the court -- and the court agreed -- that when SSA fails to communicate with blind and visually impaired consumers in an accessible manner, it is in violation of civil rights protections under Section 504 of the Rehabilitation Act of 1973.

Rather than simply telling the SSA to develop the

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THIS DAY IN DISABILITY HISTORY

November 10th, 1969

-- National Education Television debuts "Sesame Street." "Sesame Street" premiered on the Public Broadcasting Service, combining Jim Henson's Muppets, animation, live shorts and cultural references. The show was one of the first on television to regularly feature children with physical and developmental disabilities, including Jason Kingsley, an individual with Down's Syndrome who was often seen on the show in the '70s and still continues to advocate for individuals with disabilities. By its 40th anniversary in 2009, "Sesame Street" had become the most widely viewed children's television show in the world, with 20 independent international versions, broadcast in more than 120 countries.

November 13th, 1956 --

James Troesh is born. As a teenager, he suffered a spinal cord injury as a result of a swimming accident, which left him a quadriplegic. His entertainment career took off when he landed the recurring role of the quadriplegic attorney on "Highway to Heaven," starring Michael Landon. The lead role catapulted him into appearances on several other series, TV movies and films. Troesh later won the prestigious ABC/Disney writing fellowship. His first script, "Color of the Cross," was made into a film in 2006. He currently is developing a pilot for a comedy titled "The Hollywood Quad."

November 23rd, 2003 --

"The Disability Gulag" by Harriet McBryde Johnson is published in The New York Times. Johnson won widespread praise for her groundbreaking essay

about her dealings with famed controversial ethicist Peter Singer. In that essay, she discussed her visit to Princeton to debate Singer over his view that parents should be able to kill their children up to 28 days old. In "The Disability Gulag," Johnson discusses her activism and how close she came to living in a nursing home because of her physical disability. A lawyer who fought tirelessly for the rights of people with disabilities, and against Jerry Lewis, Johnson published two books before passing away in June 2007.

November 24th, 1986

-- Susan Sontag's story, "The Way We Live Now," is published in The New Yorker. The short story describes the beginnings of the AIDS crisis in the early 1980s, as the disease began to claim members of the New York cultural elite. The story is told entirely in the form of fragments of conversation, mentioned and whispered by numerous friends of an unnamed man who lies sick in a hospital bed. Although AIDS was new to many who read the story when it first appeared, "The Way We Live Now" remains a signature work in the literature of the epidemic.

November 25th, 1950

-- Janine Bertram Kemp is born. Bertram became famous in the 1960s as a member of the radical anti-war group the George Jackson Brigade. Her husband, Evan Kemp, became head of the Equal Employment Opportunity Commission in the '80s. Bertram Kemp is a tireless advocate for the rights of the disabled; she is active in the prison rights movement and is working to end the institutional bias of Medicare.

December 1st, 1937 -- The federal government bans the use of cannabis with the passage of the Marijuana

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CoverStory

June Isaacson Kailes: A 'Big Picture'

Focus

By Janine Bertram Kemp

Some people make history. June Isaacson Kailes builds futures.

Kailes, one of the founders of the independent living movement and an expert on accessible telecommunications, is smart and quick on the verbal draw. She has authored several books and been an active player in the disability rights movement since the late 1970s.

In 1972, Kailes was in her second year of graduate school in southern California when a friend invited her to drive up with him to see the Center for Independent Living in Berkeley, which was then operating out of an apartment. It was an "ah-ha" moment for her. "It blew me away," she said. "It was like coming home. I mean, you could feel it, you could touch it, you could smell it, you could see it. It was a whole different approach."

Working as a medical social worker at Rancho Los Amigos National Rehabilitation Center in Downey, Calif., had a lasting effect on her life and attitude. "I

saw many people being forced to go into nursing homes because community services were not available," she said.

While there, Kailes worked with Doug Martin, Nancy Becker Kennedy, Sherman and Sue Clarke, Sandy Burnett and others to design what became the Westside Center for Independent Living (WCIL) in Los Angeles. She joined the staff there to develop peer counseling program and other services, became a member of the board of directors and then, in 1981, was named executive director.

"There I was: director," she said. "I didn't know anything except that I'm organized. I knew certain things had to be done correctly, like personnel and payroll. And I was never hard up for ideas. I went to meetings with other directors and asked millions of questions. At that time (in the very early days of the independent living movement) none of us had a blueprint."

Kailes sought and organized training sessions whenever and wherever she could cobble them together, utilizing the Center for Nonprofit Management, which offered classes on a variety of management issues. She became the technical assistance coordinator for the California Coalition of Independent Living Centers. "Back then, I would bring in trainers for every meeting. Whatever I didn't know, I figured other people didn't know either."

After a decade of providing services to individuals, she saw that nothing would change giving assistance person by person. "We had to affect the big picture or we would get nowhere fast," Kailes said.

Her commitment to systems change grew, and she became less interested in service delivery. "That created tension," she said. "There was a battle

because lots of people were interested in service delivery and were not interested in the big picture. They didn't want to be part of actions, demonstrations or lobbying the state legislature. To run a center, you have to be a generalist and do a bit of everything. I was feeling the need to delve into systems change in depth. I didn't know what I would do next, but I'd lost interest in what I was doing."

Kailes left WCIL in 1989. She worked as a consultant for the National Council on Independent Living and the state independent living (IL) organization, and conducted training sessions for Independent Living Research Utilization.

She later narrowed her interests and expertise to accessible health care and accessible emergency services. She began work on emergency management in the mid-1990s, long before 9/11 and Hurricane Katrina made headlines.

"June doesn't mince words," said Alexandra Enders, a longtime friend and colleague. Enders has been a senior researcher and policy analyst for 20 years at the Rural Institute at the University of Montana. "June's always been an interesting character. If she says something is good, you should believe it. She moves in a number of worlds, but most people who describe June know only one aspect of her work. Like so many IL leaders, she maintains a consistent orientation to disability rights. She's brought that orientation into the mainstream through her work: accessible emergency services, telecommunications and accessible health care."

Brenda Premo, another pioneer of the independent living movement, is Kailes'

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close friend and colleague. They are both professors at the Center for Disability Issues and the Health Professions at Western University of Health Sciences in Pomona, Calif.

She and Bob, her husband of 30 years, don't frivolously spend money, Premo said. "They save and go traveling four to six weeks a year. It's like an art for her. She and Bob immerse themselves wherever they are, and she always looks at access.

"June has an unbelievable work ethic. Her talent is the ability to pinpoint a problem and 'laser' in on what needs to be done. It may not be possible to do at the time, but she will keep trying different approaches until she succeeds."

Kailes, who turned 60 last May, is multifaceted and has numerous interests. She is a painter and a "techie," collects old technology and reads medical fiction.

Kailes has worked tirelessly to bring IL concepts into accessible medical care and emergency preparedness. She has argued that if society doesn't provide equality of service, people will face discrimination because of pity.

"Because of the way she does things, many have not seen what an impact she has," Premo said. "June's work is done mostly through writing and speaking skills. Consequently, many in the disability movement don't realize what she has contributed."

Enders noted that Kailes dragged her into the arena of disaster preparedness, arguing the importance of including people with disabilities in emergency planning and looking at the big picture. She challenged the concept of "special needs,"

instead emphasizing "functional needs" that are common to many people. Hurricane Katrina proved her right.

Kailes told Enders she knew that half the U.S. population met the federal government's typical "special needs" definition (disability, seniors, children, those who do not speak English). Working with Kailes on a paper, "Moving Beyond Special Needs: A Function-Based Framework for Emergency Management and Planning," Enders ran the data for special needs populations and found that Kailes was right: 49.8% fit the government's definition of special needs.

"Previously, June just had an opinion," Enders said. "Now, June also had data, and she knew what to do with it. There was a work group meeting, and June spoke after Michael Chertoff (former U.S. Secretary of Homeland Security). Chertoff is a great speaker, and she was a little worried about following him. But June is a fine presenter, with good slides, and she had the audience. They were finally starting to comprehend that the issue was not special needs but universal design. When she put up the slide with the data showing it actually was half the population, the whole timbre changed. They were saying, 'Oh, my God. This is real.'"

Kailes' persistence paid off --- her function-based definition is now included in the Department of Homeland Security-Federal Emergency Management Agency glossary for special-needs population. Though the government has not changed the label, it has changed what it means. Kailes, though, believes there is a long way to go to create emergency preparedness practices

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Disability Rights Journalist Shapiro Gets it 'Write'

By Mike Ervin

The man who wrote the definitive history of the disability rights movement has no disability himself.

Joe Shapiro is the author of "No Pity: People with Disabilities Forging a New Civil Rights Movement," published in 1993. Shapiro, who was raised in a middle-class neighborhood in the nation's capital, remembered Washington, D.C., as "an exciting place to grow up."

"I remember being on Pennsylvania Avenue for parades to welcome home astronauts, for John F. Kennedy's funeral and to protest the war in Vietnam," he said.

Witnessing so much history made him want to be a journalist. After attending Carleton College in Minnesota and majoring in American studies, Shapiro spent a summer helping a friend start a weekly newspaper in an Iowa town of 1,200. Then he went to Columbia University for a year of graduate school.

In 1986, Shapiro landed his "dream job" as Rome bureau chief for U.S. News & World Report magazine. But financial pressures shut the bureau down less than a year later, and Shapiro returned to the magazine's Washington headquarters. It was a time when the disability rights movement was really catching fire, mostly under the radar of the mainstream press. Shapiro took notice and chronicled the stories of the people involved in the movement, eventually carving out a journalistic niche.

"It was pure accident that I started writing about disability," he said. "I was assigned to write about social policy, but there were already other reporters

doing the two biggest parts of it, health and welfare, so I was scrounging around to find something to cover. "

Today, Shapiro is a correspondent on the science desk of National Public Radio and covers aging, disability and children and family issues. He continues to report about disability with a clarity and empathy unparalleled in the mainstream media.

Q: When you were growing up, were there any moments or events that caused you to "get" the disability thing?

A: Did I "get" the "disability thing" when I was a kid? No way. My mother would tell you otherwise. At the book party for "No Pity," which was filled with important disability civil rights figures, my proud mother told Judy Heumann and anyone else who listened that as a kid I'd gone out of my way to be kind to "Albert the crippled paperboy." Ouch. I'd completely forgotten about him. And I'm not sure what I ever did for him. He was an older teen with cerebral palsy who delivered the afternoon paper.

Growing up, I didn't know people with disabilities. My interactions were pretty traditional. One of the first times I can remember thinking about disability was, at about age 10, raising money for the Jerry Lewis telethon. I think my sister and I came up with about \$6. I don't remember getting thanked by Jerry.

In high school, I was a member of a service organization. I remember going to the segregated special ed school which still exists in D.C. I drive by it

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Ski for Light Event a Real Eye-Opener

By Deborah Kendrick

I was a young mother who had left her two toddlers at home with her husband and had just ridden a bus 14 hours for an adventure my only blind friend had persuaded me would change my life. The bus ride was long and miserable, and temperatures fell along with the snow as we sped further north onto Michigan's Upper Peninsula.

When I finally arrived at the hotel, I received a message that my friend was delayed and wouldn't be there till the next morning. I was assigned, temporarily, to room with two other women -- one blind, one sighted -- who had come for the same adventure but seemed to me so much older and more sophisticated than I. They were.

I put on my extrovert persona and managed to enjoy the new friendships. Morning came, Marcia arrived, and we moved to our own room.

Norwegians, they say, are born with skis on. There, toddlers like mine ski long distances with their parents, and blind people do so, too. A blind man, in fact, had brought the gift of this program, Ski for Light International, to the United States. Erling Stordahl was his name, and in his country he was a renowned musician. In Norway, the Ridderren, a program that teaches blind Norwegians to ski, was alive and thriving. With his experienced ski guide/instructor friend, Olav Pedersen, Stordahl "transplanted" the program to the U.S. a few years earlier. About 200 of us, 100 blind and 100 sighted, had come to Traverse City for a week of fun in the snow.

I was physically fit enough, but I had never done anything particularly athletic in my life. On the other hand, Marcia, who had talked me into joining this enterprise, had raised and ridden horses all her life and was a swimmer, avid cyclist and, in a few short years of cross-country skiing, one of the fastest skiers in this group. I couldn't stop asking myself what I'd been thinking.

Then it was Monday morning and we were out in the cold where, despite my layers of clothing, I thought I'd never be warm again. I had been fitted for boots and skis, which my guide/instructor Betty now handed to me.

I had been a rehabilitation teacher of blind adults for a while and knew that the traditional way to teach blind adults was with loads of "dry run" preparation. To show people how to iron, for example, you would have them handle the iron, review its controls, practice the motion on a piece of cloth, and do these steps repeatedly before plugging the thing in. No such pedantry here!

Betty showed me how to line up the pins on my boots with the holes in the skis' bindings. After much fumbling with freezing fingers, I was standing on two narrow six-foot-long pieces of wood! Within seconds, it seemed, I was skiing!

At Ski for Light, participants ski all day every day, improving their technique, as the guide and blind skier becoming acquainted with one another's preferred method of communication. We skied in preset tracks, grooves in the snow that fit the skis, two sets cut parallel throughout the course -- one for skier

and one for the guide. Betty told me when the course ahead was uphill or downhill, when we were approaching trees, and what the surroundings were like. Participants learned that, as speed increases, verbosity decreases.

Saturday is always race day at Ski for Light, and the excitement is palpable. Skiers choose between a competitive 10K race, lined up according to estimated race times. Many Norwegians participate each year; some of them are so experienced that guides ski in front of them and ring a bell for them to follow rather than wasting time on verbal cues.

The event, which has been held for more than 30 years, is conducted at different sites and attracts skiers from throughout the United States, Canada and Norway, as well as several other countries. A motto of the organization is: "If I can do this, I can do anything." Indeed, once you have experienced the thrill of flying down a hill, completely untethered to any human or mobility device, snow crunching beneath your feet, wind in your face, the tasks of daily life seem simpler, and a challenge is far more welcome and inviting.

More than a decade would pass before I was able to return; when I did, the event and the sport were more glorious in reality than in memory.

We were in Granby, Colo., in 1995 when I attended Ski for Light again, and the event was both better and the same. One difference was the substantial contingency of wheelchair users. The mobility-impaired participants (MIPs, as they are called, as opposed to the visually impaired participants, the VIPs), use what are called sit-skis and shortened poles. Somewhat resembling small sleds on skis, a sit-ski requires upper-body strength to propel and control the

skier's movement. Until trying one a few years ago, my own misconception was that skiing for the MIPs was more of a thrill-seeking "ride" than the rigorous workout that traditional cross-country skiing typically is for the rest of us. What I discovered in my brief experiment, however, was that propelling oneself uphill from a sitting position with short ski poles was exhausting, and to do so for any significant duration was well beyond my arm power.

Of course, there's much more that goes on during a Ski for Light International week. Skiing is conducted during the day and a smorgasbord of après ski activities are offered in the evening. Dances are held most nights, and other activities include live concerts, a local arts and crafts showcase, a talent show, and Norwegian Night (featuring Norwegian food, music, customs and Norwegians in traditional native dress).

Ski for Light International didn't make me a world-class skier, but it did, however, broaden both my perspective and expectation. The world, I learned, was full of people who are smart, attractive, engaging and competent in any conceivable realm of physical, intellectual or artistic prowess -- many of whom happen to have visual or mobility disabilities. I left my first event knowing that there were many challenges I had never met and was eager to find some of them. And I wanted more -- much more -- of the fantastic sport that is Nordic skiing because it's so much fun and because it reminds me that "If I can do this, I can do anything!"

(The 35th annual Ski for Light International Week will take place from Sunday, January 31st through Sunday, February 7th, 2010,

Ski
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Second of two parts**New Device Gives Hope to Stutterers***By John M. Williams*

Embarrassed by his stuttering, Sir Isaac Newton (1643-1727) demanded that the windows of Parliament be closed so the public would not hear him stutter.

In more modern times, Aneurin Bevan, a British Labor Party leader in the 1930s and an opponent of Winston Churchill in Parliament, was considered one of the greatest orators in Parliament. Bevan made public speeches as often as possible to help overcome his stuttering. He also developed a remarkable vocabulary by substituting words to avoid stuttering.

Lots of people think that they have stuttered from time to time, but stuttering is much more complex than occasionally repeating or stumbling over words. Stuttering does not mean that the person is excited or cannot think of the word they want to say. It is an involuntary behavior; people who stutter cannot help it. When asked once why he stuttered, Churchill replied, "I don't know why I stammer." (Stammering and stuttering are synonymous.)

The cause of stuttering is still unknown. In the past, people believed that stuttering was caused by nervousness, bad parenting, genetics, inability to coordinate the speech muscles, psychological problems or talking too fast. Current evidence tells us that stuttering has a large genetic component. This inherited genetic factor may cause speech pathways in the brain to be less efficient. The inefficiency of the pathways makes it difficult for children to meet fluency demands by getting their words out quickly. Genetics may also have an adverse effect on children's temperament, causing them to react negatively to their own early stuttering behavior. Combined, these

elements may increase the likelihood that some children will stutter.

The tendency of children to persist with or recover from their stuttering may also be genetically determined. Some outgrow stuttering on their own, possibly because their brains reorganize the speech pathways or because they eliminate their negative reactions to their behavior. But some children may continue to stutter into adulthood, possibly because they maintain inefficient brain pathways and a reactive temperament. Boys may be genetically preprogrammed to persist in their stuttering more than girls.

Dealing with stuttering can be traumatic because there aren't quick and easy solutions, and it has no cure. It takes lots of hard work and practice to control the involuntary stuttering behaviors. Some stuttering remedies focus on having the person speak in a novel manner; for example, talking in time to rhythmic movements of an arm or speaking in a monotone. These offer only temporary solutions. The novel mannerisms can become habituated, and then they no longer help people control their stuttering. Slowing the rate of speech, relaxation techniques, and learning to smooth out the involuntary stuttering behaviors are some things that can help them overcome stuttering.

Speech language pathologists tell people going through therapy that they should not conceal their stuttering, should not substitute words for the ones they are trying to say, and should speak slowly. Many pathologists say that it is vitally important that a child who stutters does not come to believe that stuttering is a reason to withdraw from interacting

with other people and that parents and teachers should help prevent negative emotions from becoming part of a child's stuttering experience. This means that even if the child does not speak fluently he or she can at least speak freely.

Ben Kordsmeier has a cousin who stutters. Dane Stephens and Austin White say they do not have any relatives who stutter. The three boys stutter but do not have friends who do so. None of the three boys believes he is intellectually deficient. In fact, there is no evidence of differences intellectually or emotionally between children who stutter and those who do not.

All the boys use SpeechEasy, a portable and inconspicuous fluency-enhancing prosthetic device that fits in or behind the ear. SpeechEasy users receive therapy, part of which includes being trained on the device. Each of the three boys receives speech therapy anywhere from once to twice monthly. Part of their SpeechEasy training is learning to use the product so that they pay attention to the auditory feedback. Most users learn that after a few days of actively reminding themselves to listen to the device, the process becomes automatic.

"It wasn't long after I started using the SpeechEasy that I would remember to concentrate on what I was saying," White said. "Once I started doing that, my speech started being fluent." He has been using the SpeechEasy for two years and said he feels comfortable using it.

Part of the continuing therapy associated with the SpeechEasy is stretching vowel sounds to achieve the voice inhibition through difficult sounds. As the boys approach a sound they know is difficult they stretch out the vowel sounds on a few words prior to pronouncing the difficult sound. They

apply this technique by stretching the vowel sound on small words throughout their reading or during a conversation.

"By stretching vowel sounds, I have more fluency," Stephens said.

When either putting the SpeechEasy into their ear or behind it, the boys do warm-up exercises for about a minute to become accustomed to listening to the device. They may count from 0 to 10, recite the months of the year or say something. They also practice the "uh" method. When they do, they read out loud, and when they stop to take a breath, they resume reading by saying "uh." This exercise contributes to an improvement in their conversational speech.

The SpeechEasy has to be specially fitted to each user. There are three types: One fits completely in the ear canal, another fits into the canal and the outer ear, and a third type fits behind the ear. The device, which is easily inserted and removed, comes with a battery, microphone, volume control and vent. It should be cleaned daily.

The boys wear the SpeechEasy almost all the time when in school and pursuing social activities. They do not wear it when showering, playing, swimming or in places, such as restaurants, where there is a lot of noise. They love the benefits it brings them. When the boys are not wearing the SpeechEasy, they say the carry-over effect ranges from 90 minutes to two hours, especially after they have worn it all day.

White echoed the sentiments of the other two boys when he said, "The SpeechEasy improved my whole life for the better."

The boys say that, as a result of the device, they

Stutterers
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Commentary**It's Time to Fight for Olmstead Plan Implementation***By Janine Bertram Kemp*

The disability rights movement is all abuzz about "the Missouri Letter." For the first time in 10 years, the federal government may enforce the Olmstead decision and protect the civil rights of people with disabilities (PWDs) who choose to live in their community.

(The Olmstead decision is based on a 1999 Supreme Court judgment on behalf of two women with developmental disabilities who were voluntarily admitted to a hospital for treatment in a psychiatric unit. They later indicated their preference for discharge, and the professionals working with them assessed that they were ready to move into a community setting with appropriate support. They were not successfully discharged from the hospital, however, and a lawsuit followed. The Supreme Court eventually ruled that under Title II of the Americans with Disabilities Act, the women had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA.)

Many national leaders now believe that we in the disability community have a chance to change the course of history as it pertains to getting and keeping people with disabilities out of nursing homes and other institutions. Leading disability activists believe the U.S. government has signaled that it is willing to let people with disabilities out of institutions -- what some advocates have called "prisons."

The late Justin Dart Jr. used to encourage disability advocates by calling us

"patriots" and exhorting us to "lead on." Kirsten Dunham and Paraquad (the St. Louis CIL) have been leaders in the struggle to force their state to implement Olmstead.

Dunham is associate policy director at Paraquad and was a key player in the Disability Coalition on Health Care Reform's campaign to stop Missouri from applying the "homebound rule" to people with disabilities on Medicaid. Their efforts led the Center for Medicare and Medicaid Services (CMS) to write the Missouri Letter.

On October 30th, 2009, 10 years after the Supreme Court issued the Olmstead decision, the CMS wrote the state of Missouri saying, in essence, that if the state did not comply with the Supreme Court's Olmstead ruling, Missouri would lose its Medicaid funds.

The letter directs Missouri to comply with an earlier CMS directive sent to all 50 state Medicaid directors early in the administration of George W. Bush. CMS said that people with disabilities have a choice -- the choice to be given services in the most integrated setting: in their own homes and in their own communities.

In 1999, after the Olmstead decision was filed, CMS came up with policy guidelines. One of those guidelines was that states should not use the Medicare homebound rule in their Medicaid programs. According to Medicare home health regulations, persons must be homebound to receive community-based services. Basically, that means they can leave their homes for medical appointments

only -- not for going to the movies, to restaurants or to other activities, including jobs.

Although the disability community has made numerous attempts to get that rule overturned, it still stands. Despite the fact that CMS directed states not to use the homebound rule with Medicaid, many still follow it, including Missouri. Last year, advocates began a campaign to get that state to stop and began by writing to Missouri's Medicaid director with no results. Then they began writing to the director of the CMS. Several letters went out that included support from many social justice groups and health care advocates.

"It was a systems advocacy effort that brought some results," Dunham said. "In Missouri, we focused on the homebound rule. In other states, advocates can use other tools like civil rights complaints and lawsuits to make your state implement Olmstead and the ADA."

"The homebound rule forces people with disabilities to choose between getting services and getting out and living your life," said Michelle Steger, leader of the Missouri chapter of ADAPT. "I have not heard that the CMS letter is making a difference yet in Missouri."

According to Dunham, Missouri recently responded to the CMS before the 30-day deadline to do so expired. The state claimed it does not know if it can comply with the elimination of the homebound rule, citing budget constraints. It asked for more time to comply.

Is Missouri calling CMS' bluff? If the state refuses to comply with the directive, then CMS will either yank the state's Medicaid dollars or let it keep violating the civil rights of its citizens with disabilities.

Even if the CMS letter has not yet translated into

a policy of real choice for Missourians with disabilities, it is of national importance to disability rights advocates.

"Although we had some run-ins with the Obama administration, this action by CMS gives us hope that, at least with enforcement on Olmstead, the feds are moving in the right direction," said Bob Kafka. Kafka, ADAPT's national organizer, is an expert on disability policy.

The "run-in" to which Kafka referred occurred at a meeting with health care czar Nancy-Ann DeParle and her assistant, Henry Claypool (a longtime disability advocate). DeParle dismissed ADAPT representatives by stating, "You'll just have to get used to the institutional bias."

DeParle's imperious words and attitude aside, top administration officials at the Department of Justice (DOJ) have signaled to NCIL, ADAPT and other disability organizations that they are quite interested in enforcing the Home and Community-Based Services (HCBS) provisions of Olmstead and the ADA.

"Send us some solid cases," Tom Perez, assistant attorney general of civil rights at the DOJ, told disability leaders. Attorney General Eric Holder also expressed interest in enforcing Olmstead.

Mike Oxford, executive director of the Topeka Independent Living Resource Center and former president of NCIL, attended the meetings with DOJ officials. He characterized Perez as "gung ho about Olmstead."

Kafka agreed. "The HHS (Health and Human Services) Office of Civil Rights may take some steps to enforce Olmstead, but the big enchilada is the

Olmstead
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Disabled Author Not Running from New Challenges

By Amy Halloran

Twenty-one years ago, Floyd Skloot was afflicted with a virus that damaged his brain. He is an award-winning author of 15 books, three of them memoirs that touch on, among other topics, the subject of disability.

Independence Today recently talked to Skloot, a resident of Portland, Oregon, about his career and his life with his wife, Beverly.

Q: I'm curious about how you had a career in public policy and you were a poet. Tell me about those diverging impulses.

A: I had discovered poetry when I was about 20 years old and recognized that it was something I would be doing for the rest of my life, writing poetry. I completed my undergraduate work and was interested in studying with a poet that I admired. I ended up studying for almost two years with the Irish poet Thomas Kinsella and, during that time, it became clear to me that I was not necessarily interested in pursuing an academic life. I began to interview in 1972 with potential employers who didn't rule you out if you had a master's degree in English. I ended up signing up for an interview with the Illinois Bureau of the Budget, and I got that job. The career path in public policy was in some respects complete serendipity, and it became a way for 17 years for me to use writing, a different kind of writing, for earning a living while doing my creative writing on the side.

Q: You were going to a conference on public policy when you got sick. Has that career ever come back into your life?

A: I'm totally disabled, I

don't have a career. I can't work outside the home. It's one of those cases of be careful what you look for. I used to think, since I was working full time and raising my child and running as a competitive long-distance runner, 'Gee, I wish I didn't have to work, because then I'd have more time to write.' Then I got sick and I'm unable to work, but I actually have less time than I had before because of the ups and downs of my health. The best way of conducting myself is to be able to write for those few hours a week when I am capable of writing.

Q: Tell me about your latest memoir.

A: There's a sequence of three memoirs, the first being "In the Shadow of Memory." There's a sequel called "A World of Light." If "In the Shadow of Memory" is about putting myself together and at the same time my mother is falling apart, "A World of Light" is her falling apart, the end, and moves my consideration from instead of trying to put myself back together (to) trying to find a way out into the world, in some fashion, as a disabled person. The third memoir is "The Wink of the Zenith: The Shaping of a Writer's Life." It's about the forces that I believe made me a writer from childhood on, and about halfway through the book, at the point where I think I've begun to understand the forces that made me the sort of person who can only cope with what happens to him by writing about it, the emphasis changes toward how the writing gives shape to the life. So it starts out by being the forces that shape a writer and leads to talk about the way a writer shapes his life.

Q: You lived in the woods for 13 years. Do you miss it now that you are back in Portland?

A: It was a wonderful experience for us. I mean I'm a boy from Brooklyn, New York, for gosh sakes. It was a wonderful experience and exactly what I needed. We moved back three years ago. I'm now 62. It was beginning to be a lot of work for both of us, for Beverly and for me, to sustain our life on such remote and demanding terms. I miss the tranquility and isolation, the quiet, but I feel like we were done out there. An interesting thing is we live in Portland like we lived there. I don't go anywhere, other than an occasional grocery errand.

Q: So you haven't had much trouble reintegrating into society?

A: I've tended to keep society still at bay because I don't think it's good for my health, from an immunological standpoint, a neurological standpoint, from a focus and concentration standpoint, from a writing standpoint. It's just not good for me to have too much going on.

Q: Were you a very involved person before the illness?

A: I had a rich social life; my life was very busy. I was at the tail end of raising my daughter, who was 16 when I got sick. We did some entertaining. I was very engaged as a runner. That was taking up hours every day, training and competing. I was on various civic boards and commissions as part of the work life that I had, so, yeah, I was pretty engaged and trying to sustain my life as a writer amidst all that. So it is a bit of change. I feel it suits me as a person. I am by nature I think more reclusive than I was allowing myself to be and less interested in spreading myself as thin as I used to spread myself. Being ill forced me to evaluate what is good for me, what is right for me as a person and

particularly as the person I've become.

Q: Before you were disabled, did you ever have an appreciation of people being disabled?

A: In some senses I guess I would say I did. My father -- when I was 11 -- was critically injured in a car accident. Both of his legs were completely shattered. He was hospitalized for the better part of a year, and when he came home, we had physical therapists come to the house, we had parallel bars in the bedroom. He eventually got to where he could get out of bed and get in a wheelchair, and with a built-up shoe, finally stand. So I witnessed that sort of a recovery when I was a boy, which culminated two years later in his death from a sudden heart attack, ironically enough. I never thought of my father as disabled so much as having busted legs and having to learn to walk again, but of course he was disabled, and I guess that gave me an early window into what you do when something like that happens. You do the work you have to do to get back.

Q: Do you miss running?

A: Oh, yes, very much. I would do the training on these trails throughout Portland, so I found ways to compensate for that, like living in the woods, but this sense of myself as being integrated in this body that worked beautifully ... well, I had to relearn my relationship to my body and accept and be comfortable with a body that didn't work the way it did before. I miss running; I miss the physical capacity that I always felt filled with. I can't really do aerobic exercise, but I try to walk 20 minutes to 40 minutes a day. Nothing aerobic, really, but I can go up hills. Beverly and I tend to walk together every day, and it's a really nice

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Olmstead
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Justice Department.”

What CMS did by writing the Missouri Letter could be the sea change that opens the way for getting people with disabilities out of nursing homes and institutions and into HCBS. For 10 years, the federal government backed states' rights, that is, it would not enforce the ADA or Olmstead because it claimed that states have the right to decide how federal dollars are spent -- even if they are violating civil rights laws.

The states' rights argument was used to avoid enforcement of the 1964 Civil Rights Act that mandated equality for racial minorities and women. After Olmstead, people with disabilities were locked away in institutions and had their civil rights violated. Though not lynched or beaten, like African Americans were in the 1950s and 1960s, PWDs are still abused, neglected and sometimes killed in institutions.

“This could be the signal that the Department of Health and Human Services' Office of Civil Rights (OCR) and the DOJ are finally going to take a civil rights view of disability,” Kafka said. “We hope they are signaling that they will hold states accountable for Olmstead like they did during the civil rights era.

“People bitch and moan but won't go to the trouble of finding out what their states are doing vis a vis Olmstead and institutionalization policy. Now is the time for advocates in all 50 states to learn what Olmstead violations exist and lodge complaints. We cannot blithely say the sky is falling. We must know what our states are doing. If there are cuts to HCBS, we need to file those complaints with HHS, OCR

and DOJ.

“This is a key opportunity that the disability community has not seen in decades. I'm hoping that DOJ and the Office of Civil Rights at HHS are inundated with complaints. The power of CMS is in rule implementation and money. We must make them hold states accountable.”

Currently, many states are cutting HCBS services but not decreasing the dollars they spend keeping people in institutions (the nursing home industry has a powerful lobby). The first step for CILs and other advocates is to assess their state's implementation of the Olmstead decision. They should find out whether there is a formal Olmstead Plan or what the policy is for implementing “the most integrated setting.” Learn what number of people will be diverted from institutions and how many will be transitioned out each year.

Does your state have a waiting list for HCBS? Disability rights attorney Steve Gold thinks that in itself may be an enforceable civil rights violation under Olmstead and the ADA.

Locate people in nursing homes and other institutions who want to live in the community and file civil rights complaints with the Department of Justice (<http://www.justice.gov/crt/drssec.php>) and HHS Office of Civil Rights (<http://www.hhs.gov/ocr/> -- click on “How to File a Civil Rights Complaint.”)

“We can't let states off the hook,” Dunham said. “We have enforcement tools with CMS and DOJ. Advocates should use these when states try (to) balance their budgets on the backs of people with disabilities. We've got to make sure that they are not making budget cuts in a way that violates the rights of people in nursing homes or at risk of going into nursing homes.”

Questions for Evaluating Olmstead Compliance in Your State on page 11

The time is now. The resources are there. It's up to advocates in each state to make sure the Olmstead decision is implemented.

ADAPT compiled a number of detailed questions and benchmarks advocates can use to learn if and how their state is implementing Olmstead. These points can be used to request information by writing state officials. Start with the state Medicaid director. If your state stalls on giving answers, send the questions as a Freedom of Information Act request.

Janine Bertram Kemp, a writer and disability rights activist, serves on the board of Disability Rights Oregon and is a member of ADAPT. She lives in Mt. Hood, Ore.

Stutterers
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are accepted as being “normal” among their peers. Being accepted by their peers is an important aspect of growing up.

National Stuttering Association
<http://www.nsastutter.org/>

Stuttering Home Page Chat Room
<http://www.mnsu.edu/comdis/kuster/chat/chatroom.html>

University of Wisconsin Family Village Stuttering Page
http://www.familyvillage.wisc.edu/lib_stut.htm

John Williams, a contributing writer to Independence Today, He is credited with coining the phrase “assistive technology.” John M. Williams has stuttered for 56 years and has written many articles on stuttering. He can be reached at jmmaw@verizon.net.

SSA
Continued from page 2

standards for effective communications, Judge Alsup delineated the acceptable methodology that the agency must utilize for communicating with people who are blind and visually impaired.

Until the suit was under way, Alsup said, “the agency refused to even acknowledge that it was obligated to follow Section 504, routinely denying individual requests for accommodation. In this litigation, it has been quick to find lame excuses for noncompliance but exceedingly slow to favor accommodations. To merely order the agency to comply with Section 85.51 would lead to more lame excuses with no accommodations.”

The ruling will require SSA to communicate with all blind and visually impaired benefits recipients on its rolls by December 31st, advise them of the availability of the two alternatives for communications (Braille and compact disc), and allow them to choose other, more effective, means of communication (e.g., large print or e-mail) if they so desire. A Social Security recipient can expect to begin receiving notices in his or her format of choice by April 15th, 2010.

In addition, SSA will be required to train its staff to communicate orally with blind and visually impaired clients who initiate telephone, written or e-mail discussions concerning relevant notices, rulings and communications.

Penny Reeder became blind as a result of retinopathy of prematurity. She lives with her husband and their six children in Montgomery Village, Md.

FOR DIRECTORS ONLY

ILUSA.Com Calendar of Events

The Internet portal Independent Living-USA.Com (www.ilusa.com) is launching a calendar of events for items of national interest. Calendars of events are nothing new on the Web or, for that matter, disability Web sites. We found some very good calendars at many disability Web sites. Many had similar characteristics, such as limiting events to one type or another. The calendar for ILUSA.Com is for many types of events.

The calendar of events provides an 18-month range: the six previous months and the 12 months ahead. Types of events are broken down into categories as follows: conferences, "webinars" and training, community events, fund-raisers and disability history. The latter category is a principal departure from most disability calendars. Categories are defined as follows:

1. Conferences include, for example, the annual parleys of the National Council on Independent Living (NCIL), the ARC, the national autism organizations, the American Medical Association, and so on. Posts should include all conferences times. As a community, we should know of conferences that might be of interest to the community or a segment of the community. Conferences such as those held annually by FamiliesUSA.Org, a key advocacy group in the health care reform effort, have embraced many, if not all, of the tenets that the disability community worked for in the Health Care Reform Act. Also

to be included in this category are conferences on assistive technology and orthopedic equipment, along with other aids.

2. Webinars and training sessions are usually announced via e-mails or e-zines. Why not let other people know of these valuable training opportunities? Why speak to only some members of the disability community or, for that matter, leave out the public at large? More important, the group sponsoring the training will benefit from gaining curious visitors to its Web site, which may result in additional members or support.

3. Community events may include local rallies, ADAPT actions, lobbying efforts on the local or national level, and Congressional hearings on disability-related legislation or regulations. Community events are, by definition, local. But as one political adage says, "All politics is local." We agree. But some community actions have national implications. Further, others who learn of a local event or rally may be interested in replicating that action in their communities. The recent local rally in Albany, N.Y., against a proposed county nursing home is a good example, not to mention the behind-the-scenes strategies and other political maneuvers.

4. Fund-raisers are events and activities that increase revenue for an organization. These include huge gala affairs, dinners with speakers, races, dances and more. Posting fund-raising events not only announces what your

organization is doing, but it is an open invitation to individuals who live within a reasonable distance of the event. Many people go to fund-raising events to see firsthand what they entail. For example, the Independent Living Center of the Hudson Valley Inc. in New York holds a fundraiser it calls the Dessert Spectacular. The center has hosted the event for more than 20 years. Since the first Dessert Spectacular, an event that showcases desserts and other heavenly sweets from local restaurants and bakeries, others have come up with wine-tasting events and even chefs' competitions.

5. Disability history items are dates of the birth or death of a disability hero or heroine, or the day of a significant disability event, such as the signing of the American with Disabilities Act on July 26th, 1990. A disability hero or heroine need not be a person with a disability; he or she can be a parent, a doctor, an inventor (such as Dean Kamen, the developer of the iBot wheelchair), a policymaker (such as Senator Tom Harkin, D-Iowa), a CIL director, an author or a reporter -- in short, anyone who has performed an action to advance the human rights or social standing of people with disabilities. Even the founding of an organization, such as the March of Dimes or the American Association of People with Disabilities (AAPD), may be posted under this category. We hope many of you will take the opportunity to post your birthday and your contributions to the disability rights movement, or that of your friend or sibling. Please be brief: Five or six lines should do it. You can insert a link to either Wikipedia or any Web site where your full bio or article is posted.

The ilusa.com calendar is designed to provide different views; for example, the "Today"

button takes a viewer to the current month. Another button, "12-Mon," shows a listing of 12 months, and "Scroll" lists all the events posted for that month. On the single-month view, you can distinguish among the different categories of events because they are all color coded. For example, disability history items are listed in light gray with white text, conferences are green coded, webinar and training are brown, fund-raising events are bright green, and community events are dark blue. The default view of the calendar for events is "All Categories."

When you hover over an event with your mouse, it shows the short-version name for the event. Just click on the event and a new window will be displayed with the information posted. The calendar highlights "today" in yellow. It shows all national holidays, major Jewish holidays and some lunar-based observances. Four lunar phases are embedded. Basically, it has everything you need to schedule something without conflict.

To post an event, go to ilusa.com and click on the lower left-hand side of the calendar where it says "P. Figueroa" and submit an e-mail. The direct e-mail for submissions is: events@ilchv.org. Please submit events at least three weeks before they are to occur.

More on the ILUSA.Com Calendar of Events will be mentioned in later issues of Independence Today.

-- By *Patricio Figueroa*

**VISIT ILUSA.COM
FOR DISABILITY
NEWS, NATIONAL
HEADLINE NEWS,
TOPIC OF THE DAY,
DAILY OBSERVANCES,
DISABILITY BLOGGERS,
AND MORE.**



Call for Presenters

NCIL 2010 Annual Conference on Independent Living

20 Years of the ADA: The Fight Goes On!

July 19th-22th, 2010; Grand Hyatt, Washington, D.C.

Submit a Workshop Proposal

Please share your ideas and experiences with others in the Independent Living Movement at the NCIL 2010 Annual Conference, "20 Years of the ADA: The Fight Goes On!"

In the two decades since President George H.W. Bush signed the Americans with Disabilities Act into law on July 26th, 1990, we have seen access and attitudes improve exponentially. However, as a community, we remain painfully aware of the significant work that remains to be done. Successes like the Olmstead Decision have been dampened by a lack of action or urgency by Federal and State Governments. The promises of equal opportunity in hiring and employment have been decimated by a skeptical judiciary. Substantial increases in accessible housing and transportation are mitigated by the fact that nationwide, the lack of these vital resources remains the largest barrier to independence for people with disabilities. In the context of balance between success and continuing challenges, we will celebrate the 20th Anniversary of the Americans with Disabilities Act.

There will be plenty of celebration at the 2010 Annual Conference on Independent Living, so we ask that workshop proposals acknowledge the work that remains. In addition to the following topic suggestions on the ADA and the ADA Amendments Act of 2008, we always value workshops for new advocates and attendees that offer basic and historical information on the Independent Living Movement, Centers for Independent Living, Statewide Independent Living Councils, advocacy, systems change and non-profit management.

Workshop Ideas: Successes and failures in one of the five Titles of the ADA; New regulations and provisions of the ADA Amendments Act of 2008; and topics for new IL staff, such as:

- IL History & Philosophy;
- CIL / SILC Management;
- Advocacy and Systems Change;
- Reauthorization of WIA / Rehabilitation Act;
- The Independent Living Administration; or
- Reform of Healthcare and Long Term Services & Supports.

Deadline for Submission is Monday, January 15, 2010. No proposals will be accepted after 11:59 p.m. Eastern time.

All proposals must be submitted electronically to be compatible with screen-reading software. If you

are unable to submit your proposal electronically, please contact angela@ncil.org to make alternate arrangements.

PLEASE NOTE: We are returning to the Grand Hyatt Hotel again this year. NCIL's block of sleeping rooms will open in late February 2010. Watch for your registration brochure with more details, coming in February!

This Call for Presenters is the only request for speakers, group facilitators, or poster presentations that will be issued.

Questions for Evaluating Olmstead Compliance in Your State

1. Does your state have a formal Olmstead Plan, a state policy that implements the most integrated setting? Does it list by year the number of people who will be diverted from entering nursing homes (NH)? How many in NH who will be transitioned out each year? Have dollar estimates been made of what it will cost to transition or divert people out of NH each year?
2. Has your state cut or reduced home and community programs and services (e.g., waivers, PCO) while leaving nursing home programs status quo? What are the details of each program?
3. Has your state kept home and community programs at about the same reimbursement level but increased nursing home reimbursements?
4. Has your state used proportionally less drastic cuts on nursing homes than on home and community programs and services?
5. What is the pattern of funding NH and community services over the last 10 years?
6. Are there inequities in state budget policies that mandate increases for NH but not for community services?
7. Does your state do "global budgeting" (placing institution and community funds together in one budget)?
8. What are other inequities between NH and community policies and funding?
9. Do any of your HCBS programs that would divert people from NH have waiting lists? How many people are on them? How long do they wait for services? What obstacles in each program are keeping people from being placed in the community?
10. Does your state have a uniform assessment policy or form that focuses on diverting people from entering NH, such as a community integration screen? Does your state have a policy to divert people from NH? What is the state policy?
11. Does your state have a proactive process to inform

Olmstead Questions*Continued from page 11*

people entering NH of all the programs available in the community? Could you explain what the state does before a person enters a NH? Does it use the "most integrated setting" as a criterion?

12. Has your state developed, submitted and signed a data use agreement (DUA) with CMS so it can obtain and release Q1 data (which can identify by name nursing home residents who want out)?

13. Does your state have a proactive process to inform the Q1 people of community services and programs that are available to help them move from NH to the community? Does it make referrals to community organizations such as AAAs and CILs or give assistance in relocating or transitioning? Does it have community integration coordinators? How does your state identify who wants out of a NH?

14. Does your state have a federal or state MFP project or policy? How many people have transitioned out of NH?

15. Does your state use a "too risky" criterion or require "informal care" as a reason to deny community services? Does your state make determinations that there are people in NH who are too significantly disabled to live in the community, such as "too physically ill" or "service needs too great"?

16. Does your state have a policy or program linking nursing home-eligible people to available behavioral health services that may not be available in traditional aged and disabled community programs?

17. Are there inequities in wages for the waiver or PCO work force versus the nursing home work force or inequitable wage increases for people doing similar work? Can you describe the inequities in each program?

18. Does your state have a formal policy or procedure to assist people either in NH or at risk of going into NH in obtaining affordable, accessible, integrated housing? Are there any housing coordinators or community integration coordinators available?

19. Does the Medicaid office have a relationship with the state housing office or with public housing authorities that helps people attempting to obtain housing avoid going into or getting out of NH?

20. Does your state have a policy or funding to acquire needed durable medical equipment or assistive technology that would allow people to remain or transition into the community?

21. Does your state have a nurse delegation or assignment policy or legislation to allow for qualified non-licensed people to perform health maintenance tasks?

-- *Compiled by ADAPT/Institute for Disability Access*

Commentary**Activists, Lawyers an Essential Team in Reform Movement***By Mike Ervin*

Lawyers and activists working together using litigation always have been crucial in advancing the cause of disability rights.

This was illustrated again last fall. California Governor Arnold Schwarzenegger has been hell-bent on making drastic cuts in the state's In-Home Support Services (IHSS) program. Under the budget approved in July, more than 120,000 people with disabilities would have had the vital in-home assistance they receive through the program cut off or significantly reduced. Street activists fought back in the manner they know best:

They protested. They sat outside Schwarzenegger's office until they were hauled away by security. They did what they could to draw media attention to the injustice.

But it took a lawsuit to stop the cuts from being implemented. On October 19th, U.S. District Court Judge Claudia Wilken enjoined the state from eliminating or reducing anyone's IHSS support until a lawsuit challenging the cuts could be heard. The suit was filed by Disability Rights California (DRC), the California protection and advocacy agency, on behalf of five plaintiffs who are IHSS recipients.

Last summer, David Oster of Torrance, Calif., who has autism and is bipolar, was scared to death that he would lose his IHSS support. Through IHSS, his aide, Juila, assists him up to 63 hours a week with tasks such as housework, food preparation and taking medication.

"Julia's like second family," Oster said. "Before I received services, my apartment was out of place. I was completely off." He said Schwarzenegger's budget cuts would eliminate him from IHSS. "I heard about the cuts and I had a nervous breakdown. I had to go into the mental hospital."

So he contacted DRC for help. Before he knew it, he was a plaintiff in a class-action lawsuit, *V.L. v. Wagner*, that challenged the cuts. Outside the courthouse before the hearing at which Wilken issued her injunction, about 100 people rallied in their

Author*Continued from page 8*

experience for us to have together.

Q: Is she still painting?

A: She's painting, she's weaving, she's making baskets. She's taught herself the violin, the piano and now the guitar, which is quite a neurological challenge as you get older. She's remarkable.

Q: Sounds like she was an inspiration for you to challenge yourself as you recovered.

A: We're together all day every day, pretty much. We get on very well. She was so supportive from the start. We weren't together when I got sick. We knew each other, but we weren't together. That didn't happen until four years after I got sick. So she knew what she was getting into.

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

Activists*Continued on page 14*

Kailes
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June Isaacson Kailes
working in her office.

that are accessible. She also sees huge barriers remaining to accessible health care.

Nineteen years after the passage of the Americans with Disabilities Act, Kailes gives mixed reviews about disability and society. "It's like we are playing the game Chutes and Ladders and right now, especially in California, we are going down a long chute."

Despite the hurdles she has encountered, Kailes has retained an optimistic, big-picture view.

"The disability movement runs broad and deep," she said. "We don't have enough people to cover the waterfront, but we have some very good people. Advocacy is not about being right. It's about the processes, the pressure points and the legal actions. It's all got to work together. Writers write, activists demonstrate and lobby, bureaucrats press from the inside. It all contributes."

Janine Bertram Kemp, a writer and disability rights activist, serves on the board of Disability Rights Oregon and is a member of ADAPT. She lives in Mt. Hood, Ore.

Shapiro
Continued from page 4

on the way to work. We'd take kids in wheelchairs fishing. I'm sure I felt good about helping out.

At Carleton, I joined a group who volunteered at Faribault State Hospital, a state institution for children with intellectual disabilities. At the time -- early 1970s -- Minnesota was talking of moving people into group homes. We got a house on campus and drove a big turquoise 1967 Cadillac with fins down to the institution. We'd bring two kids a night up to the house to experience what it meant to live in a house, eat family style at a table, use a private bathroom and "adjust" to living in a house, not in an institution, where you shared a cot in a room with three dozen other people. The idea was that the kids would stay overnight with us, model our behavior, and that would help them succeed in a group house. Not that modeling after 12 college kids would teach someone how to live in any kind of optimal way. I probably went into this thinking it was another kind of do-good service activity. But this time, I really got to know someone with a disability. I worked with a 12-year-old named Jim Gordien, who'd lived in the institution from the time he was 6.

Q: What was the first disability-angle story you wrote?

A: I tell the story in "No Pity" how I got a call from Arney Rosenblat, a PR woman at the MS Society, in 1987 to interest me in a story about some group of presidential appointees who were drafting some law called the Americans with Disabilities Act. I went to a Washington hotel where Justin Dart, Lex Frieden and others were talking about access and rights barriers. I don't think I'd quite understood it all. I wouldn't really get it until I left the hotel. There were two cabs in line. The first



Joseph Shapiro covers health, aging, disability, and children and family issues for NPR.

picked me up. Behind me was a man in a wheelchair. The driver of the second cab saw him and did a U-turn and sped away, leaving the man. I watched through the back seat of my cab, and it all clicked. If this man can't get a cab, how can he get around? Washington's subway is pretty accessible, but it only goes so far.

I went back to my office at U.S. News and wrote my first story about disability, about this thing called the disability civil rights movement, how disabled people were rejecting traditional views of them as objects of pity or inspiration, creating their own culture, saying their issues were of rights, not health, and how they were trying to change both physical barriers and attitudinal ones. I'd quoted important people from Pat Wright to Cheryl Wade. It was well-written and interesting. My editor thought it too far-fetched that people with disabilities had their own civil rights movement. The story didn't get printed.

That might have been the end of my attempt to write about disability. But about three months later, students at Gallaudet University shut down the school when the board of trustees refused to name a deaf person president of the school. The Gallaudet protest got a lot

of national attention. For the first time, Americans were hearing about disability and civil rights in the same sentence. I've always thought the Gallaudet protesters got attention, and sympathy, because their leaders had preppy, all-American good looks. They weren't in wheelchairs or anything too scary to Americans who don't want to think about disability. I covered the Gallaudet protests for U.S. News, and I then sold the earlier, unpublished story on the disability civil rights movement to the Washington Post health section, which did a special issue on Gallaudet and Deaf culture.

Q: What is it about this disability beat that interests you so much?

A: I kept writing about disability issues because there was always something fresh and interesting to say. I keep writing because there is always a disability angle to any social policy issue. Seeing things from a disability angle gives me a fresh and smart understanding of issues. The people I met kept teaching me. It was self-advocates who first told me about Johnny Lee Wilson, a man with a mild developmental disability who confessed to a murder he didn't commit. I went to Missouri and did reporting that helped get Wilson released from prison. For NPR, I did a series on soldiers and Marines back from Iraq and Afghanistan dealing with injuries. Those were all disability stories -- the narratives about people dealing with physical injuries, PTSD, head injuries and trying to live independently. If you did an analysis of all my stories, the word that probably pops up most frequently, other than disability, would be "independence."

Q: How did "No Pity" come

Shapiro
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Commentary

Helping Each Other with Personal Care

By Kimberly R. White

We are two of the most uncommon friends. I am the caregiver, a licensed registered nurse diagnosed with multiple sclerosis. My client is a retired correctional officer who is legally blind. She is also hard of hearing and uses a walker to get around. I was asked by the client's daughter to stay with her mother until a permanent caregiver could be found. It was supposed to be temporary, but I didn't count on making the feisty woman, Louise, my friend.

Her granddaughters began calling her "Gangster Granny" because she had worked as a correctional officer in Indiana in 1968. As it turns out, working with felons was a lot easier than enduring a recent visit to the hospital this month.

With hazel eyes and a quick smile, she has endured many of life's high and low points. She was around when Franklin Roosevelt was president and saw five brothers go to World War II and return. But today, she faces more obstacles. I visited her during a recent trip to the hospital for a surgical procedure in which she required nourishment and fluids. It was during her hospitalization that I became acquainted with the difficulties confronting individuals who are both deaf and visually impaired.

For one thing, she couldn't tell if her call light was answered. Because of her visual impairment, she didn't know where the food was on the plates served at meal time. She didn't know where her eating utensils were. No one on the staff took the time to describe and assist her, even though her impairments were known. She said she prayed for a nice roommate who could answer her calls

and speak to the nurses over the intercom when they answered the call light.

Louise couldn't see, couldn't hear and was unable to get to her walker. She asked me to visit, to assist and to talk to her nurse over the intercom during visiting hours. But at night, Louise was terrified by the thought of being left alone in a strange hospital. After I received special permission to stay with her after visiting hours were over, she was finally able to doze off to sleep.

Gangster Granny made me and many of the staff and nursing personnel aware of how a trip to the hospital can be a terror-filled experience. It can be a real nightmare to our most vulnerable citizens.

Louise has since recovered and returned to live with her son Allan. Her daughter Wynetta and Allan make sure all of her needs are met at home. Another son, Daniel, is always willing to travel the long distance to visit when work and time permit. It is a rare occurrence when Louise's vulnerability is exposed. With both her son with the flu and her daughter needing emergency surgery, Louise was left to depend on me as a friend and the staff at a nearby hospital for care.

What a brave woman she is. I can only tip my hat to Gangster Granny and others like her. They make the difficult seem easy and give new meaning to the word "challenging."

Kimberly R. White is a registered nurse and frequent contributor to Independence Today. She lives in Florida.

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Tax Act. Since the mid-1990s, disabled activists and people with AIDS, multiple sclerosis and other disabilities have fought the government ban by arguing that the plant has medical benefits for individuals with glaucoma and muscle spasms. Thirteen states have legalized cannabis in one form or another; many states also have decriminalized the possession of small amounts of marijuana. In February 2009, the Drug Enforcement Agency announced that it was no longer a federal priority to prosecute medical users of the drug.

December 3rd, 1992
-- The United Nations first celebrates the "International Day of the Disabled Person." It has since been celebrated with varying degrees of success around the planet. Typically, the day's activities are conducted by volunteers. In 2008, the Convention on the Rights of Persons with Disabilities had a theme of "Dignity and justice for all of us." The day is a reminder of the International Year of the Disabled in 1981.

-- *Compiled from various sources by Mike Reynolds*

Do you know of an important date in disability history?

Send it to Mike

Reynolds at:

uppitycrip@gmail.com

For a complete news roundup, go to:
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News Summaries supplied by David Reynolds from

Inclusion Daily Express.

www.InclusionDaily.com

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slickers in a drizzle. Oster stood on a wooden bench and addressed them with a bullhorn. "I said my name is David Oster. I'm a name plaintiff. I said I live independently. I said I didn't want to go back into the mental hospital, so please don't cut IHSS."

For me, this brought to mind the protracted but successful battle for public transit access some of us waged in the courts and the streets of Chicago in the 1980s. At the time, there wasn't a single lift-equipped main-line bus in Chicago.

Some of us formed a chapter of Americans Disabled for Attendant Programs Today to demand that the Chicago Transit Authority (CTA) order only accessible buses. We blocked a downtown intersection and were arrested. We disrupted CTA board meetings with noisemakers and bullhorns. But, ultimately, it was a court decision that forced the CTA to surrender. Street activists with bullhorns and T-shirts successfully collaborated with lawyers with their business suits and briefcases. But it wasn't a partnership without tension and doubt.

The 1980s lawsuit, Jones v. CTA, was initiated by the Chicago Lawyers' Committee for Civil Rights Under Law. Jeff Gilbert was an attorney at a Chicago law firm but had little experience in disability civil rights cases. He specializes in securities law.

"When I first got involved, I expected to win for my clients because that is what I do," Gilbert said. "I had no appreciation for the enormity of the challenge. I did not fully appreciate the time and resource commitment the case would require." The Jones case

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about?

A: In 1990, I got a grant from the Alicia Patterson Foundation, which allowed me to take a one-year sabbatical to study and write about the disability civil rights movement. I started with a trip to Berkeley. I spent time at ADAPT rallies. I went to the first meeting of self-advocates with intellectual disabilities in Connecticut. And I started to think about whatever happened to Jim Gordien at Faribault. I figured he'd be living in a group home or maybe his own apartment. I found he was still living in the same cottage where I'd last seen him 16 years before. I flew to Minnesota to see Jim. I asked him if he wanted to be part of "the community." He said yes, he'd seen others he'd lived

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in the Wasatch Mountains of Utah. Participants will stay at the Marriott Hotel and Conference Center in downtown Provo and ski at the Soldier Hollow cross-country ski area in nearby Midway, Utah. For more information, go to www.sfl.org.)

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

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with go to "the community," but he didn't really know what it was. So I took him to see group homes and community-based jobs. I pushed and got him out of the institution. My Patterson year was the start of the reporting for "No Pity."

Q: How much of a struggle is it getting editors and journalists to understand the newsworthiness of our stories? Has it gotten better?

A: NPR hired me to write about disability, so, for the most part, I don't have difficulty getting interest at NPR in disability stories. The ADA changed a lot. You can see it in the coverage of disability. You don't see flat-out pity or inspiration stories so much now in the media. But you don't see disability civil rights stories, either. We get a strange mixture of the old and the new -- pity mixed with rights. Journalists only partly get it. There's still education to do.

Q: Do you consider yourself to be an activist?

A: I don't think of myself as a disability activist -- just someone who learned a lot from disability activists. As a journalist, I always think of myself as an observer. But I feel fortunate to have met and interviewed a lot of the important people who changed the way we look at disability. And the best thing disability activists do is to be patient, steady teachers. I know that's not always easy when it looks like disability issues get ignored. I think journalists want to get disability issues. But we're not brought up in a society to get it. I got things wrong in some of my first stories. But there was always someone who was willing -- patient and polite -- to explain what I didn't quite get. A good journalist will listen and get it the next time.

Mike Ervin is a writer and member of ADAPT, a group that works for the civil rights of people with disabilities.

CILs Aid Seniors with Housing, Technology Help

By John M. Williams

Maryland resident Tom Stoddard is 74 years old. He retired from work "but not living" on December 31st, 2006. More than a year ago he started experiencing difficulty walking and seeing. The impact was "psychologically menacing," he said. Living on a fixed income, he was afraid of losing his independence. He knew he needed help finding a place to live, so he visited the Maryland Statewide Independent Living Council in Silver Spring. One of the council's referrals was the Maryland Department of Housing and Community Development.

Centers for independent living (CILs) are typically non-residential, private, non-profit, consumer-controlled, community-based organizations that provide services and advocacy by and for persons with all types of disabilities. Their goal is to assist individuals with disabilities to achieve their maximum potential within their families and communities.

CILs also serve as a strong advocacy voice on a wide range of national, state and local issues. They work to assure physical and programmatic access to housing, employment, transportation, communities, recreational facilities, and health and social services.

Established in the late 1980s, the Maryland Statewide Independent Living Council serves as an advisory, planning and advocacy group to promote independent living services across the state. The council is composed of individuals with disabilities, representatives of advocacy groups, and service providers of private and public agencies. It provides

guidance to Maryland's Division of Rehabilitation Services (DORS) through development, review and evaluation of the State Plan for Independent Living.

The Maryland Department of Housing and Community Development (DHCD) and the Maryland Department of Aging are undertaking a pilot project to promote accessibility-related improvements to homes of seniors. The improvements may include installation of grab bars and railings, widening of doorways and installation of ramps. For many older people, such improvements represent "the key to remaining in their homes and maintaining their independence," said a spokesperson for the state.

Stoddard was introduced to the Homeownership for Individuals with Disabilities, a program that provides low-interest mortgage loans to eligible disabled homebuyers. He said he is delighted with the results and is waiting to hear if he qualifies.

"I have learned so much about independent living from so many folks here that I am overjoyed," Stoddard said. Stoddard has seen many of his peers his age at different centers being counseled on accessible housing and assistive technology.

To help Stoddard deal with his low vision, his grandson Cameron purchased a low-vision product for him. Cameron learned about low-vision products from the Maryland Department of Aging.

"Occasionally seniors seek

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was filed in 1983 but not settled until 1988. The trial lasted 10 weeks.

During that five-year period, we in ADAPT kept pursuing our access demands on the streets. We didn't trust the courts. We had every confidence in the righteousness of our cause and the excellence of our lawyers. But judges are fickle beasts, as susceptible to cultural and political prejudices as everyone else. You can do everything right in court and still lose.

We hit the streets even though our lawyers counseled against it. Gilbert worried that our theatrics would undermine the lawsuit. "I want to litigate the case in the court rather than in the media," he said. "My general view is that you lose control when your message is translated through a third party. You also run the risk of prejudicing the court or judge against you. And I thought that aggressive protests could further polarize the two sides and make it harder to resolve things if settlement became an option."

Rachel Scherer, a DRC attorney who has worked closely with Oster on the Wagner case, said attorneys and plaintiffs alike were in favor of the rally outside the courthouse.

"I think it's inspiring," Scherer said. "People showed up because it was so important to them to prevail. They wanted to offer support for the attorneys, for the plaintiffs, for people they love and care about. It makes everyone realize all the people that are impacted. It makes it real and personal, and it fires you up a little as you go into the courtroom."

But wasn't there a risk that the judge might feel unduly pressured and thus resentful? "Maybe in certain circumstances," Scherer said. "But in this

case, having persons with disabilities have a voice in all this was outweighed by any harm it could have done. There's no point in silencing that."

Dara Shur, DRC's director of litigation, said it is also important for plaintiffs and their lawyers to assess how drawing media attention to a case may influence the resolution of the issue the case addresses outside the courts.

"We have a full time communications director," Shur said. "We work closely with our allies and clients to determine when and how it is important for the public to know about our litigation. Because of its broad and serious impact, this case has received a lot of media attention. We are hopeful this will help educate legislators when new budget cuts are discussed in this coming year."

In the Jones case, lawyers and plaintiffs agreed to let each other do their thing. When our lawyers needed a show of solidarity, we sat in the courtroom gallery and behaved. When we testified, we washed up and dressed up. But we continued to harass the members of the CTA board who refused to submit to our demands. When a judge ruled in our favor on Martin Luther King Jr. Day in 1988, it was front-page local news.

What does Gilbert think lawyers and activists can learn about working together from the Jones case?

"I think we formed a good team because we all were willing to listen to each other. We also respected each other. We tried to understand each other's perspectives and what we needed from each other in order to accomplish the shared goal of access to main-line transit."

Personally, I still don't trust the courts as the sole forum for grievance. I believe now as I did then

in piling it on, in applying pressure on any front that might lead to success. But quite often the courts are one of these fronts. The best way to ensure that the disability community wins genuine victories in court is for lawyers to closely collaborate with activists who are the most seriously affected by the outcomes of the cases.

Mike Ervin is a writer and member of ADAPT, a group that works for the civil rights of people with disabilities.

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counseling to assist them on learning about hearing products, low-vision products or other assistive technologies," said David Burds, a counselor at the ENDependence Center of Northern Virginia Inc. (ECNV).

ECNV has a modified kitchen and bathroom to assist individuals in learning new technologies. It gives classes on assistive software on computers and helps individuals learn skills to achieve independence. The center is managed by and for people with disabilities. It operates from a philosophy of consumer control and peer-to-peer relationships to empower people with physical, mental, cognitive and sensory disabilities to direct their own lives.

Cindy is a widow in her seventies who lives near Albany, N.Y. (She would not reveal her actual age or her last name.) She is losing her sight and has lapses of memory. She is fiercely independent and likes living alone. To address her vision, cognitive and other challenges, she sought guidance from the New York Council on Aging. To meet her desire to develop independent living skills, the council put Cindy in contact with a CIL. Cindy won't say which center she contacted and, out

of respect for her privacy, neither will the N.Y. Council on Aging.

Cindy received information on low-vision products and bought a low-vision product through assistance from the state.

"My life changed once I got my low-vision product," Cindy said.

She is reviewing literature from the council and the center on technology developed for cognitive challenges. Cindy has recommended CILs to peers her age.

**John Williams, a contributing writer to Independence Today, He is credited with coining the phrase "assistive technology."*

He can be reached at jmmaw@verizon.net.

Stevie Wonder Named



Stevie Wonder and UN Secretary-General Ban Ki-moon.

On December 3rd, 2009, musical legend Stevie Wonder was named a United Nations Messenger of Peace.

Wonder, blind from birth, has more than 30 top-10 U.S. hits and has won 22 Grammy Awards.

U.N. Secretary-General Ban Ki-moon announced the appointment, calling Wonder "a musical genius" and a "great humanitarian."

**HAPPY
NEW YEAR
AND A GREAT
NEW DECADE!**