

THE REAL
CLASS WAR

THE LOSS THAT'S
NOT THERE

independence today

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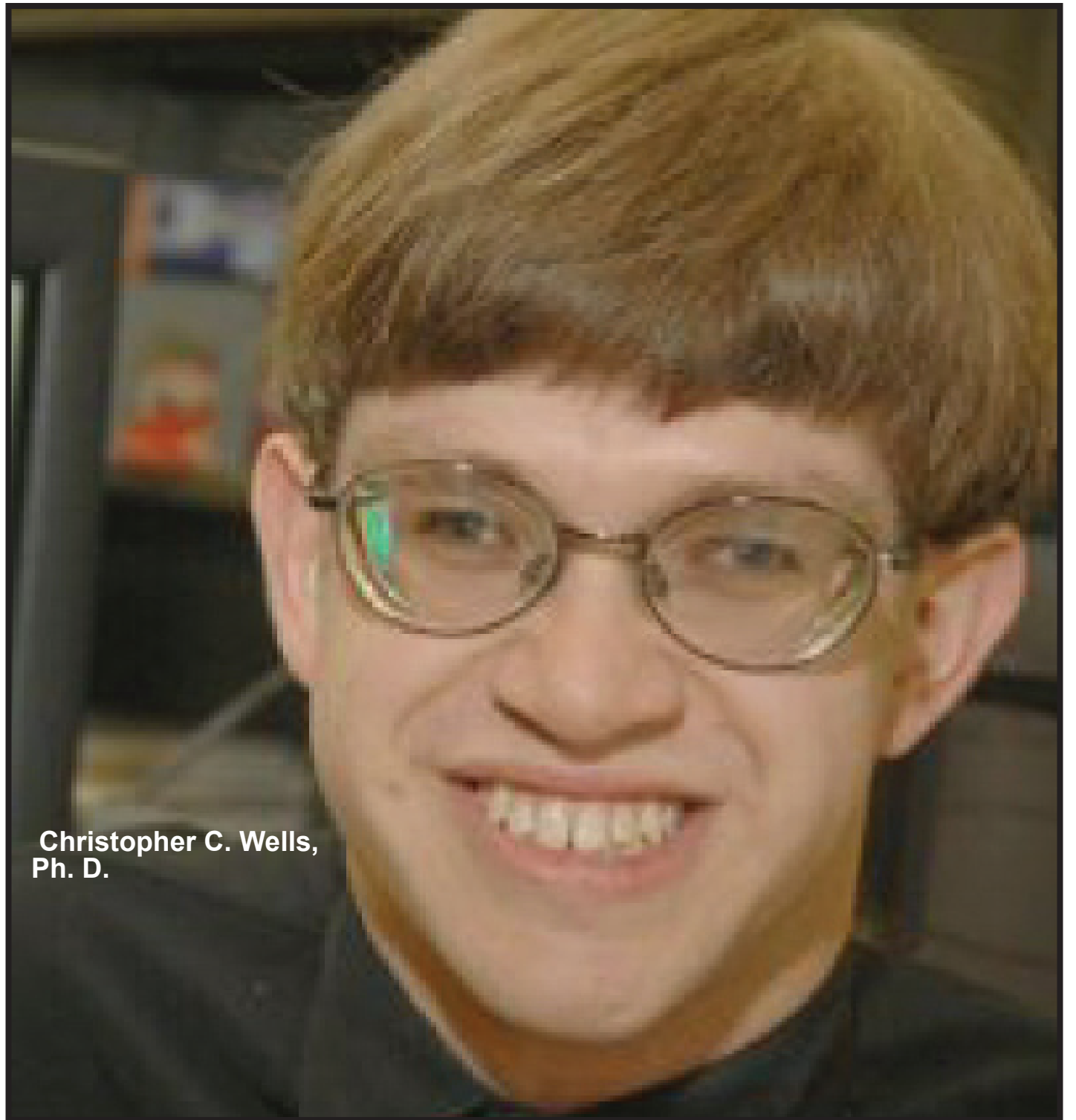
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ALTERING
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OUTLOOK



Christopher C. Wells,
Ph. D.

Christopher C. Wells received his doctorate in inorganic and physical chemistry May 14th from the University at Albany in New York state. While completing a Ph.D. is quite an accomplishment for anyone, it should be noted that Wells is legally blind and profoundly deaf

Commentary

Can't We Make Our Own End-of-Life Decisions?

By John M. Williams

Recently, I was sitting in a doctor's office waiting to see a doctor. Sitting across was an elderly gentleman whose hands shook so much that he could not turn the pages of a magazine. After repeated failures to turn the pages, he looked at me and asked, "Can I get your assistance in turning these pages?"

"Sure," I said.

We were the only patients in the waiting room. His appointment was running late.

I turned the pages and he said, "Thanks."

When he finished reading, he put the magazine on top of others, and he started staring at me. He reached into his shirt pocket and, with his hands still trembling, wiped his glasses and asked, "What is your name?"

"John Williams," I said.

"That's a popular name -- Williams, I mean. I'm Harold."

We shook hands.

"What's your profession?" Harold asked.

"I'm a writer."

"I'm a retired structural engineer. I've built bridges in Maryland, Pennsylvania, New York, Ohio, Florida and a few other states. I retired 10 years ago when I was 72. How old are you?"

"Sixty-six."

"Sixty-six? You're still young yet. Are you retired?"

Before I could answer, he said, "The biggest mistake

I ever made was retiring. I was not ready."

"No. I'm not retired. I don't expect to retire for many years."

He nodded his head and was quiet for a couple of minutes. "You said you are a writer. What do you write?"

"I write mainly about special-needs technologies and their benefits to people of all ages."

"You do?"

I nodded my head yes.

"I am. Rather, I know what you're talking about. I use a CCTV and text-to-speech software. They have strengthened my independence."

"I'm familiar with both technologies. I have written about them scores of times. Do you use any other assistive technology?"

"Voice recognition for calling people and turning lights and other appliances on and off in my house."

"How long have you been using assistive technology?"

"At least 10 years. Not longer. Williams. You said your last name is Williams? I may have read your articles. I know I have."

An alarm on his watch sounded. He pressed a button to turn it off, and then he reached into a plastic bag and pulled out a water bottle, popped a pill into his mouth and took a long swallow.

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INTO THE LIGHT

By Peter S. Kahrman

The Loss That's Not There

I recently had the pleasure and, in a very real sense, the privilege of speaking to the Death and Loss Education Coalition in Liverpool, N.Y. The coalition is an admirable group that seeks to educate and heighten awareness for professionals and individuals in the areas of death and loss; it is hard to imagine a more honorable purpose than that. We all face the experiences of death and loss, and we all have little say over when these experiences come into our lives. But we do have quite a bit of say over how we manage them and the choices we make in response to them.

I was asked to speak to this group of rather extraordinary folks about the loss those of us who live with brain injuries experience. I sustained my brain injury when I was held up and shot in the head in 1984.

As late as the day of the presentation I was not entirely sure what I would say. In the first place, all brain injuries are different. Some who have them exhibit symptoms with greater frequency than others. Others have difficulty with memory, difficulty with initiating and following through on things, impulsivity, various forms of paralysis, challenges with speech, and so on. Obviously, all these things

confront the person with loss of some kind. And in order to manage loss, any loss, one has to first accept it and not give in to it. The philosophy I fiercely believe in goes like this: You have to accept it in order to manage it, and you have to manage it in order to get as free of it as possible.

Yet even though I knew all this and knew all this was worth mentioning, I was missing something. Dare I say I was at a loss as to what I really wanted to say and, in truth, what really needed to be said.

And then as I was driving to the presentation, the loss that needed to be talked about the most came to me: the loss of our complete humanity in the eyes of others, the fact that when we are either born disabled or sustain a disability somewhere down the road, we are immediately seen as being less human and less valuable and of less worth than others.

When I talk with survivors of brain injury and other folks who live with a disability of some kind, the number one complaint I hear is, *We get treated like we're children*. Tied for a close second? *We get treated like we're stupid* and *We get treated like we're crazy*.

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CoverStory

This 'Black Swan' Soars Way Above Expectations

By Amy Halloran

Christopher C. Wells received his doctorate in inorganic and physical chemistry May 14th from the University at Albany in New York state. While completing a Ph.D. is quite an accomplishment for anyone, it should be noted that Wells is legally blind and profoundly deaf. At his graduation, the 32-year-old also received the 2011 Distinguished Doctoral Dissertation Award, an accolade for the best dissertation in any field in the College of Arts and Sciences.

"Most of the time I find things easy to overcome, but I spend a lot of time reaching out to people," said Wells, interviewed recently at his home in Lake George, N.Y., with his godmother Pat Thompson interpreting and his mom, Eileen, and brother Bobby nearby. "I think most people could work beyond their limits if they tried. I took three years of Spanish, and I did great."

His appetite for learning is huge. He's teaching himself Japanese, Swahili and Polish, and he likes to try to communicate with people on the computer in those languages, though the keyboards don't always have the right characters.

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Wells was born two months premature; at birth, he weighed 2 pounds and was deaf. He had bleeding in the brain when he was a baby, which damaged some of his cranial nerves. As a result, it is difficult for him to swallow food, and he cannot breathe very deeply. He has cerebral palsy, which slightly limits his range of motion and affects his balance.

Despite that, he swims and works out regularly and plays basketball, billiards and bowling. He has a shelf of bowling trophies in his room, along with much larger collections of rocks and Transformer toys. All of those, though, are outnumbered by his book collection, which includes plenty of physics, chemistry and philosophy titles, along with novels. Among his favorite books are Ralph Ellison's "Invisible Man" and anything by Ralph Waldo Emerson. Another writer he admires is bell hooks (Gloria Watson), especially her book "Killing Race: Ending Racism in America." "I'm really into learning about black culture and how they overcame things," Wells said. He sees the discrimination against African Americans as paralleling the prejudice leveled against people who live with disabilities.

On the birthday of Dr. Martin Luther King Jr. this year, he posted a long note on his Facebook page about the civil rights leader's legacy.

"Genetically, we are too similar to be different," he wrote. "Any two humans among the nearly 7 billion living on Earth share over 99.9 percent of their genetic information. We must apply this information as our defense against discrimination and keep King's legacy alive!"

In March of this year, Wells flew to Texas to present a paper on the energy states in graphene at the American Physics Society. He was the first deaf-blind doctoral student to present

research at this annual meeting. Graphene became the focus of his work after a three-month internship at NASA in 2007.

"My research is about enabling electronics to be improved with a pure-carbon material that is 1 atom thick," he wrote in a reporter's notebook. "My work has identified ways in which this material (graphene) can be controlled for electronics. This piece of pencil lead has energy states that remain the same in energy and my research hopes to find gentle ways to make these states differ in energy and describe these conditions for future device designs incorporating graphene."

At some point, Wells said, he plans to write for scientific journals and work more with Dr. Lawrence Snyder at the University at Albany. He's also looking for computational chemistry work. If he can find a location he likes, he will consider moving. Otherwise, he will stay local.

Wells lived with his family throughout his undergraduate work at Siena College in Loudonville, N.Y., and the nine years he was at Albany. Initially, he planned to get only a master's degree, but after a year, his advisers suggested he skip that and go straight for the Ph.D.

His family members, who have a strong knowledge of services for the developmentally disabled, have navigated the logistics of his schooling. Eileen Wells became his foster parent when he was 4, and she adopted him when he was 7. This is the 40th year she has worked for Prospect Child and Family Center, which serves several counties in the lower Adirondack region. Pat Thompson has been

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Commentary

The Legacy of Steve Jobs and Accessible Technology

By John M. Williams

I met the late, legendary genius Steve Jobs twice in San Francisco. One meeting took place in 1990, the other in 1993. Both times I asked him if Apple was making its products accessible to people with disabilities.

In our first meeting, which lasted 20 minutes, accessible Apple products for people with disabilities weren't on his radar screen. He was annoyed that I brought up the subject. He told me so and then abruptly left.

Three years later, he was more receptive to the idea of accessible technology for people with disabilities from a manufacturer's perspective. "If they can use my products, they can buy them," he said with a gleam in his eye.

In our second meeting, Jobs asked me how long I had stuttered. When I told him, I then asked why he wanted to know.

"I know someone who stutters," he said. "You remind me of him."

Then Jobs asked, "Is there any technology on the market to help someone who stutters?"

I told him yes, and we said good-bye.

I don't know what changed him between 1990 and 1993 -- maybe nothing. Maybe all along, his goal was to make Apple products accessible. I believe he recognized the economic benefits of expanding a consumer base for Apple's products among people with disabilities.

Recently, an Apple employee told me: "It is an Apple policy that our products are usable by people with disabilities. Mister Jobs stressed this policy repeatedly."

I know that Apple claims that for decades it has provided new and innovative solutions for people with disabilities, allowing them to access and use the Mac, the iPod, the iPhone, the iPad and Apple TV.

When Steve Jobs died on October 6th, he left this legacy for people with disabilities:

□ Standard features in Apple products include assistive technology. For example, the iPhone, the iPad, the iPod and the Mac OS X include screen magnification and VoiceOver, a screen-access technology, for the blind and visually impaired. To assist those with cognitive and learning disabilities, every Mac includes an alternative, simplified user interface that rewards exploration and learning. And, for those who find it difficult to use a mouse, every Mac computer includes Mouse Keys, Slow Keys and Sticky Keys, which adapt the computer to the user's needs and capabilities.

□ Inventions such as Braille mirroring, which enables deaf and blind children to work together on the same computer at the same time; the world's first screen reader that can be controlled using gestures; and captioning of downloadable digital movies, are prime examples of Apple innovation.

□ As part of Apple's commitment to accessibility, its retail associates are specially trained to serve customers with disabilities.

□ Consumers can learn how Apple technology is being used to address the needs of students by visiting Apple's special education page. If consumers have comments or suggestions about accessibility, they can send an email to accessibility@apple.com.

□ Apple's accessibility website highlights all the accessibility technologies for people with visual, auditory, physical or motor, literacy and learning, and language and communication disabilities. It also features third-party products and Section 508 information.

□ Since 1985, Apple has been committed to helping people with disabilities access their personal computers. Apple's commitment to accessibility is evident throughout the Mac OS X operating system, which is not only easy to use but also includes a wide variety of features and technologies specifically designed to provide access to users with disabilities. Apple refers to these features collectively as universal access and has integrated them into the operating system so they can be used in conjunction with a variety of applications from its company and other developers. Apple is also changing the ways people interact with technology through innovative products like the iPhone, which brings new possibilities for making user interfaces accessible to people with disabilities.

□ Apple works to make products and technologies accessible to all people, including those with a range of disabilities. Apple offers products such as its Mac OS X operating system with accessible



Steve Jobs introduces the iPhone at Macworld

speech recognition, zoom-text enlargement features, closed captioning and special hardware. Other products, such as the Apple iPhone, are equipped with accessible features such as visual voicemail, zoom, TTY support, large fonts, hands-free usage and alternative alerts.

In a recent filing with the U.S. Patent and Trademark Office, Apple has indicated that it is seeking to patent a method for connecting IOS (a type of software) devices to accessories that could act in place of a touch screen. A person with mobility impairment could, for example, use a joystick to control an IOS device. And an individual who is visually impaired could "see" the screen using a Braille attachment. The accessories would be linked to the touch-screen device via a wireless connection or a physical one.

I have been told that Apple is making its iPhone and iPad more user friendly for people with disabilities. But because the products all use touch screens, however, some with visual or mobility impairments may have trouble using them.

Steve Jobs is to be

Steve Jobs
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Visitability: Housing Advocate's Life Goal

By Janine Bertram Kemp

Eleanor Smith invented the concept of "visitability" (aka inclusive home design) and has led the Atlanta, Ga.-based organization Concrete Change since the mid-1980s.

After taking part in an ADAPT demonstration for access to public transit, she thought, "Why can't we do that for housing?" Now Smith, nearing 70, is seeking a new home for the visitability movement. She hopes to find a center for independent living that has the will and resources to commit to the fight for inclusive home design.

According to Smith, visitability requires that every newly built home have the following:

1. At least one zero-step entrance, at the front, back or side of the house.
2. Main-floor doorways, including bathrooms, at least 32 inches wide.
3. At least a half bath -- a full bath is preferable -- on the main floor.

Within the movement, there is confusion about the difference between inclusive design and universal design (UD). UD is affiliated with academia and includes a plethora of accessibility features, all equally weighted. UD features include a lever door handle, knee space under cabinets and a wide doorway. An architect or builder could pick and choose among UD features. Thus, the UD mindset is great for a specially built house but not for policy-driven solutions that affect all new houses. The three requirements of visitability mean everyone can get into a home and use the bathroom -- or "Get in and pee," as Smith says.

There have been other

leaders in the struggle for equality in housing, but Smith -- a quiet, unassuming wheelchair user -- has remained focused on visitability for the past 25 years.

"One of the things that Eleanor Smith has done for disability rights is start from nothing, stay true to the grass roots, and produce the terms and regulations that define how we talk about inclusive home design," said Tom Olin, photographer and national disability organizer. "She has made sure it means access to a community and all its parts.

"It is imperative that Concrete Change continue because we are still on the threshold, the proverbial doorstep, of finally making the big developers and regulators be part of the solution instead of part of the problem."

Meg Traci of the University of Montana Rural Institute said that Smith helped advance academics. "Eleanor got us 'unstuck' here in Montana and gave us a common language to move forward," she said.

The story of Concrete Change is that of a seemingly ordinary person committing to a goal, sticking with it, and altering the world.

A non-disabled architect once said that disability "is not caused by the physical condition. Disability is caused by the built environment." When Smith, grounded in the civil rights movement, heard that quote, it hit home.

Of course, behind the revelation in that quote were the myriad life experiences of hurtful

discrimination experienced by every person with a disability. If the disability is mobility-related, the experiences are about lack of physical access. For Smith, these seminal, hurtful instances occurred before there were any civil rights protections and at a time when non-disabled people had little concern for the obstacles others faced.

Sometimes she would be invited to a party at a friend's inaccessible house, which took place up a flight of stairs. She would arrange with her friend to call before leaving home so others would meet her and carry her up those stairs. When she got there, she would wait awhile in front of a long staircase until it dawned on her that no one was coming. The friend had forgotten her. She then would drive back home, take off her party clothes and spend the evening alone.

Now Smith lives in a co-housing community in Atlanta where she attends dinners and barbecues, and where she can and does visit her neighbors. If a neighbor has a crisis, Smith can get in to provide assistance.

In Smith's neighborhood, "every home is visitable," said Mark Johnson, director of advocacy at Shepherd Center in Atlanta. "She has accomplished all this while working out of her house. There is a fascinating history about visitability that is not out there. But if you peel it back and peel it back, Eleanor's name is going to show up as the key player. In many ways she has had more impact than anyone would know. In the next five to 10 years, with the number of aging baby boomers, the demand for inclusive home design will accelerate."

Smith has seen visitability laws enacted in about 50 cities and counties around the nation, although the laws are uneven and

enforcement more so. Smith acknowledged that ableism (discrimination or social prejudice against people with disabilities) has been the unspoken force that slowed the visitability movement. It takes a person "really getting it" to create change.

"Visitability only happens in cities, counties and states because a local person really gets it and decides they have the energy to press for it," Smith said. "Some (localities) were unsuccessful; they tried very hard, (but) their bill didn't pass. But I still say they planted the seeds. Others had quite a lot of success, striking success, to where two advocates, a husband-and-wife team from Arizona, got through the first law that covered all the houses, whether public money was used or not."

The Arizona law to which she referred covers Pima County, a community of about 1 million people that includes Tucson. As of September 2010, more than 21,000 visitable homes have been built in Pima County. Yves Khawam, Pima County's chief building official, wrote Rep. Maxine Waters, D-Calif., in support of a national Inclusive Home Design Act. The letter was a testimonial regarding Pima County's experience with builders' reactions and the real estate environment.

"While these requirements were at first resisted by builders based on the fact that they would require costly changes to conventional design and construction practices, it became evident that with appropriate planning, the construction could result in no additional cost," Khawam said. "Indeed, the jurisdiction no longer receives builder complaints regarding the ordinance, and the ordinance has

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with the center for 30 years. Chris Wells read large-type books throughout high school but switched to normal-sized type before college, a decision that allowed him access to the specialized texts necessary for his studies.

His mother advocated for him on numerous occasions throughout his education. Once, when he was in the seventh grade, she enlisted the services of a lawyer when SAT moderators wanted him to take the tests in a separate room. (The tests were administered by the Johns Hopkins Center for Talented Youth.)

Normally, his grades would have been marked nonstandard because of the accommodation, but Eileen Wells' perseverance resulted in a precedent-setting victory: now, the visually impaired can be in the same room as other test takers. She also fought for her son to read his Spanish Regents and answer in sign language. That battle was won, too.

Chris Wells taught his brother sign language when the latter joined the family 11 years ago. Bobby, who graduated from high school earlier this year, considers his big brother his role model.

Chris Wells' graduation sparked articles in local newspapers. In one of the stories, he advised people to turn disabilities into abilities. He was asked how he did that.

"It was easy -- like alchemy. That was the old science, before chemistry. If you think you can change something, you can. People tend to think that disabilities are a burden, but I never think down; I think up. It's figuring out how to use what you have, how to use it to work with what you don't have. Think about silence -- being in silence

all day long, being able to focus. It's not a bad thing." That focus has served him well. Though her son was sickly as a child, once his health stabilized, he learned quickly, picking up 100 signs in a weekend, Eileen Wells recalled.

"In grade school I loved math, and I had many other interests," he said. "Then science came, and I could visualize the movements and molecules in my head. Chemistry was my main love. I started reading books about atoms and power and realized I could do well in chemistry. I loved chemistry. I loved physics.

"I had an interpreter in elementary and high school. Students would take notes for me in high school and in college. Some typed, but most of them wrote. I could read most of them enlarged."

In college, many of the notes "had to be finger spelled because of the letters in chemistry," said Wells, who noted that his interpreter in graduate school understood his research and work. Sometimes, he said, he felt like her teacher, but that was an asset. "Teaching helps you to learn. To explain things, you also improve the ability to learn from that person."

Technology plays a big role in Wells' research and in his daily life.

"I would use (computer) modeling programs when I was younger, so in college everyone wanted me in their group. I use a lot of different interfaces. I have a lot of different scientific programs on my computer, for my research. Things that people do in labs I can show much more quickly by using quantum chemistry software. I can work it up on the computer and show them 3D."

He uses a program called WordPad on his iPhone to communicate with people, such as store clerks and people who don't sign.

Of meeting people through technological outlets, he wrote, "My disabilities are well-hidden, eclipsed by my abilities, so well-hidden that people never recognize that I am deaf or visually impaired when they first encounter me." Texting, he noted, cannot distinguish between people who hear and people who are deaf.

When asked what he might say to the disability community, he wrote: "Never let what society uses to define what a person can do or cannot do deter you from consideration of unprecedented acts by individuals that seem at first glance unlikely to be capable (of doing them). Let the 'black swans' speak for themselves and redefine what capability in society really means. Black swan is something that's very improbable and no one thinks exists, but it can. I



Christopher Wells, a third-year doctoral chemistry student from Lake George, N.Y., at the State University at Albany.

am. I'm like a black swan."

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

Leadership Forum, History Week Altering Disabled Youths' Outlook

By Mike Ervin

The second week of October was, for the second time, designated as Disability History Week in California. The legislation, which passed in August 2010, states that "public and private institutions of higher education, state and local agencies, nonprofit and community-based organizations, and private businesses and corporations" are encouraged "to observe Disability History Week by dedicating appropriate classroom instructional time or by coordinating all-inclusive activities to be conducted during that week to afford opportunities for students and the general public to learn more about the disability community and to celebrate and honor its role in contemporary American society."

This may sound like one of those empty, feel-good proclamations legislators frequently pass

unanimously because they carry no weight and create no change. In fact, this legislation did pass unanimously, which might indicate that no one perceived it as a threat. To many in the disability community, the passage and implementation of this law in and of itself is meaningful because it is a hopeful sign that young people with disabilities, aided by older mentors, can find political and emotional strength by discovering each other.

Rosie McDonnell, 17, of Oceanside, Calif., applied to be and was selected as a delegate to the California Youth Leadership Forum for Students with Disabilities in 2010.

"Before that summer, I was completely oblivious to

History Week
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We Remember...

James Troesh (Nov. 13th, 1956 – Oct. 1st, 2011). Troesh, an actor, screenwriter and entertainment industry disability advocate, died at St. Joseph Medical Center in Burbank, Calif. He was 54.

Troesh, who lived in Los Angeles, was perhaps best known for his three-season role as a quadriplegic attorney on "Highway to Heaven," the NBC drama starring, and produced by, Michael Landon that ran for five seasons in the 1980s.



Troesh wrote an episode for "Highway to Heaven" and, among other projects, co-wrote the 2006 film "Color of the Cross" with Jean-Claude La Marre and Jean Claude Nelson. In recent years, Troesh created the television pilot "The Hollywood Quad," a sitcom he wrote, produced, directed and starred in along with guest star Bryan Cranston. The project was a comedic look at Troesh's journey in the industry. The program later was turned into a podcast series.

Troesh was a member of the Writers with Disabilities Committee of the Writers Guild of America West and the first quadriplegic to join the Screen Actors Guild. He was the only quadriplegic dual member of WGAW and SAG.

He was a former president of the Media Access Office and one-time national chairman of AFTRA's Performers with Disabilities Committee. He was active in the Academy of Television Arts & Sciences, served on the Academy's Performers Peer Group executive committee and contributed articles to the organization's official publication, Emmy magazine.

"He was a really good writer, and he was a whiz at Photoshop (a graphics editing program)," said neighbor and friend Linda Fulton.

To get around his neighborhood, Troesh would maneuver his power wheelchair with his chin; he wrote at his computer using a stick, or stylus, he held between his teeth. And on June 10, 1989, in a tandem jump, he became the first quadriplegic skydiver.

"He had ambition and determination; he was very driven," said Fulton, who later became Troesh's primary caregiver. "When he wanted to do something, he was a force to be reckoned with."

In the 1990s, Troesh was a frequent visitor at the house of comedian and actor Avery Schreiber, from whom he honed his talent at improv. Later, he put together a troupe and performed – along with Fulton -- in a theater across from the apartment where he lived. From his wheelchair, he taught improv to children.

"His whole life was improv," said Fulton, now the owner of that theater, named after Schreiber. "(Because he was confined to a wheelchair), he had to find other ways of doing things."

Dave Troesh, Jim's older brother, remembered that Schreiber had a huge effect on his sibling.

"Avery gave him a whole lot of confidence in improv," he said. "(Jim) did motivational speaking; he'd go to schools and talk to kids -- and adults too, (at) senior centers. He took his show on the road."

The WGAW's 2011 Media Access Awards, held in October, were dedicated to Troesh, who received the prestigious Michael Landon Award. The Media Access Awards honor projects and artists that promote accessibility, improve awareness and champion accurate representations of the disability experience.

He was the fourth of five children born to Raymond Troesh, a postal worker, and his wife, Lorna, a homemaker. Growing up in Whittier, Calif., Jim was "a normal, happy kid," according to Dave Troesh.

When he was 14, while attempting to hook up an antenna to a home-built radio tower on the roof of his family home, Jim accidentally made contact with a power line. The resulting power surge sent 240,000 volts through his body, breaking his neck and knocking him off the 30-foot-high roof. He was unconscious for days and remained in the hospital about a year before he was sent home in a manual wheelchair.

His first acting break came in 1984 when he got a part in "AfterMASH," a TV series that ran for two years. He later was cast in "Highway to Heaven" after being spotted by Landon. It was the actor, according to Dave Troesh, who purchased Jim's first power wheelchair, in 1985.

When his stint on "Highway" ended, Troesh found occasional work on such television shows as "Boston Legal," "Special Unit," "Notes From the Underground," "Rise and Walk: The Dennis Byrd Story" and "Airwolf."

"It was interesting watching him on TV," said Dave Troesh. "He called them 'roll-on roles.' He just had a wonderfully dark sense of humor."

In 1987, he was flown to the opening ceremony of the Special Olympics World Games, held that year in South Bend, Ind., in a private plane by Arnold Schwarzenegger and Maria Shriver. "He always joked that his luggage ended up at Maria Shriver's room," Dave Troesh said.

Though Jim would sound depressed on occasion when talking to his family, he always appeared upbeat in public, Dave Troesh said. Despite his disability, "he didn't dwell on it."

In recent months, Jim Troesh was dropped while being transferred between his wheelchair and his bed, according to his brother. After that, "his blood pressure and his (body) temperature would spike," he said. In September, he was taken to the hospital and later died of what officials there said was pneumonia, according to Dave Troesh.

Survivors include stepson, Eric; older brothers Dave and Jack; older sister Ginger; and younger brother Ken. The family has requested that donations be made in Troesh's name to Total Improv Kids -- Jim Troesh Scholarship, c/o Linda Fulton, Avery Schreiber Theatre, 11050 Magnolia

Commentary The Real Class War

By Peter S. Kahrmann

OK, if we're going to talk class warfare, let's really talk class warfare, and let's maintain a relationship with reality while we do.

Recent claims by Republicans that raising taxes on the rich and reducing loopholes for big business is class warfare compels me to throttle a blast of expletives. Let's just say that the Republican claim is disingenuous and hateful. However, in the spirit of honesty, I suspect that if it became clear that the rich and big business were truly about to be taxed fairly, you'd hear some Democrats squawking too.

The fact is that class warfare has been going on for some time in this country and, for the most part, it pits big business and their elected-official protectors against everyone and anyone who even hints at reducing its wealth or slowing its growth.

The targets of its brutal assaults on the lives of others? The poor, minorities, the disabled and, with ever-increasing ruthlessness, the middle class.

There is little doubt this war escalated with the election of President Barack Obama, a black man. Not only is our president a black man, but he has displayed a penchant for economic fairness on some fronts that rubs big business the wrong way.

Some big business leaders such as Charles and David Koch -- owners of the incredibly secretive Koch Industries Inc. -- quickly realized that funding and manipulating racists would (they are no doubt hoping) increase their chances of getting Obama out of office. The Koch brothers

and others have funneled money to the Tea Party, and all have remained silent about Tea Party events that include racist signs such as "Obama's Plan: White Slavery."

It ought to chill the blood of every American to learn that the Southern Poverty Law Center's Hatewatch says hate group leaders reported a marked increase in their membership since Obama was elected.

The fact is that the people (I am using the word people loosely here) and big businesses the Republicans are trying to protect have been like gamblers who've been allowed to cheat and so they always win, and now the president and others have decided to stop the cheating. It is also worth noting that nearly all the members of Congress are, well, rich and, not at all incidentally, white.

If you think there is any truth to the Republican claim that taxing the rich and removing loopholes for big business is class warfare, let me share some facts with you.

□ California cut \$577 million for the developmentally disabled this year on top of the \$700 million in cuts for the same segment of the population two years ago. Target: the disabled.

□ House Republicans this September proposed a bill that would cut heating subsidies for the poor by \$1.3 billion, reduce grant eligibility for low-income college students and cut funds for job-training programs. Target: the poor and the middle class.

□ Florida is calling for \$55 million in cuts for aging persons with disabilities,

which comes in the wake of \$65 million in cuts to the same group earlier this year. Target: seniors and the disabled.

□ Fresno, Calif., is calling for \$91 million in cuts for the disabled. Target: the disabled.

□ The Brennan Center for Justice at New York University School of Law recently released a study of new voter registration laws in 14 states proposed primarily by Republicans that, the center estimates, "could make it significantly harder for more than 5 million eligible voters to cast ballots in 2012." Target: the poor and minority voters.

□ New York is planning to cut \$27 million in funding for New York City's senior centers which, according to New York City Mayor Michael Bloomberg, would

result in the closing of 105 of the city's 256 centers. Target: seniors.

Needless to say, the list goes on and on. The list represents the real class war, a war that has begun to elicit a response as evidenced by Occupy Wall Street and similar protests growing around the country. These are protests that many hope will grow in size and strength, and I suspect they will.

As for the Republicans who claim it is class warfare to tax the rich and big business ... well, it's hard to take them seriously when they themselves have no class at all.

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

(This is one of an ongoing series of articles on actors and performers with disabilities.)

Organizer Brings Determination - and Change - to Acting Industry

By Kathi Wolfe

Growing up in Los Angeles, Tari Hartman Squire was always interested in acting. While in high school, she filmed a commercial for Clairol and eventually became a member of the Screen Actors Guild (SAG).

In 1979, while in graduate school, the arc of her life changed when one of the abused children with whom she was working kicked her and sprained the cervical part of her spine, Squire wrote in an e-mail. "Wearing a neck brace, (I) went out on an audition at Fox, and the casting director looked at me, shook her head and walked away." (Her disability turned out to be temporary.)

It was the first time she'd ever experienced discrimination, Squire said

in a telephone interview. "I was angry," she said. "But if you can channel your anger into organizing, you can work for change.

"Furious from this maiden voyage into the world of discrimination," Squire said, she met with then-SAG president William Schallert, famous for playing the father on TV's "The Patty Duke Show," to find out if the union had any actors with disabilities. They searched "Station 12" (SAG's "skills and talent" survey), a clearinghouse for casting directors looking for performers with unique skills.

"No one knew why, but 'handicapped' (the word

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used then) was one of the listings,” Squire said. “We ran a search, and we discovered that the guild did have members with disabilities. There were actors who were blind (and) deaf, and (there were) little people.”

Encouraged by these findings, Squire and Schallert reached out to two other key unions: the Actors’ Equity Association (AEA/Actors’ Equity) and the American Federation of Television and Radio Artists (AFTRA). (According to Squire, SAG represents actors working in films; AEA represents stage actors; and AFTRA represents performers, broadcasters and recording artists in television and radio.)

Actors with disabilities from all three unions had a meeting, Squire said. “We felt these actors would have issues in common. Were blind actors at auditions receiving their scripts in alternative formats (then audio tape and Braille)? Were there qualified sign language interpreters at auditions? Were auditions wheelchair accessible?”

That meeting took place in 1980 after a period of union strikes. After the SAG contract was signed, “disability was (for the first time) mentioned in the non-discrimination and affirmative action clauses (along with other marginalized groups: women, seniors and ‘minorities’ – the term used then) to more accurately portray the American scene,” Squire said. That was a huge breakthrough, as it was a decade before the Americans with Disabilities Act, she added.

What does it mean to “more accurately portray the American scene”? It means to show a more “realistic” depiction of people with disabilities in the entertainment media,

to have characters with disabilities working, getting dressed, hanging out with friends, dating – things that all those with disabilities do in everyday life, Squire said.

“Children of a Lesser God,” starring deaf performer Phyllis Frelich, opened on Broadway in 1980, and Frelich won the Tony Award for best actress. After that, “people could no longer say they couldn’t find actors who were deaf,” said Squire, now CEO of Ein Sof Communications Inc., a marketing and public relations firm specializing in diversity, disability and public policy.

During that time, the casting clearinghouse received a call for an actor with one leg, Squire said. “We found one! It was fabulous! We set a precedent. They (producers, directors and others) couldn’t use the excuse ‘we can’t find any actors with disabilities.’”

Spurred on, Squire continued her organizing. She helped to form the SAG, AFTRA and Actors’ Equity Committee of Performers with Disabilities, after which, in 1981, she went on to become the founding executive director of the Media Access Office. Under her direction, the office began not only to distribute Media Access Awards honoring the media and entertainment industry, but to serve “as a true liaison between the disability community and the entertainment industry,” Squire said.

In the early 1980s, there were signs of progress, Squire said. Actress and comedienne Geri Jewell, whose book “I’m Walking as Straight as I Can” is out this spring, landed a recurring guest-star gig on the hit sitcom “The Facts of Life.” (Jewell was the first person with a visible disability to appear on prime-time TV.)

At that time, “there was a

television remake of the movie ‘Johnny Belinda.’ They cast it with a hearing actress,” Squire said. “We did some advocacy work. They couldn’t recast it, but they promised to do things differently in the future – to start looking for actors with disabilities.”

If this had been a Hollywood movie, everything would have ended happily ever after. But in real life, that’s not what happened. Despite the breakthroughs of the early 1980s, many actors and performers with disabilities, because of discrimination, have been unemployed or underemployed over the past 30 years, Squire and others in the industry said.

Jewell, for example, though highly talented, had few acting gigs between “The Facts of Life” and her work on the HBO western “Deadwood” (2004-2006). Though there are 54 million Americans with disabilities, according to the U.S. Census Bureau, “realistic” characters with disabilities have remained, by and large, invisible from American TV, stage and screen.

A 2005 Screen Actors Guild survey of performers with disabilities in the entertainment industry documented how dismal employment prospects have been for those actors. The research -- conducted by Olivia Raynor, Ph.D., and Katharine Hayward, Ph.D., M.P.H. from the National Arts and Disability Center at the University of California, Los Angeles -- demonstrated the following findings:

-- Only one-half of one percent of words spoken on TV are said by a person with a disability.

-- 56 percent of background performers with disabilities earn less than \$1,000 a year.

-- More than one-third of

those surveyed said they’d experienced some type of workplace discrimination, such as not being cast for a role or being refused an audition because of their disability.

In recent years, actors and performers with disabilities, along with their allies, became determined to change this situation. In 2008, the Performers with Disabilities Tri-Union Committee (of SAG, AFTRA and AEA) launched the I AM PWD (Inclusion in the Arts and Media of Performers with Disabilities) campaign. The campaign works to increase employment opportunities for actors, broadcasters and sound recording artists in the entertainment and news media.

“The normal struggles any performer faces ... are complicated tenfold by our industry’s reluctance to include people with disabilities in the full landscape of entertainment,” said “CSI” star and I AM PWD chair Robert David Hall. “Society’s values and priorities are ... reflected in film, television, theater, news and music.

“If you aren’t seen and heard, you’re invisible,” added Hall, a double amputee who walks with prosthetic legs. “People with disabilities are largely invisible within the arts and media landscape.”

It’s still difficult for performers with disabilities to get traction, Squire said, “but there’s been some significant progress.”

One encouraging example of this progress, she said, was an event held last July called Lights! Camera! Access! The gathering was hosted by the Academy of Television Arts & Sciences and co-hosted by the U.S. Department of Labor Office of Disability Employment

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End-of-Life
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"I take a dozen tablets a day for one ailment or another. I take a tablet to control my high blood pressure. One to lower my cholesterol. Another for my Parkinson's. Another to control my appetite. Hell, seniors my age keep the pharmaceutical companies prosperous. But do you know what?"

"What, Harold?"

"Despite all this technology and medications, my quality of life sucks. I don't want pills to keep me artificially alive."

He looked at his plastic bag, shook his head and continued. "I'm 82 years old. I've been married 55 years. My wife, Helen, and I have four children, a football team of grandchildren and three great-grandchildren. God blessed me that way."

He stopped and looked at his watch. He laid it on the empty chair to his right. "In another hour I'll pop another pill. And two an hour after that. Yet, for all the pills I pop daily, I go through the humiliation of having my wife or son dress me daily. It's embarrassing to have my wife put my underwear, socks, shoes, shirt on me most mornings. It's disgusting to wet myself, and I'm unable to change wet underwear. I want to die. However, I'm Catholic, so suicide is not an option."

"Have you discussed these feelings with your family and others?"

"Yes. My wife cries when I do. My children don't want to listen, and so they walk away. But I've made a will that states I am not to be put on life-support technology if that situation occurs."

Before he could say anything else, a doctor's

assistant told him the doctor was ready to see him. He grabbed his heavy cane and asked, "Will you help me up?"

I assisted him. I watched as he walked, his body bent over, ever so slowly to the door. Then he was gone.

I waited until he came out of the doctor's office to ask him if I could write a column about our conversation. He said I could.

A day after my conversation with Harold, my 80-year-old father-in-law died. He had been sick for a number of years. He had told me numerous times over several years that as he aged and confronted numerous ailments -- he took 18 medications daily -- that he saw his quality of life deteriorate, and he wanted to die. Like Harold, my father-in-law questioned the wisdom of keeping seniors alive when they could no longer live with independence and dignity.

For years, I have questioned the policies of keeping people alive who are a burden to themselves and their families. I know that I do not want to live if I become a personal and financial burden to my family and community. I do not want my quality of life to suck.

John M. Williams can be reached at jwilliams@atechnews.com. His website is www.atechnews.com.

Do you know of an important date in disability history?

Do you know a disability hero or heroine?

Do you have an upcoming event?

Send the info to events@ilchv.org

History Week
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the disability community and the disability rights movement," she said. Her disability, osteogenesis imperfecta, a genetic disorder sometimes known as brittle bone disease, forced her to spend a lot of time in special education classrooms. But it wasn't until she attended the youth leadership forum (YLF) that she began to remotely understand the concept of disability pride. "After my experience at YLF, I was changed for life. My eyes were open to a completely new and amazing disability world. I wanted to share my newfound passion for disability rights with the world."

For Christina Mills, who has the same disability and attended the same forum in 1994, the experience had the same effect on her. "I had disability encounters before that time, but my impression of disability was very negative. YLF really changed my attitude and personal stereotypes. In fact, it shaped my career."

Mills, 34, is deputy director of the California Foundation for Independent Living Centers, a statewide disability rights, public policy, nonprofit trade organization made up of 25 California centers for independent living. Mills oversees community organizing and advocacy programs, including YO! Disabled & Proud, a group for disabled youth that CFILC launched in 2009 (yodisabledproud.org).

"I envisioned starting a youth program that was focused on building our community for the next generation of disability rights leaders," Mills said. "I came to realize that most of the time youth weren't given an opportunity to share what was important to them. They would be invited to meetings, even appointed to high-level

boards and committees, but weren't deeply engaged because they didn't have the space to discuss what they wanted to work on."

Shortly after YO! was launched, CFILC organized a two-day disability history summit at which 40 youth were selected to attend. Sara Moussavian, 20, of Palo Alto, Calif., was one.

She has Apert syndrome, a congenital disorder characterized by malformations of the skull, face, hands and feet. "When I was a child and in my early adolescence, I had not really had much contact with other individuals who had a disability," she said. "I would say on a scale of one to 10, with one being the least, I had a rating of one in my level of interactivity with the group."

But after learning about Ed Roberts, Justin Dart and other disability rights leaders, Moussavian and other young leaders in YO! decided to undertake the disability history week campaign. Moussavian, with the guidance of Mills and others at CFILC, was one of the youth who crafted the language of the bill and secured sponsors.

"To be honest, I felt grateful to be a part of what I now called family, (whom) I can turn to for support, as most of them are youth with disabilities who have experienced similar situations like I have," she said.

McDonnell, who came aboard after the bill was passed, is involved with its implementation. She does disability history presentations at schools, conferences or wherever she can get an audience.

"Initially, I wanted to share my experience in learning

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The Loss
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None of these three forms of dehumanization are true. Nevertheless, they are prevalent, and they are brutally destructive.

The tragedy for many of us who live with disabilities is that when you get the message day in and day out, year after year, that you are worth less than others, you begin to believe it. And if there is one thing any person has a right to do, it's to reclaim the whole of his or her humanity.

The loss we experience when inundated with the "less than" message is, in fact, not there. We only have to pay attention to ourselves and each other to know this is true. If we pay attention, we will recognize that people do not have to stand up to stand tall; they do not have to have sight to have vision in life; they do not need to have hearing to know the sounds of justice and injustice. People don't need anything but the awareness of their very existence to know they are whole.

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

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Steve Jobs
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congratulated for his policy of making Apple's products accessible to people with disabilities. I believe Apple will continue his legacy, and the lives of people with disabilities will continue to benefit.

John Williams can be contacted at jwilliams@atechnews.com.

Visitability
Continued from page 5

been so well incorporated into the building safety plan review and inspection processes, that there is no additional cost to the county to enforce its requirements.

"From a real estate perspective, homes built to this standard are deemed more marketable, but even more importantly, the accessible features of these homes remain unnoticed when toured by individuals not seeking accessibility. One of the initial concerns of the ordinance implementation was that it would result in homes appearing institutional in nature. This has not occurred within Pima County. As such, it would seem reasonable to anticipate like benefits and impacts by extending these requirements on a national level in line with the proposed Inclusive Home Design Act."

Clearly, Pima County developers and real estate agents have learned the benefits of visitability. Smith believes CILs could benefit from understanding the negative correlation between visitability and institutionalization.

"Centers for independent living and others in our movement need to know about visitability," Smith said. "What are the strengths and weaknesses of the arguments we make? The strength is visitability says everybody's house needs to be accessible.

The weakness is we have not really touted the obvious other half of the picture. You are less likely to be kicked out of your own house.

"How many people get kicked into nursing homes because their house lacks access, and we can't come home to where we live? With aging baby boomers, the numbers could be staggering. Among older and younger people, the lack of home access dropkicks people into nursing homes. The extent to which lack of access in one home is a factor in nursing home admission is an ill-researched and acknowledged fact."

Smith's target retirement date is April 2013. "I am going to fold the tent and go cold turkey when I turn 70," she said. For the CIL that takes on Concrete Change and visitability, she is adamant that everything be open for discussion. "I want to make it clear that a complete transition will be taking place, and the only thing I would offer is technical assistance for that group itself."

Smith is searching for a large CIL that will be around for the next 10 years, one with a history of direct action and policy work. She wants a center "with an ADAPT frame of mind as well as policy experience." The center, Smith said, should have enough employees to afford to assign one, preferably a skilled organizer, who would devote at least half of his or her working hours to the issue of how new houses are built.

With more baby boomers aging and becoming disabled, the next 10 years are projected to be an explosive time for inclusive home design. For a CIL with the resources and commitment, incorporating Concrete Change and taking the lead on visitability could push it into the forefront of the independent living

movement.

For more information or to contact Eleanor Smith, go to www.concretechange.org.

Janine Bertram Kemp is a writer and disability rights advocate who lives in Zig Zag, Ore. She is currently working with Tom Olin on the Disability Rights Center Photo/Oral History Project.

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about disability history and the leaders' amazing stories," she said. "Now after being involved with the campaign for over a year, I'm starting to create a more unique and individual reason why disability history week is important to me. As I grew up not knowing anything about the disability community, I spent a lot of time trying to figure out what I was missing in my life. It took me almost 16 years to find out about my community, and I instantly felt as if I was whole again. If people with or without disabilities don't know about our rights and our history, I don't believe that we will ever be seen as equal in society. Once I share our struggles that we overcame, the rights we have and some of the great leaders, many people suddenly feel like they know more about me and other people with disabilities."

Today, Moussavian and McDonnell work together as volunteers on another YO! initiative, the Own My Power anti-bullying campaign, in which young people with disabilities unite to expose and eradicate the bullying to which they and others have been subjected. Though McDonnell and Moussavian are full-time college students, they plan to make disability rights their life's work. Moussavian, in fact, worked part time at the Silicon Valley Independent

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We Remember

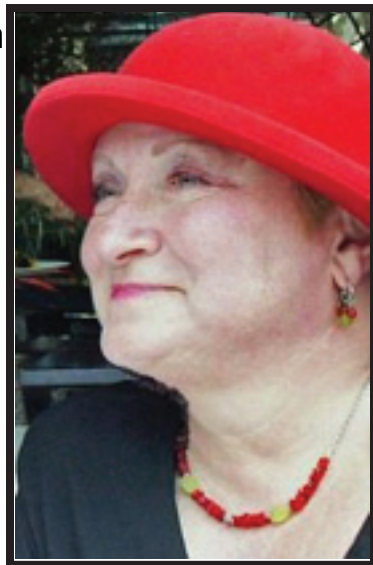
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Blvd., North Hollywood, CA 91601. All contributions will be tax-deductible.

By Mike Piekarski from various sources

Susan M. Daniels (Oct. 23rd, 1948 – Oct. 20th, 2011).

Daniels was a former official in the U.S. Social Security Administration and a national and international advocate for the rights of the people with disabilities. She was 62.



As deputy commissioner for disability and income security programs in President Bill Clinton's administration, she led Social Security disability reform initiatives that resulted in passage of the Ticket to Work and Work Incentives Improvement Act of 1999.

As an associate commissioner in the U.S. Department of Health and Human Services, she started the federal Home of Your Own program to assist people with disabilities in becoming homeowners, and she also supported a national Home of Your Own technical assistance center to expand homeownership opportunities for people with disabilities to other states. Home of Your Own networks have since expanded to 27 states.

In 1997, in her role as Clinton administration disability official, she and Judy Heumann, then assistant secretary for education, organized the first International Leadership Forum for Women with Disabilities. The forum quickly expanded into a conference of 600 disabled women and their allies from 80 countries, sponsored by 25 U.S. government agencies. The forum served as an impetus for subsequent regional and international meetings concerning equalization of opportunities for women.

She spoke about disability policy at international conferences and research forums in Africa, Europe and Asia, and she served as president of the U.S. Council of International Rehabilitation and as Rehabilitation International's deputy vice president for North America.

Daniels, who was born in New Orleans, La., contracted polio at 6 months of age and spent much of her young life in rehabilitation institutes and hospitals.

Michael Imperiale, (June 18th, 1937-October 10th, 2011) was a disability activist in New York City. He had hemiplegia, and was born with a condition called dystonia. He was the partner of the late Frieda Zames, who passed-away in 2005. He was an infantryman, a front-line fighter. He was a long time member of Disabled In Action (DIA) of New York City, an organization founded by Judy Heumann in the 1970s.



Like a good soldier, Imperiale would do whatever was asked of him, and do it well. Once, he lay in front of a NYC bus to keep it from moving until the driver deployed

the lift in the rear, and allowed Frieda to get on the bus with her scooter. The NYC activist community lost a real dedicated advocate. He was well liked and respected. We're all saddened by his loss.

--Compiled from various sources

History Week

Continued from page 11

Living Center in San Jose as a youth leader.

Of the young people she has met, Mills said, "so many of them have become loud, proud disabled leaders! I'd be lying if I didn't say I had hoped for similar legislation when I was their age. The campaign made me realize that being an adult ally is important. I was able to be the person that youth came to when they needed support or need someone to run an idea by. I felt like I got to be their cheerleader. I've enjoyed watching the campaign grow and change the way youth with disabilities see themselves."

If older disability community leaders of today make the effort to seek and genuinely welcome youth into the community, McDonnell said she believes they'll always find plenty of young people yearning to connect.

"I feel as though with more education and awareness, more people will find a way to connect, whether it is through work, conferences or maybe even new social networking sites," she said. "The technology has helped different types of people all around the world connect no matter what community they feel they belong to."

Mike Ervin is a Chicago-based writer. His blog, "Smart Ass Cripple," can be found at smartasscripple.blogspot.com.

Organizer

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Policy. Secretary of Labor Hilda L. Solis issued a "call to action" to the entertainment industry.

Assistant Secretary for Disability Employment Policy Kathleen Martinez, who is blind, issued a "soft challenge" calling for increased employment opportunities "in front of the camera and behind the scenes," Squire said.

"It is my hope that the Labor Department, Congress and our partners in the private sector will help open doors for people with disabilities to join growing careers like those in the entertainment industry," Solis said at the gathering.

As a result of Lights! Camera! Access!, NBC Universal (now Comcast) brought in 45 recent graduates and veterans with disabilities for resume review and "speed interviewing," Squire said. "It was a first. It was phenomenal."

Yet, even with this increased visibility, the majority of performers with disabilities still encounter discrimination.

"Much more work needs to be done," Squire said.

Kathi Wolfe is a Washington, D.C.-area based writer and poet who writes frequently on disability issues.

Follow these stories and other news on the most popular disability web portal on the net: www.ilusa.com.

