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GARDENS A
GROWING TREND

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COLLEGE
STUDIES

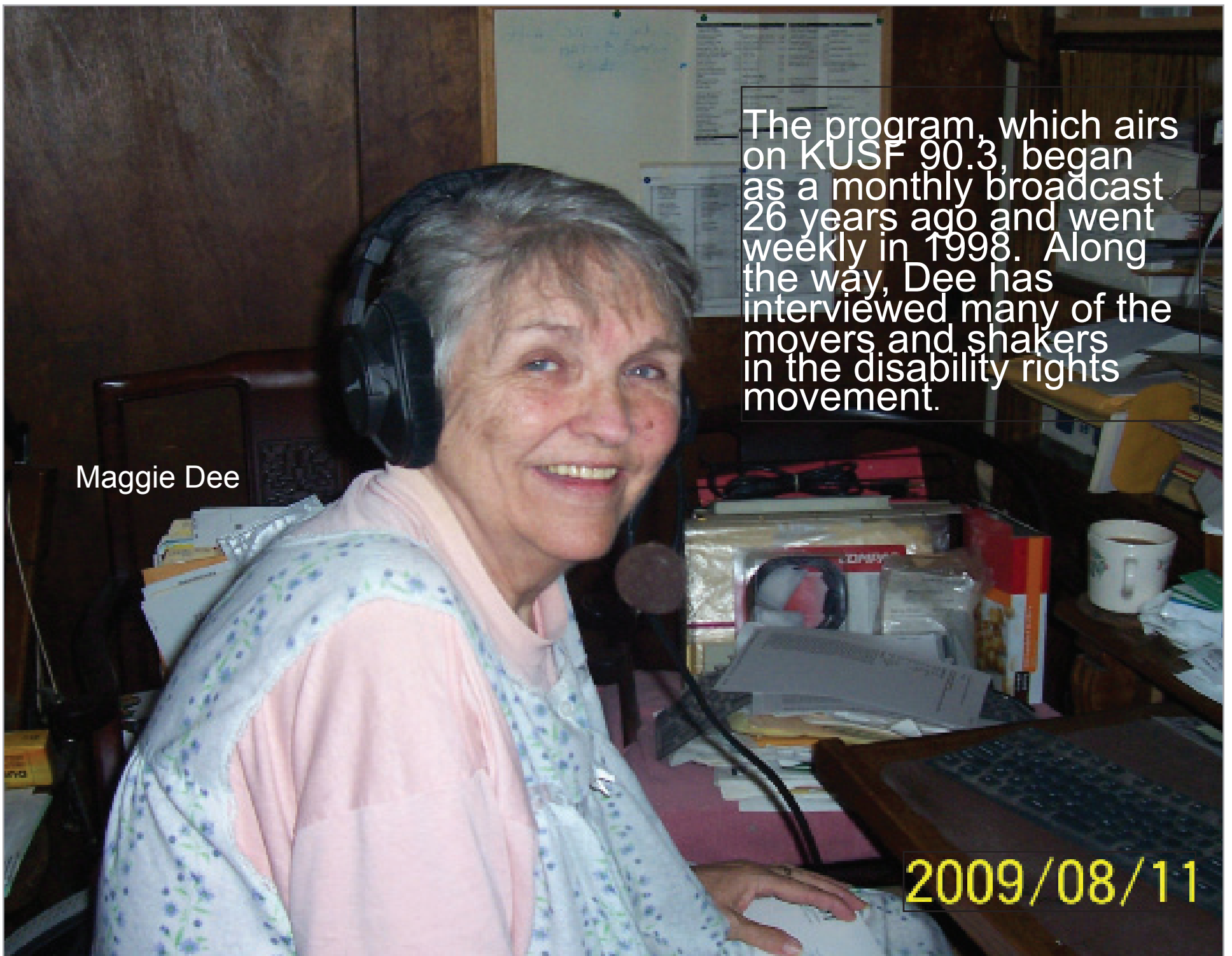
IT'S TIME FOR
UNIVERSAL,
AFFORDABLE
HEALTH CARE

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independence today

Volume 3

Issue 4



Maggie Dee

The program, which airs on KUSF 90.3, began as a monthly broadcast 26 years ago and went weekly in 1998. Along the way, Dee has interviewed many of the movers and shakers in the disability rights movement.

2009/08/11

PEOPLE WITH OCD
FIGHTING BAD DAYS
WITH
'GREATER GOOD'

GIRL WHO DOESN'T
AGE MAY HOLD KEY
TO LONGEVITY

TIME TO RETHINK
OUR OWN
DECLARATION OF
INDEPENDENCE

FOR DIRECTORS
ONLY:
AN INVITATION

Commentary**Time to Rethink Our Own
Declarations of Independence***By William Loughborough*

For the first few years of our lives, all of us are totally dependent on others for survival. Then, after discovering that we can survive without a full-time personal attendant -- usually "Mommy" -- we think that we are fully independent.

There used to be a widespread notion of an individual's absolute independence from everyone and everything. It was -- sometimes grudgingly -- acknowledged that we were dependent on others for many things, but there was still the feeling that we were somehow independent of being beholden to everybody else for essentially everything.

No one seriously considers him or herself, in that sense, "independent" any longer. Every time there is a need for help, our mutual dependence is emphasized, whether it is because we need someone to keep the power grid running or to turn us over in bed to avoid pressure sores. Somehow, the latter sort of assistance is regarded widely as a "special accommodation" because, after all, the overwhelming majority of us can turn over by ourselves.

The truth is, we never get over needing special accommodation. Whether it is because of others growing our food or keeping our air and water safe or teaching us how to stay alive, we are all highly interdependent. We are all in this together and, luckily, we are dependent on one another.

In point of fact, the entire global electrical distribution system is a special accommodation for those individuals who, unlike blind people, cannot read in the dark and thus

have a "special need" for manmade illumination. But blind people are taxed with furnishing this special accommodation that they have no special need for. Similarly, there are billions of chairs, mostly seldom used, wherever people gather in groups, but people who bring their own rolling chairs are taxed to provide this seating service for those who failed to furnish their own chairs.

Of course, most of society sees it the other way around, but the fact is that if everybody learned to read Braille and used wheelchairs it would be a huge savings for society. Because we have for so long considered "difference" as a sort of punishable inferiority, we think those who fit certain categories (for example, the lame, halt or blind) are being given undeserved entitlements while those who makes the rules are considered automatically eligible for their own ease and comfort. Lighting is "affordable," but environmental accessibility for certain functionally diverse people is not. We never ask how we can afford aircraft carriers but always question housing vouchers for poor people who must sleep in doorways.

For a long time, people with different levels of functionality have been labeled as having special needs that create a burden on society. They are put into labeled groups and often discriminated against -- sometimes very substantially -- just for being different, despite the fact that their functional diversity is what makes it possible for humanity to survive and evolve.

Independence
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**THIS DAY IN
DISABILITY
HISTORY**

July 1st, 1961 -- Diana Spencer, the future Princess of Wales, is born. Following the announcement of her engagement to Prince Charles, Diana immediately became a public figure and remained the focus of near-constant media scrutiny in the United Kingdom and around the world. The princess openly wrote of her struggles with bulimia. She was credited with helping to change the public perception of people with AIDS when she was photographed holding the hand of a person who had contracted it. She also devoted much of her time to campaigns to end the use of land mines. Her death in a car crash in August 1997 was followed by a spontaneous and prolonged show of public mourning.

July 9th, 1934 -- Michael Graves, an American architect, is born in Indianapolis, Ind. Graves became well-known for designs for domestic products sold at Target stores in the United States. Graves and his firm, Michael Graves & Associates, have earned acclaim for a wide variety of commercial and residential buildings and interior design. In 2003, he suffered an unknown infection that left him paralyzed from the waist down. He currently uses a power wheelchair for mobility. In addition to his popular line of household items, Graves was elected a Fellow of the American Institute of Architects in 1979. In 1999, he was awarded the National Medal of Arts and in 2001 the gold medal from the American Institute of Architects.

July 26th, 2000 -- President Bill Clinton celebrates the

10th anniversary of the Americans with Disabilities Act, the highlight of which is the "Spirit of ADA" Torch Rally, sponsored by the American Association of People with Disabilities. Clinton's speech, at the FDR Memorial in Washington, D.C., received worldwide coverage and placed a large spotlight on the landmark civil rights legislation for people with disabilities.

August 1st, 1942 -- Jerome John "Jerry" Garcia is born. Garcia was an American musician best known for his work with the band the Grateful Dead. One of its original founders, Garcia performed with The Grateful Dead for their entire three-decade career, from 1965 to 1995. He was well known for his distinctive guitar playing and was ranked 13th in Rolling Stone magazine's "100 Greatest Guitarists of All Time" cover story in September 2003. Later in life, Garcia was sometimes ill because of his unstable weight, and in 1986 went into a diabetic coma that nearly cost him his life. Although Garcia's overall health improved somewhat after that, he also struggled with heroin addiction. He died of a heart attack in August 1995.

August 16th, 1996 -- The Paralympics Summer Games, which opens in Atlanta, is the first to receive mass media sponsorship. The 10th Summer Paralympics, which recognizes exceptional disabled athletes, hosted 104 countries. A total of 1,577 gold, silver and bronze medals were awarded over the course of 10 days. The 1996 event also featured a cultural element in which artists with disabilities showcased their talents, including a film festival.

August 29th, 1930 --

This Day
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CoverStory

Maggie Dee: Disability Leader Can't Be Kept Down

By Janine Bertram Kemp

Maggie Dee, the California media maven, has earned her stripes as a member of the disability rights community.

In 1983, she sustained a spinal cord injury in a car accident. In 2000, her wheelchair malfunctioned and propelled her out of a van when the ramp was up, leaving her with a head injury. In addition, she was born dyslexic, which left her struggling in school and facing disability prejudice at an early age.

Like many disability leaders and activists, Dee made lemonade out of what many of the non-disabled view as lemons. She is a deejay for what may be the longest-running disability radio show in the country. The program, which airs on KUSF 90.3, began as a monthly broadcast 26 years ago and went weekly in 1998. Along the way, Dee has interviewed many of the movers and shakers in the disability rights movement, including Ed Roberts, considered the father of independent living.

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In 2007, though, illness and pestilence descended on Dee as if she were living the biblical tale of Job. First, she came down with Methicillin-resistant Staphylococcus aureus. MRSA is a virulent infection that does not respond well to medications. It is often contracted in hospitals.

As Dee described it, "I had it for 22 weeks, and it gave me 44 boils where the sun don't shine."

In September 2007, her doctor discovered she had anal cancer, and 35 weeks of radiation treatment was later recommended.

"I totally lost my center," she said.

A specialist told Dee that if she did nothing, "You will die within two to four weeks, vomiting stool."

Dee endured radiation treatment five days a week for seven weeks, except when the burns were too severe and she took four days off before starting again. The pain and discomfort were intense. She took Sitz baths five times a day and was on morphine and Norco patches.

Finally, at the end of 2008 she got the all-clear sign on her cancer. Then she had a heart attack. How, she was asked, did she endure so much?

Concerning her MRSA diagnosis, she credited her personal assistants. "All the cleaning and isolation -- if not for them, I wouldn't have survived."

Thriving through anal cancer was more involved.

"During the two months before treatment, while I was finding my center, I could not make a decision," Dee said. "I took a journey to Fort Cronkhite. (Fort Cronkhite is a former World War II military base located in the Marin Headlands on the Pacific Ocean.) A good friend of mine had cancer

and had passed away. She was a Buddhist and (practiced) some Native American spirituality. I freed her spirit at the beach. As I freed her spirit, the answer came to me that I needed to do radiation."

Dee lives in Contra Costa, about halfway between the Bay Area and Sacramento, so only about 10 people visited her. But people responded in other ways.

"I put out that I had cancer on ADAPT and Berkeley listservs," Dee said. "There were lots of cancer survivors that asked what I needed to support my decision. Music was beneficial. So were biofeedback and nature sounds. I asked for CDs and received all kinds of help from the community. I was scared by some of the horrific stories but still grateful because they were real.

"The cancer institute at (the) John Muir (Medical Center) had no accessible treatment room," Dee said. "The accommodation they made was examining me on a gurney and then taking me in on the gurney, so it was not impossible to get on the radiation table."

She explained that she survived through support from cancer patients and from a mix of people. People with whom she had no personal relationships embraced her. They sent her books and tapes, prayers and good wishes.

At one point Maggie was worried about funeral expenses. A dear friend, Liz Figueroa, former California state senator and legislator, came up with a solution that seems quintessential California.

"She thought she wouldn't live very long, and I asked what I could do," Figueroa said. "Her friends all wanted to chip in, so we had a bon

Maggie
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Commentary**It's Time for Universal, Affordable Health Care***By John M. Williams*

I know from personal experience what it is like to pay seven, eight and nine thousand dollars a year for medical bills because I did not have health insurance. There were lean years in which I paid more than \$12,000 out of pocket for medical care.

That was money taken away from my retirement and sometimes meant no vacations and late car and mortgage payments. I had to hold on to a clunker of a car longer than it was safe to drive. Over the years, I have paid out more than \$100,000 in medical expenses.

Why did I have to pay so much? Because I could not afford to pay the premiums, which ranged from \$1,200 to \$2,000 a month. Some health insurance companies wanted \$2,300 a month in premiums to cover three people.

One of the personal indignities of not having health insurance is going to a pharmacy to pay for medications and having someone at the counter say: "The price is \$180. I see you do not have medical insurance. Can you afford this medicine?" Most times, I just smile and pay with a credit card. A few times, though, I lose my cool and verbally explode.

Every rational person recognizes that the health care system in this country is broken and will become even more damaged if we do not repair it. President Barack Obama's administration and the overwhelming majority of Democrats across the country know that we need to repair the way medicine and medical care are delivered in this country. Some Republicans recognize the necessity of

changing the way medicine is practiced.

Democrats and Republicans believe that medical care should be affordable, portable and universal. They also believe that insurance companies should not deny people medical insurance because of pre-existing conditions. And they believe that insurance companies should not cap medical expenses. Lastly, a recent poll revealed that 72% of the American people want a single-payer option in any national health care program.

But despite all the horror stories associated with medical bills bankrupting hundreds of thousands of families -- a number that is still rising -- and the fact that people are suffering and dying because insurance companies are rationing health care, moderate and conservative Democrats and nearly every Republican in both houses of Congress are willing to gut plans to reform the health care delivery system because they think it costs too much or because they do not want a single-payer option.

Republican and Democratic opposition to health care reform shows that we have the best Congress that the insurance companies, pharmaceutical companies, doctors and other opponents can buy. None of these people have any shame. They want business as usual. We must remember that the essence of business is profit at any price.

Today, opponents of health care reform are spending more than \$1 million a day in Washington, D.C., to protect their interests. And that figure is rising. These opponents have

hired Republicans and Democrats to make sure their financial interests are protected. An insurance representative told me, "From our perspective, it is a mortal sin if my company does not make at least 30 percent profit a year." Out of fear of reprisal, the representative did not want to be identified.

Recently, a health insurance company reported a 155% profit over the previous year.

Democrats and Republicans on Capitol Hill know about these huge profits. Even though the profits were gained partly from human suffering, the money paid to both parties and former staff members trumps their consciences.

The propaganda pouring out of the mouths of Republicans opposing health care reform is straight out of the health industry's playbook. Senate Minority Leader Mitch McConnell of Kentucky, Senator John Kyl of Arizona, Judd Gregg of New Hampshire and House Minority leader John Boehner of Ohio have parroted the health insurance industry's opposition to a single-payer plan. All have said the following: "a single-payer plan puts a government bureaucrat between a patient and his doctor," "a single-payer plan leads to rationing of health care," "a single-payer plan leads to socialized medicine."

Senator Max Baucus, D-Mont., chairman of the Senate Finance Committee, opposes a single-payer plan. He has taken hundreds of thousands of dollars over the years from the health insurance industry.

The Blue Dog Democrats who oppose a government-operated single-payer health insurance plan are heavy recipients of money from the health insurance industry.

From their perspective,

it's OK to have a for-profit bureaucrat come between you are your doctor, and it's OK to have a for-profit company bureaucrat ration and even deny health care to someone who needs it. Medicare and Medicaid and our VA hospitals are government-run health care programs. Who wants to abolish them?

Democrats and Republicans know they are talking garbage when discussing the alleged negatives associated with a single-payer plan. They ought to be ashamed of themselves. Unfortunately, they are not.

The American economy needs a major overhaul in the health care field. The American people know this. Most members of Congress know this. A minority in both houses of Congress has the ability to stop reform. Americans should speak out against these obstructionists who are serving the interests of big business and proving that the U.S. has the best Congress that money can buy.

Individuals should have affordable and portable health insurance. Congress can give me that opportunity. I am not asking for a handout. I am asking for access to affordable health insurance. So, yes, I support a single-payer government health insurance plan.

Lastly, if Congress obstructs health care reform, it should relinquish its own. The American people should shout loudly, "No health care for us, absolutely no health care for you."

John Williams, a contributing writer to Independence Today, coined the phrase "assistive technology." He can be reached at jmmaw@verizon.net. His Web site is www.atechnews.com.

CLASS Act Seen as One Piece of Reform Puzzle

By Mike Ervin

The July 27th edition of Newsweek magazine featured an essay by Sen. Edward Kennedy, D-Mass., titled, "The Cause of My Life: Inside the Fight for Universal Health Care."

In the essay, Kennedy wrote: "Social justice is often the best economics. We can help disabled Americans who want to live in their homes instead of a nursing home. Simple things can make all the difference, like having the money to install handrails or have someone stop by and help every day. It's more humane and less costly -- for the government and for families -- than paying for institutionalized care. That's why we should give all Americans a tax deduction to set aside a small portion of their earnings each month to provide for long-term care."

In the last Congress, Kennedy introduced the Community Living Assistance Services and Supports, or CLASS, Act. It provided for a public long-term-care insurance pool to be funded by voluntary payroll deductions. Workers who paid into the system for at least 60 months would then be eligible to receive a cash benefit to help pay for in-home attendant services and other costs of independent living.

The CLASS Act languished and died but was reintroduced in March. Kennedy said at the time: "Too many Americans are perfectly capable of living a life in the community but are denied the supports they need. They languish in needless circumstances with no choice about how or where to obtain these services. This is an issue I intend to address in the reform of the nation's health care system."

When the Senate's Health, Education, Labor and Pensions (HELP) Committee, which Kennedy chairs, passed the Affordable Health Choices Act on July 15th, its version of health care reform, the CLASS Act was included. (A version of the CLASS Act is also part of the America's Affordable Health Choices Act passed by the House Energy and Commerce Committee.) This came about after Health and Human Services Secretary Kathleen Sebelius wrote the HELP committee on behalf of President Barack Obama, urging just such a move. The president believes, Sebelius wrote, that "this important legislation would expand resources available to individuals and families to purchase long-term services and supports..."

If any meaningful health care legislation passes with the CLASS Act as a component, it will be the first significant attempt to create a long-term care option other than Medicaid. The CLASS Act, Kennedy said in March, "makes a simple pact with all Americans: 'If you work hard and contribute, society will take care of you when you fall on hard times.'"

But the problem, critics say, is that because it is employment-based, the CLASS Act concept does nothing to help those who have not paid into the system and still must rely on Medicaid. It's another example, they say, of how the current Democratic notions of health care reform soothe the middle class at the expense of the poor.

Subtitle H of the Affordable Health Choices Act establishes a "national voluntary insurance program for purchasing

community living assistance services and supports." Workers who don't opt out would be eligible for benefits after 60 months (and at least 12 consecutive months) of payroll deductions that can't exceed \$65 per month. They could receive a benefit of not less than \$50 per day if they are unable to perform not fewer than two listed activities of daily living for at least 90 days.

The intent is "to purchase nonmedical services and supports needed to maintain a beneficiary's independence at home or in another residential setting, including home modifications, assistive technology, accessible transportation, homemaker services, respite care, personal assistance services, home care aides and added nursing support."

But Bob Kafka, national organizer for ADAPT, said the CLASS Act might actually be harmful in some respects for fixed-income people with disabilities if it is not enacted in tandem with the Community Choice Act (which gives those receiving Medicaid-funded long-term services and supports more help in avoiding institutionalization).

"ADAPT's position on CLASS is that we support it if it has language that ends the institutional bias in Medicaid," Kafka said. "CLASS has its merit because we need a national long-term services and supports program, but our concern is if it passes without fixing Medicaid (is that) it will evolve (in) to a two-tier system."

This fear was echoed in a letter sent to Obama on July 26th, the 19th anniversary of the signing of the Americans with Disabilities Act. Signed by the American Association of People with Disabilities, ADAPT Montana, the Arc of the United States and the Autistic Self-Advocacy Network, the letter said,

"We also join with millions of other Americans of all ages, income levels and political persuasions in calling on you and leaders of both parties in Congress to make certain that the health reform legislation that is enacted immediately eliminates the institutional bias and ensures equal access to affordable, high-quality community living services throughout the United States.

"Unfortunately, the conventional wisdom held by many of our nation's elected officials is that our country cannot afford to end the institutional bias in public policy and private coverage plans that perpetuate the needless institutionalization, isolation and degradation of millions of children, adults and elders with disabilities as well as their families.

"We applaud you and HHS Secretary Sebelius's (sic) support for the CLASS Act ... However, it alone will not end the institutional bias of Medicaid nor meet the immediate needs of over 4 million low-income Americans with disabilities of all ages who are on Medicaid and require such services and supports. The inclusion of the Community Choice Act in the final health reform legislation that passes Congress is crucial to making this happen. Throughout last year's Presidential campaign, you made clear that the enactment of both pieces of companion legislation is critical to giving a new birth of freedom to millions."

Though Obama was a co-sponsor of both bills as a senator, as president he has thus far refused to include the Community Choice Act or its concepts in his vision of reform.

In his Newsweek essay, Kennedy wrote, "Incremental measures won't suffice anymore."

Kafka said: "The problem

CLASS
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New Initiative: CIL College Studies

By Kathi Wolfe

Susan Menhard, 50, who lives in St. Louis, had always been into wolves. But until she was in the hospital after becoming a quadriplegic through a gymnastics accident, she never thought a wolf could be an emotional lifesaver.

At 43, Menhard was a social worker who worked with homeless people and competed in national trampoline events. One day, while practicing on the trampoline, "I opened too early on the last element ... and landed on the back of my head," she said. "I heard my neck snap ... (I) severed my spinal cord."

For the first two and a half years after her injury, Menhard often wanted to commit suicide. While looking around her hospital room, she saw what she called the "first turning point" in her change of heart. "There was a sketch of a wolf on the wall," she said. "I used that (drawing) to escape a little bit. It had been sketched by a man who was as disabled as I am. He had no ability to use his arms."

Menhard's second "turning point" came when she visited Paraquad, Inc., the nationally known independent living center in St. Louis. There, she met Doug Landis who, using a mouthstick, had drawn the wolf that had been so life-affirming for her.

"He just happened to roll into the office," Menhard said. "It was an instant connection. He just started talking about things I was so embarrassed about – like needing help with eating and other kinds of personal care."

After that conversation, Menhard felt much less humiliated when she talked about needing assistance with wiping her nose or

other intimate tasks. "I started owning my disability at this point."

Menhard earned a bachelor's degree in social work from Southeast Missouri State University in 1983 and a master's from the Brown School of Social Work at Washington University in 1988. But even with two social work degrees, she was clueless as to what it meant to live with a disability until after her injury, Menhard said.

Landis proved to be exceptionally helpful to her. "You just don't know what (having a disability) is like until you've been in that person's shoes," Menhard said.

Today, Menhard is learning how to teach people with and without disabilities the professional skills needed to fully understand the challenges of a person with a disability (PWD). She is a research assistant with the Disability Studies Initiative, a program offering disability rights-focused courses (including independent living, disability history, advocacy and universal design) at Maryville University in St. Louis.

Colleen Kelly Starkloff, director of education and training of the Starkloff Disability Institute, a St. Louis disability think tank, organized the initiative. Many colleges and universities offer disability studies courses, but the curriculum the initiative developed for Maryville University is believed to be the first of its kind, Starkloff said in a lengthy telephone interview.

Most courses on disability studies focus on academic subjects such as disability in literature or in history. What makes the curriculum she introduced to Maryville unique is its emphasis on

the practical applications of disability rights and history to independent living, Starkloff said.

"I'm not aware of another curriculum that focuses on training people to work in independent living centers, non-profit groups, corporate human resources departments or other settings that serve people with disabilities," she said.

In 1970, Starkloff, with her husband, Max Starkloff, co-founded Paraquad. Colleen Kelly Starkloff does not have a disability; her husband is quadriplegic. In 2003, the Starkloffs left Paraquad and established the Starkloff Disability Institute, and in 2005 Colleen started the Disability Studies Initiative.

Centers for independent living (CILs) grew out of the disability rights movement, Starkloff said. The aim of the movement was to "maintain the dignity and advocate for the rights of people with disabilities," she said. "The philosophy has been to have persons with disabilities running the show."

To ensure this, the majority of CIL leadership positions – at least 51 percent – should be held by people with disabilities, Starkloff said.

In the beginning of the independent living movement (in the 1970s and '80s), CILs were much smaller, Starkloff said. "You could go in with passion – with fire in your belly – and work for disability rights then. People with disabilities were involved, and their hearts were in their work. You didn't need to have so many credentials."

But over the years, many CILs have changed, Starkloff said. "A lot of the CILs have become bigger – with larger staffs and budgets. Fewer of the centers are embracing the philosophy of the disability rights movement (and) fewer people with



Colleen Kelly Starkloff

disabilities are working in CILs."

In too many cases, people without disabilities are holding the majority of leadership positions at independent living centers, Starkloff said. "Some CILs have lost their souls," she added.

One reason this is happening, Starkloff said, is the changing nature of the field of disability. Today, directors and staff members of CILs and other organizations providing disability advocacy and services need "administrative, advocacy and case management skills," said Starkloff, an adjunct faculty member of Maryville University. CILs have had trouble finding people with disabilities who possess these skills, she said.

Starkloff, in an e-mail, said that she devised the Disability Studies Initiative because "I am strongly committed to the IL (independent living) philosophy, to the training of people with disabilities to work in the field of disability, and because I think the students have much to gain by having teachers with disabilities in the

CIL College
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CIL College
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classroom.”

The Initiative is located in Maryville’s Rehabilitation Counseling Program, and the seven courses offered constitute a certificate in independent living, in addition to a bachelor’s in rehabilitation services. The courses range from “The Rehabilitation System: History, Philosophy, Laws and Structure” to “Independent Living: Consumer Involvement and Self-Management” to “Case Management and Independent Living.”

Students who take the courses and earn the certificate in independent living will be qualified to work in any independent living center or group serving people with disabilities.

“Max Starkloff is 74 years old,” said Colleen Starkloff, who is developing a course on universal design for the fall for Maryville’s Interior Design School. “We need to train the next generation of Max Starkloffs.”

The initiative’s curriculum, according to Starkloff, will provide a historical perspective on people with disabilities “going back to the earliest period of time that we can find -- to the beginning of the modern disability rights movement in Berkeley and New York to the Americans with Disabilities Act and today.”

Most of the students taking the independent living courses now don’t have disabilities, Starkloff said. While teaching these students is valuable, she said, “we hope more students (with disabilities) will take these classes.”

In addition to Menhard, the social worker who sustained a spinal cord injury, Steve Foelsch is part of the Disability Studies Initiative. Foelsch, 44, who became a quadriplegic as a result of a motorcycle

accident when he was 20, is an independent living instructor.

Foelsch, who uses his arms to control his motorized wheelchair, lives in St. Louis. For years after his injury, he tried to distance himself from his disability as much as possible. “I consciously made an effort not to be around disabled people – not to be involved in any kind of disability advocacy,” he said. “I didn’t want my disability to influence any decision that I made.”

Foelsch earned bachelor’s degrees in history and anthropology from Missouri University in 1994 and a master of education degree in 1996. He also has two teaching certificates.

When he moved back to St. Louis after living in Mexico for a year, Foelsch applied for teaching jobs in the schools. He’d get calls for interviews, but when he would ask about wheelchair ramps, “I could hear their voices drop,” he said. “They’d say, ‘You need to go downtown to human resources.’”

“They didn’t want to hire me,” Foelsch said. “I just kind of laughed. I thought that’s how it was ... It took me a long time to stop being angry at everything.”

After substitute teaching, Foelsch met Starkloff, who told him about the Disability Studies Initiative. Initially, he was reluctant to get involved with the project because “I didn’t want my disability to influence any vocational decision that I might make.”

But Starkloff was persistent. “She gave me books like ‘Nothing About Us Without Us: Disability, Oppression and Empowerment’ by James I. Charlton,” which talked about disability in social, political and economic terms rather than

CIL College
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A New Chapter for Readers with Print Disabilities

By John M. Williams

In a recent breakthrough for thousands of people with print disabilities, universities and publishers have agreed to provide digital books to a World Wide Web-based company’s online library. Benetech CEO Jim Fruchterman announced digital-book partnerships between Bookshare and universities nationwide and between Bookshare and publishers.

Bookshare is a digital library that provides people with print disabilities the same ease of access to books and periodicals enjoyed by those without disabilities. Benetech is a nonprofit organization that operates the Bookshare library.

Bookshare allows a book to be scanned once and then shared with others who require digital formats that are easy to download, search and navigate. According to Fruchterman, the new Bookshare University Partnership Program is uniting universities throughout the country to increase the number of accessible post-secondary textbooks to students with print disabilities that hinder reading a printed book. Those disabilities include blindness, low vision and physical disabilities.

Typically, hundreds of thousands of students with print disabilities in higher education wait months after the start of a semester before having their textbooks converted into a format they can read. Those formats include audio, various print sizes and letter shapes, Braille and e-books.

Joining Fruchterman at the event sponsored by the National Press Club were Jim Marks,

president-elect of AHEAD (Association on Higher Education and Disability); Allan Adler, vice president for legal and government affairs of the Association of American Publishers; and Eugene Skonicki, a third-year student at Georgetown University Law Center and co-founder of the university’s Disability Law Society. Marks and Skonicki are blind.

The publishers’ agreements will reduce the burden of scanning and proofreading traditionally done by volunteers nationwide. Agreements with publishers will add a wealth of accessible titles to Bookshare, including children’s books; general trade, fiction and non-fiction works; best-sellers; academic, scientific and technical textbooks; and books for students in grades K-12 and beyond. “Digital media is the future for individuals with print disabilities,” Fruchterman said.

Currently, fewer than 5 percent of books are in accessible formats. Fruchterman made the point that people of all ages and classes benefit from Bookshare’s services. “Making Bookshare available to students with print disabilities in grades K through 12 increases their opportunity to compete equally with students who do not have print disabilities,” said New York City special education teacher Diana Ewebank. “I am happy to hear that seniors like myself have another channel for accessible content through Bookshare,” said reader Mark Stephens, 70, who is blind.

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Home and Community Gardens a Growing Trend

By Amy Halloran

Rising food prices and concerns about food safety have inspired people to take up a habit fostered by many of our grandparents: gardening. Back yards and community gardens, where you can plant and tend a plot side by side with other gardeners, are filling with edibles. Growing food is a survival tool, and resources for accessible gardening are gradually increasing.

One example recently opened in Hyde Park, Utah. There, the Utah Conservation Corps helped build about 30 raised beds in the Cache Valley Community Garden. The raised beds have different designs to suit the varying needs of gardeners, and specialized tools are available for use. While paths are hardened, there is also a rough-terrain wheelchair on site. The Center for Persons with Disabilities at Utah State presented a class in accessible gardening that was open to all gardeners.

Even though this community garden is the exception rather than the rule, raised beds and hardened paths are sometimes available in community gardens. Community garden groups will generally offer scholarships or reduced rates to people for whom paying a small fee is prohibitive. But if you can't find the perfect place for a garden, you can make one on a very small, fairly portable scale, using containers. Libraries have great books on the topic, and there are online guides, too. You may be able to find a local workshop, such as the one offered by Mary Ann DeFrees of the Independent Living Program at the Alliance of People with disabilities in Washington state.

"I provided containers that were recycled 3- and 5-gallon pails," DeFrees said. "Some of them had been used for pickles and other things. I punch holes in the bottom (and) put the soil in ... I provide the seeds, and I get those donated, too. My main emphasis with this was you can put a few containers on your deck, or at a friend's house, or whatever it was that it took so you could grow a few vegetables. A lot of people I work with are different nationalities, and sometimes that's something they already knew from home; they just didn't have access to seeds and something to grow it in."

The ideas and resources DeFrees gave participants, such as the phone number for the local Garden Hotline, and information on P-Patches, Seattle's brand of community gardens, spread like dandelion seeds in the wind. Word of mouth is a great delivery system, and the visual information of a patio full of container tomatoes in a housing complex is a great ad for growing your own food.

Iliana Filby grew up



First Lady Michelle Obama plants herbs in the White House kitchen garden with students from Bancroft Elementary School in Washington on the South Lawn of the White House.

gardening, so she didn't need anyone to advertise the wonders of fresh vegetables. She credits gardening with feeding her body and soul as she recovered from a serious bicycle accident.

"First of all, when I first had my accident, I was in the hospital for 11 months, and when I got out I was living at the Lawrence Center for Independence in Schenectady (N.Y.)," Filby said. "I planted a huge garden, and I have to say in all seriousness that it was gardening that reseeded my very primal relationship with nature, which had kind of gone. I would slide out of my wheelchair and bounce along on the ground. It was a real central part of my life and a real central part of my healing process. Since then I've gardened constantly."

For Filby, who lives in an accessible apartment in an elderly housing complex in White River Junction, Vt., constant gardening means growing plant starts from seed for two plots at a community garden, and at her home garden, too.

Creative strategies help her tackle gardening challenges, such as building an arbor for green beans from twigs. For that task, a friend cut a bunch

of sturdy but thin branches that she tied together with twine to make a framework for the plants to climb. Filby harvests green beans by wheeling along planks underneath the structure. Not one to waste an inch of dirt, she planted lettuce between the planks.

Though people help her execute her ideas, Filby pursues gardening on her own. Those interested in it can find information online from such groups as the Accessible Gardening forum on GardenWeb (<http://www.forums.gardenweb.com/forums/accessible/>).

Those seeking a local program may want to look into the American Horticultural Therapy Association (<http://www.ahta.org/>). This group focuses on the therapeutic benefits of gardening and is dedicated to all sorts of gardens, not just ones that grow food. The National Gardening Association offers information on its Adopt a Garden program at <http://assoc.garden.org/ag/>.

"One of the things to think about whether you are a disabled person yourself or somebody who wants to support a disabled person who is gardening, is that any kind of solution or support system you are trying to develop needs to be tailored," Filby advised. "For instance, in my case I am one-legged, and that opens up possibilities for me. That's always important in every situation: You want to remember it's an opportunity to create a unique situation. I don't know of anything better for nurturing that sort of primal relationship we have with nature and the food that we eat -- particularly for a disabled person, because it saves a lot of money, and you get better quality food."

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

Maggie
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voyage party. Everything was donated, including the Alameda County Fairgrounds where it was held. People volunteered. There was music, dancing, and many wheelchair riders and disability activists.”

To Figueroa, the overwhelming response of donations was no surprise.

“Maggie is a unique blend of spirituality, common sense and feminism,” she said. “She has gone through a lot in her life. She could be a bitter woman, yet she still loves life. She has a great capacity to love others, and she gives more than she gets.”

For others who receive a diagnosis of cancer, Dee has this advice: “Give yourself time to panic. The bottom line is when you hear the word cancer and it is attributed to something in your body, panic is appropriate. Then ask every question, go to everyone, and get the truth about cancer so you can make informed decisions. If you pray, pray. I welcomed everyone’s spiritual interventions: Buddhists chanted, witches circled, Native Americans did ceremony, Mormons prayed.”

Besides working as a deejay, Dee calls herself a background worker in the California Democratic Party’s Executive Committee. Marta Russell, Maggie’s longtime friend, disagreed.

“I don’t know what we would do in California without her,” said Russell, a Los Angeles activist and author of “Beyond Ramps: Disability at the End of the Social Contract.”

“Just about every piece of legislation that gets considered by the (state) Legislature, Maggie watches. She’s been active in pushing the strongest disability agenda possible.

Personally, I admire her for her interest in and focus on issues that have to do with poor disabled people. It is important to her that people remain out of institutions and that they have the support systems needed to do that. She knows what’s available is too little and keeps people living below the poverty level. Maggie is committed to stopping further decreases in people’s quality of life. She has developed lots of contacts.”

Many of those contacts in the California Legislature and disability community came through for her during her cancer diagnosis and treatment. Patrick Connolly, a Bay Area disability rights leader, took over the radio show while she underwent radiation.

Dee is back to handling two-thirds of her radio shows, with Connolly handling the rest. As an online advocate, she has resumed full duties on a number of disability rights listservs.

Dee “is one of the strongest people in terms of her own character, in terms of her inner strength,” said Marta Russell. “She is far beyond average. She is someone without a victim consciousness. She is a fighter.”

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.

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Commentary

Mentoring Matches Inspire Success

By Deborah Kendrick

Although I’ve been blind since early childhood, I never knew a blind adult until I was one myself. How much simpler life would have been if I had I been able to pick up the phone and ask an older, wiser ally how to go about handling some new challenge or other related to my disability. I have heard this sentiment echoed by many adults who grew up with disabilities and from both perspectives. They either wish they’d known some others with their same disability or recognize their good fortune in having done so.

In the fall of 2007, I became coordinator of the Ohio Mentoring Project, one of six programs established around the country with the help of a U.S. Department of Education grant obtained by the National Center on Mentoring Excellence, a division of the National Federation of the Blind. In each state, coordinators interviewed and identified qualified blind or visually impaired mentors and then matched them, one on one, with blind youth ages 16 to 26.

Mentors are both men and women, black and white, totally blind or with vision sufficient for reading large print and recognizing visual landmarks. Nearly all are employed, among them, teachers, counselors, computer trainers, executives and industrial workers. The young people are in high school or college, or without college plans and working or seeking employment. In other words, it is a diverse group, and they have come to operate as something of a family.

Each mentor-mentee duo has certain goals they are expected to meet, including an estimated eight

hours of communication monthly. This time can include e-mail messages, instant messages, phone conversations, text messages and face-to-face activities. As a guideline, e-mail messages can be counted as five minutes, phone conversations as 30. If a pair gets together once a month to go to a movie and have dinner, for instance, talk on the phone once a week or so, and send some e-mails and text messages along the way, the eight-hour benchmark is easily met.

The variety of things mentor-mentee pairs do together is diverse as well. They have gone to movies, concerts and plays. They have picked strawberries and taken hikes. They have gone to an Air Force museum to look at tanks. And they have baked cookies, gone shopping and attended local fairs.

Because it is a statewide program, some pairs have the added burden of geography. All of them are blind or visually impaired, so none of them drive. While mentors act more as adult friends than as teachers, lessons are definitely imparted in these relationships, and transportation is often one of the necessary ones. One mentee, for instance (I’ll call her Susan to protect her anonymity), has been a straight-A student throughout high school and college, is active in clubs (both disability-related and not) and is involved in extracurricular activities.

But she has always lived through her parents -- who drove her a considerable distance to and from her college campus each day -- and has never had to

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FOR DIRECTORS ONLY

An Invitation

When we started this publication more than two years ago, we wanted to make it something different, something that would appeal to people with different disabilities and with all the problems and successes that life brings. We named it Independence Today, more a political statement than a newspaper name. Since it was my brainchild, I refused to add any of those "dis" or "able" prefixes. I hate labeling anything as if it were meant for only one group.

If we want things to change, we must speak to all segments of our community, not just people with disabilities. As a veteran of the independent living and disability rights movements, I embedded into the publication the CIL philosophy of cross-disability inclusion, a progressive approach and a dedication to diversity. Independence Today was not to be mainstream like WE Magazine, and not solely for people who use wheelchairs or people who are blind, like some other publications. And, yes, we wanted to communicate to the public at large and be understood by the mainstream.

With little money and high ambition, we launched it. We recruited some of the best writers and journalists in the disability community. We decided to use CILs as our distribution network. And why not? There is at least one center in every major city and even some out-of-the-way places. We had earmarked about 20 copies for large centers and 10 copies for small centers. We assumed not

only staff, board members and consumers -- the disability community -- would read the publication but also non-disabled people.

We expected some positive reaction and some negative. Most of the e-mails we received were very positive and encouraging. Some questioned why we didn't just use the funds available to create this publication for other purposes. But then there were those not-so-positive and downright discouraging e-mails. One was from a center in the Northwest that did not want the paper because the writer said it only contained articles from New York state. Although we did carry a few articles on New York concerning the Help America Vote Act (HAVA), it turns out the gentleman had us confused with an "able" -titled publication. But it was all right because we had other takers, many more than we had copies for.

Then came the e-mail from the center in the Appalachian region: "Please send us only one copy. Ten are too many. We don't get ten people here in a year." "Wow," we thought. "This is real bad." In a reply, we asked, "You mean you receive \$275,000 from the federal government every year and you don't serve 10 people a month?" The center's return e-mail confirmed that.

That reply really got under my skin. So these people our wasting precious resources, and they don't give a damn about it. Wasting taxpayers'

money is not something I rail about only when the Pentagon or Halliburton does it, but also when my so-called allies do it. We decided to stop sending that center copies of IT. How pitiful that no one was doing anything about this. As the year progressed, we found similar situations, even one in our own state of New York. This is a failure on the part of both state and federal governments. Those centers getting more than a quarter of a million dollars a year and not serving people should be closed and the money given to centers that are overwhelmed. Or, better yet, the money should be given to ADAPT, so that group can help place our brethren in the community. What a disappointment the people who run those centers are to the entire movement.

Because there are some very large and well-financed centers in the country, and even some small, not-so-well financed centers doing incredible work, we are inviting you to help us spread the word as to how you got where you are or about your success story. A center's success, among other factors, may lie in its place in history, its particular region, the era in which it was started or contributions by staff members no one remembers anymore. The bureaucratic phrase "best practices" does not necessarily cover the spectrum of reasons why a particular center has had good outcomes, a multimillion-dollar budget or is unique in other ways. This is an opportunity, an invitation, to let other centers know what you're doing, how you're doing and how effective you are. We call this 'peerism' -- centers helping other centers.

In the near future, we will be bringing you more opportunities to participate not only to this newspaper but to our Web sites, too. Independent Living-USA,

or www.ilusa.com, is one of the most visited disability sites on the Web. You can provide your constituents with appropriate news and other content, such as the ILC searchable database. If your center has not updated its information recently, we recommend you do it. People are looking for you not just locally but abroad, too. Put a link to www.ilusa.com on your Web site, and give your community a porthole into what is happening nationally and internationally. Plus, www.ilusa.com provides a link to the newspaper's Web site, www.itodaynews.com, and other national advocacy Web sites; such as NCIL and AAPD, along with other allied sites, such as www.familiesusa.org.

Learning from each other is how this movement got off the ground, and that is the only way to keep the network strong.

Patricio Figueroa, Jr. is an artist, author, advocate and co-founder of Independence Today. He was also the first director of a center for independent living (CIL) in New York state .

No Social Security Cost of Living Increase for 2010

The trustees who oversee Social Security are projecting there won't be a cost-of-living adjustment (COLA) for the next two years for all who receive Social Security benefits. That hasn't happened since automatic increases were adopted in 1975. Millions of older people will face shrinking Social Security checks next year, the first time in a generation that payments would not rise.

The New York Times reported earlier this year that the lack of a Social Security cost-of-living

COLA
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People with OCD Fighting Bad Days with 'Greater Good'

By Kathi Wolfe

Jeff Bell's voice is as well-known in San Francisco as the sound of cable cars. Millions of Bay Area residents listen to Bell every weekday afternoon as he co-anchors the news on KCBS, one of the country's most successful all-news radio stations.

What many of them don't know is that Bell, like nearly 2.2 million American adults (according to the National Institute of Mental Health), has obsessive-compulsive disorder, a mental illness that wasn't on the cultural radar screen until a few years ago. The TV show "Monk," starring Tony Shalhoub as Adrian Monk, the detective with OCD, has helped to bring the disability into public awareness. The program debuted on the USA Network in 2002; its final season ends in December.

People with OCD, an anxiety disorder, have recurrent, intensely intrusive thoughts that others see as obsessions. The type of obsessions varies from individual to individual. These obsessions run the gamut from anxiety about contamination to losing control (for example, a fear of harming one's self or others) to perfectionism (for example, worry about losing things). Other obsessions include unwanted sexual thoughts and scrupulosity (excessive concern with blasphemy or morality).

Hoping to get rid of these unwanted and, at times, terrifying obsessions, people with OCD repeatedly -- sometimes for hours daily -- perform rituals that others see as compulsions. People with obsessive-compulsive disorder have different types of compulsions. Rituals can include excessive washing and cleaning, checking (for

example, that one has not harmed oneself or others) and repeating (for instance, tapping or going in or out of doors repeatedly). Hoarding and constantly mentally reviewing events (to make sure, for example, that one has not caused harm) are some of the other compulsions that people with OCD can have.

People often use the words "obsessive" and "compulsive" to denote personality traits, said International OCD Foundation executive director Jeff Szymanski.

"The general public often thinks that (to be) obsessive means having a lot of worries, and that (to be) compulsive is being detail-oriented," said Szymanski, an instructor in psychology at Harvard Medical School. Those are valid descriptions of personal characteristics, but not of OCD, he said. "They imply that people are OK and can stop (being obsessive or compulsive) if they want to," Szymanski added. But someone with OCD "means having unwanted thoughts and compulsions that are out of control and cause anxiety."

In other words, if you arrange CDs eight hours a day or are a meticulous copy editor, "that's part of your job, it comes out of your personality, but it's not OCD," Szymanski said.

"Howard Hughes (the reclusive aviator and film producer) had very severe OCD," Szymanski said. "He didn't get treatment. He stopped wearing clothes -- (and kept) empty Kleenex (boxes) near his feet." Though having obsessive-compulsive disorder often was a hardship for people with the illness, the American

Psychiatric Association's Diagnostic and Statistical Manual didn't categorize OCD as a disorder until 1981. Before then, OCD was often called obsessional neurosis.

People have had OCD since the earliest recorded history, said Jonathon Abranowitz, professor and associate chair of psychology at the University of North Carolina at Chapel Hill.

Most experts believe a variety of factors, including a genetic predisposition and malfunctioning neurotransmitters in the brain, contributes to the development of OCD.

"It can be as disabling as any mental illness," said Alec Pollard, director of the Anxiety Disorder Center of the St. Louis Behavioral Medicine Institute. "If somebody has a contamination obsession and is afraid of germs, they may not leave the house. Some kids with severe OCD can't go to school. Some adults with severe OCD can't work."

OCD usually emerges in childhood, late adolescence or young adulthood, though it can begin when people are in their 30s or 40s, Pollard said. "Boys and girls have a little bit different pattern," he said. "Boys are more likely to get OCD when they're under 10 years old. Girls often become obsessive-compulsive during puberty or when they're teenagers. It depends on the individual."

When Dr. Michael Jenike, chairman of the Scientific Advisory Board of the International OCD Foundation, started working with patients in the late 1970s, he thought only a few people were obsessive-compulsive. He changed his opinion after appearing on "The Larry King Show" with a patient. "Then I realized it was a much bigger problem. So many patients with OCD were calling in (to the



Jeff Bell speaking at a conference.

show)! They needed a place where they could go (for treatment)."

To help fulfill that need, Jenike, co-author with Terry Murphy of "Life in Rewind," founded the Massachusetts General Hospital Obsessive Compulsive Disorder Institute at McLean Hospital. "I didn't want to (go on the 'Larry King' show), but it was a way for people who felt trapped to get out (to realize that others had OCD)," said Jenike, who now understands how media exposure can be helpful to people with mental illness.

There are mild to severe forms of obsessive-compulsive disorder, said Jenike, who has received a Lifetime Achievement Award at the International OCD Foundation conference. "There is hope for (people with) even the most severe forms (of OCD)."

Jenike, a professor of psychiatry at Harvard Medical School, agreed to be brought in for an episode of the A&E show "Intervention" and "we got the patient to go into treatment," he said.

OCD is generally treated with medicine and a type

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New Chapter
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"Bookshare's partnership with universities and publishers increases my independence because I have access to text in accessible formats that meet my communication needs," said Milton Johnson, who is dyslexic. He learns through listening to audio books and by reading materials in large print with altered backgrounds.

AHEAD executive Marks said the new partnerships will provide economic benefits to universities. "Scanning and proofreading a book can cost \$100 to \$1,000, depending on its complexity," he said. "A collaborative-sharing program will save campuses time and money annually."

Marks, the director of Disability Services at the University of Montana at Missoula, said the partnerships will reduce to only one the number of times a book has to be scanned and made available. In addition, he said, the partnerships will increase educational and job opportunities for people with print disabilities.



Jim Fruchterman is a former rocket scientist who has founded two of the foremost optical character recognition companies and developed successful social enterprises.

Adler pointed out that the publishing industry has made strides in recognizing the size of the print-disability population and responding to the needs. He credited Fruchterman for being a force in that endeavor.

Said Skonicki, "From a student's perspective, these partnerships are critical to a student with print disabilities receiving an education equal to an education earned by a student without a print disability."

Thus far, 11 colleges and universities participate in the program, including Arizona State University, De Anza Community College, Indiana University, Michigan State University, Ohio State University and the University of California at Berkeley. Publishers include Brookings Institution Press, De Capo Press, HarperCollins, Modern Language of America, O'Reilly Media, Random House and others.

In 2007, Bookshare received a \$32 million, five-year award from the U.S. Department of Education's Office of Special Education Programs to provide free access for all U.S. students with a print disability. The Bookshare collection now includes more than 46,000 titles and is growing at a rate of more than 1,000 books per month with contributions from publishers, universities, downloads from NIMAC (National Instructional Materials Accessibility Center), and books scanned and contributed by volunteers.

For more information, go to (www.bookshare.org) or (www.benetech.org).

John Williams, a contributing writer to Independence Today, coined the phrase "assistive technology." He can be reached at jimmaw@verizon.net. His Web site is www.atechnews.com.

Girl Who Doesn't Age May Hold Key to Longevity

By Brenda Brown-Grooms

Can the condition of a severely disabled girl unlock the secret of how to delay aging?

Her name is Brooke Greenberg. Doctors say the 16-year-old resident of Baltimore, Md., is growing older but is not aging.

Dr. Richard Walker discovered that she developed a mutation of the gene that controls aging and development. "Brooke is a unique individual because she has a mutation in the developmental phase ... " he said. "There's no hope for her, but what she brings to science is information on how we may be able to delay aging." (<http://www.foxnews.com>) "The Curious Case of Brooke Greenberg.")

According to Walker, "development and aging are at opposite poles of the life continuum, but they are controlled by the same genes."

Brooke's mother, Melanie, said her daughter grew in spurts. Her father, Howard, said then when Brooke was born, she was "a little on the small side, but nothing abnormal ... I mean you couldn't tell until you witnessed the birth and you saw Brooke." (http://www.msnbc.msn.com/id/9778227/ns/dateline_nbc/)

A month premature, she was born with anterior hip location (a rare condition) and weighed 4 pounds. Her pediatrician, Dr. Lawrence Pekula, told NBC News correspondent Sara James in 2005: "Her hips were dislocated from where they normally would be ... Hers were pushing forward and put her legs in a very awkward position." (<http://www.msnbc.mn.com/>

[id/9778227/ns/dateline_nbc/](http://www.msnbc.mn.com/id/9778227/ns/dateline_nbc/).)

That surgery behind them, Brooke's parents thought she would grow and develop normally. They became worried when she was almost 1 and still about the size of a 6-month-old. While they thought they could handle Brooke being as much as four years behind developmentally, the Greenbergs were unprepared for what eventually happened in the life of their third child.

Melanie and Howard took Brooke to one specialist after another to such places as the Johns Hopkins Children's Center and New York's Mount Sinai Hospital. They even tried growth hormone therapy, but nothing helped.

Some of Brooke's doctors labeled her with "Syndrome X," signifying that they did not know why she didn't grow. Geneticists could find no chromosomal abnormalities, and her pediatrician could find no references in medical literature. She suffered a number of unexplained illnesses that her doctors and parents thought would be fatal.

In addition to not growing, Brooke developed stomach and respiratory problems. She had surgeries for seven perforated stomach ulcers, a brain seizure and then a stroke (which appeared to have done no damage). Her tiny esophagus makes it difficult for her to handle solid food -- it often backed up and went to her lungs, causing respiratory problems -- so she has a feeding pump. It takes about 10 hours a day

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of cognitive therapy known as “exposure, response, prevention,” Szymanski said. “As with other mental illnesses, it’s a stereotype about it being bad parenting or bad character.”

With cognitive therapy, people with OCD are “exposed to what they’re afraid of,” Szymanski said. “When they realize that dangerous things don’t happen, their brains start to reduce their anxiety.” This therapy is difficult because patients “have to make themselves not do the compulsions they perform to alleviate their anxiety ... It’s no fun to be anxious.”

Some people with obsessive-compulsive disorder have other disabilities. Larry Bolger, who has a master’s degree in rehabilitation counseling from Edinboro University in Pennsylvania, has OCD. In 1990, as a result of a diving accident, he sustained a spinal cord injury. “There is absolutely a need for rehab professionals to become more familiar with OCD,” Bolger wrote in an e-mail to Independence Today. “My OCD affected my spinal cord rehabilitation greatly... There is a need for anybody involved in the medical profession to know the signs and symptoms of obsessive-compulsive disorder.”

For Jeff Bell, the KCBS radio news co-anchor, his OCD began in the early 1970s, when he was a young boy. As Bell recounts in his memoir “Rewind, Replay, Repeat: A Memoir of Obsessive-Compulsive Disorder,” he became obsessed with a gray car with a boy in the back seat. While walking with his mother and sister on the street, Bell saw (or thought he saw) the boy in the vehicle lean out the window. As the car moved away, Bell thought he heard the child shout “Heeeeyyyyyy” to him. For

days, he became obsessed with knowing who it was who’d been trying to get his attention. He couldn’t stop replaying that scene in his mind.

But just as suddenly as it came on, his obsession went away. According to Bell, it was a form of childhood OCD that lay dormant until his late twenties. Bell, who referred to himself as an “overachiever,” went on to college and graduate school, began his career in radio, married his wife, Samantha, and started a family. Everything went like a Hollywood movie with the happiest of endings until he turned 29.

One day, Bell took some friends on an outing on his father’s boat. At one point, the boat got extremely close to a cabin cruiser, and one of his friends later said he thought Bell’s craft might have “bent the nose of that boat.” Bell became obsessed with confessing the harm he had done. And that’s when things began to “spiral out of control.”

Bell became obsessed with thoughts that he might harm other people. To relieve his fears that he might cause injury, he developed “checking” and “confessing” compulsions. One rainy day while grocery shopping, he noticed that his umbrella was dripping a bit inside the store. Bell then told a checkout clerk that the “puddle” left by his umbrella might be a safety hazard. After the clerk called for someone to attend to what Bell called an “emergency,” the “puddle” was nowhere to be found.

“When I drove, I started (constantly) checking my parking brakes,” Bell said. “(For a time,) I quit driving and took public transit.”

Walking down the street, Bell felt compelled to pick up twigs and rocks because he feared they’d be a hazard to someone. “I didn’t quit work, but I got to the point where I just barely

got from point A to point B and back again.”

The only time Bell felt safe was when he was anchoring the news. “With OCD, you live in the past and worry about the future,” he said. “When I was live on the radio, I was living in the moment.”

Like many people with obsessive-compulsive disorder, Bell spent years hiding his disorder. “Outside my immediate family, I went to great lengths to cover up my compulsions,” he said. “During my lost years, my wife was the only person who knew about my OCD.” Covering up was as exhausting as performing the compulsions, Bell added.

“I started to have trouble leaving my house. My solution (to the fear caused by his obsessions) was to convince myself that everything is safe.” Of course, that is never the case, he added.

“I sought help out of desperation,” Bell said. “I was paranoid about getting caught. I’d park blocks away (from the therapist’s office) or sneak through an alley, hoping no one would see me.” The stigma surrounding OCD was a huge roadblock, he added. What, Bell wondered, would his listeners think if they knew that he, a high-powered radio reporter and personality, had obsessive-compulsive disorder, a mental illness?

Therapy was a slow, agonizing process for Bell. “One night, I looked up at the stars and blurted out, ‘Tell me how to turn around this crazy world and I’ll share my story with anyone who’ll listen.’”

That “bargain with the universe” gave Bell the motivation he needed to do the work of therapy: exposure, prevention, response. “I’d generate talk and help people with OCD by telling my story, but I know I couldn’t write the book if I didn’t have

success with the therapy.”

Bell calls the strategy of being willing to do hard work for the purpose of helping others “the greater good.” He credited that, as well as his therapy, with helping him cope with OCD.

Though there is no cure for obsessive-compulsive disorder, Bell, after much therapy and hard work, is able to manage his OCD today. He still has “bad days” when he has episodes of obsessions and compulsions, but he is able to handle his OCD now.

Sometimes, doubt is a necessary part of life, Bell said. “When you’re a reporter, you need to do fact-checking, or when you’re e-mailing, you may want to think about whether you should hit ‘send.’” But if you have OCD, doubt becomes your enemy -- penetrating your life and causing anxiety. That’s why OCD is often called the “doubting disease,” he said. Bell calls his OCD-generated doubt “my doubt bully.”

“You have to learn to choose the greater (good) of your goals,” said Bell, author of the new book “When in Doubt Make Belief: An OCD-Inspired Approach to Living with Uncertainty” and a spokesman for the International OCD Foundation (formally called the Obsessive Compulsive Foundation).

“One day I’m in a Borders (bookstore) signing books. My ‘doubt bully’ tells me that I should compulsively scrub my hands so I won’t give anyone germs. But intellectually I know I must be of service and go out of the bathroom to help others by talking about and signing my books.”

The “greater good” beat the “doubt bully” that night at Borders, Bell said. “My

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Mentoring
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deal with arranging her own transportation, public or otherwise. Her mentor (I'll call her Marie) is an educator who has been married, raised children, run a household, excelled on her job and used every kind of available transportation imaginable. Because both are blind and live about 100 miles apart, Marie has taken turns visiting with Susan for their monthly get-togethers, while coaching Susan through her share of the transportation responsibility. Together, they have ridden buses, brainstormed hiring drivers and expanded Susan's view of her future.

Diane is a mentee with partial vision – sufficient to sometimes read very large print, recognize people up close and navigate around large objects. Her mentor, Sharon, has a similar degree of vision but recognized long ago that, although she still retained some vision, adaptive techniques make her more efficient – and safe. With Sharon's encouragement, Diane began carrying a long white cane and got lessons in using it properly, traversing busy streets and riding buses with her mentor. The pair enrolled in a Braille class, and Diane is learning an alternative, less stressful way of keeping personal notes.

One mentee said she had always wondered if she could raise children. Accordingly, she was matched with a mentor in the process of raising a family. Another mentee said he was shy about pursuing dating relationships because of his inability to drive or pick a girl out across the student union. His mentor, a married man with a child and thriving career, role-plays strategies with him and has worked on navigating with a Braille GPS device to remind him that driving is one piece of

independent travel, while knowing where you're going is another important part.

A popular and vital part of the program has been quarterly group activities. Every three months, the entire group from around the state comes together for a weekend packed with activities to build confidence and independence. Activities have included snow tubing, bowling, swimming, rope-climbing and a slew of seminars to build individual awareness.

Sometimes, the seminars center on skits and games related to disability (such as creating a David Letterman-style top-10 list of things to know about blind people or conducting an Oprah-style interview with blind show guests). One weekend, a five-course progressive dinner was offered in which teams of four to six mentors and mentees prepared detailed recipes. The food was delicious.

The most popular workshops, though, have been the philosophy discussions, a host of topics related to the self-awareness of those who are blind or visually impaired. When, for example, is the best time to disclose disability to a potential employer? Is it appropriate to ask for extra time when taking the SAT? What should you do if all your friends want to play a computer game that you know is completely visual with no audio cues?

A strong research component has accompanied the mentoring work, and the results have borne out what we adults all knew to be true: Young people with blindness or visual impairments gain confidence, independence and success and are more likely to set career goals and actively seek employment when they have a blind mentor who has achieved success.

Sometimes, it is the simplest statements on

evaluation forms that make my heart soar and reinforce my belief that what we are doing is worthwhile. When you read, for instance, "I never knew I could go to a large building where I'd never been before and actually get around without hanging on to somebody (until I did it with my mentor)." you feel gratified. To me, those types of comments are simple, yet stunning.

I still wish I'd known adults who were blind – or had any disability, for that matter – when I was 19 or 20. That longing makes the gratification of "passing it on" ever so much richer for me and all of the adults participating in the Ohio Mentoring Project.

Deborah Kendrick is an award-winning writer, editor and poet. Currently, she is a newspaper columnist and a senior features editor for AccessWorld.

CIL College
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as a medical condition."

When you teach, you don't want to come off as dogmatic, Foelsch said. "You don't want to tell your students, 'Your thinking is all wrong.' You want to say, 'Let me show you another way of thinking.'"

For more information, e-mail Colleen Starkloff at cstarkloff@strakloff.org or go to www.starkloff.org.

Kathi Wolfe is a Washington, D.C.-area writer. She writes frequently on disability issues.

For a complete news roundup, go to:
www.itodaynews.com
News Summaries supplied by David Reynolds from Inclusion Daily Express.
www.InclusionDaily.com

CLASS
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is Congress, rather than looking at reforming the total system, is approaching (the matter) in a fragmented fashion. The law of unintended consequences is that if CLASS passes without Medicaid reform, Medicaid long-term services and supports could be harmed. This is definitely not what Kennedy wants."

Kennedy's staff did not respond to requests for interviews.

Mike Ervin is a writer and member of ADAPT.

This Day
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Justin Dart is born. Dart, who contracted polio in 1948, was a successful entrepreneur who founded three Japanese corporations. In 1967 he left the corporate world to devote himself to the rights of people with disabilities, working in Texas and Washington, D.C., on various state and federal disability commissions. He was named to the President's Committee on Employment of People with Disabilities and worked to help pass the Americans with Disabilities Act of 1990. In 1995, he founded Justice for All with other activists to defend against congressional attempts to weaken the ADA.

-- **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

Girl
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to feed her, but the feeding pump has cut down on hospitalizations.

Because her health is always precarious, the Greenbergs have two nurses who help them to care for Brooke 16 hours a day.

At age 4, when Brooke was diagnosed with a brain tumor -- a misdiagnosis, as it turned out -- her parents picked out a casket and the clothes she was to be buried in. She slept for 14 days but didn't die. She just didn't grow much.

When Brooke was 8 she was still the size of a 6-month-old: She weighed 13 lbs. and was 27 inches long. Today, she is 2½ feet tall and weighs 16 lbs.

Brooke attends Ridge Ruxton, a special education public school in Baltimore County. Brooke's brain functioning is low, although her sister Caitlin said she behaves in many ways like a rebellious teenager. Her mother said "she loves to shop ... just like a woman." ([http://abcnews.go.com/.](http://abcnews.go.com/))

In the journal "Mechanism of Aging and Development," Walker (who has been studying Brooke's case since 2006), pediatrician Pakula and geneticist Maxine Sutcliffe document an unheard-of range of inconsistencies in how Brooke ages, including baby teeth and bones like those of a 10-year-old.

Walker wrote: "(T)here've been very minimal changes in Brooke's brain ... Various parts of her body, rather than all being at the same stage, seem to be disconnected."

In the overwhelming majority of cases, developmental genes coordinate changes in our cells that bring us to full-functioning adulthood. Adulthood marks a point of

stability in our development. Aging erodes that stability. In Brooke's case, the aging and developmental genes have been turned off.

According to Walker, if it is possible to isolate those genes in the human genome, we might not age, or we could switch the aging process off at will.

While there may be no medical help for Brooke, her family is only concerned that she gets the best quality of life she can. Her sisters Emily (22), Caitlin (19) and Carly (13) are attuned to their sister's needs.

"She makes it known what she likes and what she doesn't like," said Emily.

Said Caitlin: "(S)he looks like a 6-month-old, but she kind of has a personality of a 16-year-old ... Sometimes we joke about how she rebels."

Younger sister Carly said, "(A)s I got older, she was just like another little sister to me." (<http://abcnews.go.com/2020/Health/Story?id=7880954&page=1>)

Her father buys her strollers and baby swings because she loves to swing, and Carly rides her around on an ottoman.

Because Brooke is medically fragile, Melanie Greenberg said the family doesn't take vacations, has few nights out and has schedules that revolve around her. As much as they can, her parents and sisters mark the passage of her life the way they would if she were physically, mentally and emotional aging.

When Brooke was 13 she, like her sisters, celebrated a rite of passage into adulthood, a Bat Mitzvah, according to her family's Jewish tradition. It did not matter that she still wears diapers, travels in a stroller

Girl
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Independence
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Diversity is essential to the selection process necessary to prevent our species from going the way of all the others that became too specialized to survive in an ever-changing world.

So rather than think of individuals as "independent," we should consider ourselves "interdependent" and, most important, not be put into some arbitrary category and relegated to the fringes of society. It is not popular to say "we are all disabled," but there can be no argument that each of us has his own particular talents and shortcomings. This diversity should be celebrated rather than punished.

A policy of "separate but equal" doesn't just affect those who are put into some "disability box," but also the society that puts them there to suffer often terrible consequences. There is no longer any question that accessibility to what is offered by our culture is a basic human right, equal to any others.

By continuing to accept mainstream views of disability, we deny the undeniable: Compared to whoever is the best in a certain field, we are all disabled, unless we can compose as well as Mozart did at age 10, or putt as accurately as Tiger Woods, for example.

A speech impediment caused by cerebral palsy is not a reason to be denied the essentials of education or, worse, to be incarcerated in a setting that has been shown to lead to abuse, neglect or even death. A person who has no means of using the mouse on a computer should not be denied access to the World Wide Web.

Another downside to continuing to speak of

ourselves as disabled is that it puts us in the position of essentially "playing the pity card" to reach our goals. What we're saying is that, if not for our disability, we are just like everyone else. Why draw attention to our differences?

The way in which each of us is like everyone else is that we are different. That is important for the survival of the species. The world needs, for example, biographical-, neurological- and mobility-diverse people to help our species evolve.

So, how are we to assert our independence? Probably by realizing just how dependent we are -- and how closely related. Accessibility should be for everyone, everywhere, always.

The "diversity model" must replace the "medical model" and the "social model." What should be "fixed" is not our differences, but society's reluctance to recognize our importance to cultural evolution. It's not the wheelchair that disables us, it's the stairs.

William Loughborough has come to the above conclusions because of his association with Javier Romañach of Madrid, Spain, from whose book (in Spanish) "El Modelo de la Diversidad" this article is derived.

COLA
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adjustment in 2010 "will be a shock to older Americans" an AARP official lamenting that, "Most seniors have never been through a year in which there was no Social Security COLA."

By law, Social Security benefits cannot go down. Nevertheless, monthly payments would drop for millions of people who have a Medicare prescription drug program because the premiums, which often are deducted from Social Security payments, are

COLA
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OCD
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Jeff Bell at a book-signing session

doubt bully will always be there urging me to carry out compulsions, (but) you have to learn to live with uncertainty -- to follow the greater good. We can all benefit from learning how to face down our fears.”

For more information on OCD, go to: www.ocfoundation.org or www.adaa.org (the Anxiety Disorders Association of America).

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

Girl
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and cannot walk or talk. She is the delight of her family. They consider her life to be a gift.

No one knows yet whether she holds the keys to eternal youth. Her parents and sisters know that she holds their hearts, as they hold hers. When the nurses go home, they continue her care. Her daddy checks on her in the middle of every night.

Brenda Brown-Grooms is an independent living coordinator for the Blue Ridge Independent Living Center in Roanoke, Va., and an ordained minister.

COLA
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scheduled to go up slightly.

The reason for the benefits staying flat is that COLAs are pegged to inflation, which has been negative this year, largely because energy prices are below 2008 levels.

Advocates say older people still face higher prices because they spend a disproportionate amount of their income on health care, whose costs rise faster than inflation. Many also have suffered from declining home values and shrinking stock portfolios just as they are relying on those assets for income.

“For many elderly, they don’t feel that inflation is low because their expenses are still going up,” said David Certner, legislative policy director for AARP. “Anyone who has savings and investments has seen some serious losses.”

About 50 million retired and disabled Americans receive Social Security benefits. The average monthly benefit for retirees is \$1,153 this year. All beneficiaries received a 5.8 percent increase in January, the largest since 1982.

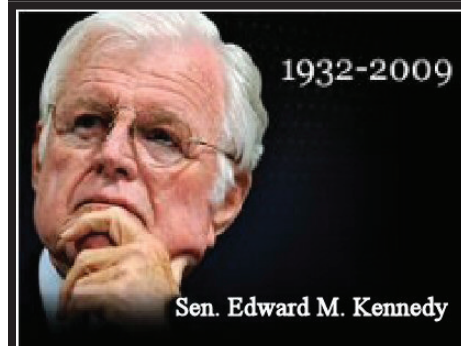
More than 32 million people are in the Medicare prescription drug program. Average monthly premiums are set to go from \$28 this year to \$30 next year, though they vary by plan. About 6 million people in the program have premiums deducted from their monthly Social Security payments, according to the Social Security Administration.

Sen. Bernie Sanders, an independent from Vermont is working on a proposal for a one-time payment for Social Security recipients to make up for the premium hikes and no COLA.

Sources: AP, New York Times



Senior White House Advisor Valerie Jarrett, left, and Annebeth Rosenboom, right, Chief of Treaty Section Office of Legal Affairs of the United Nations, watch as Susan Rice, center, U.S. ambassador to the U.N., signs the U.N. Convention on the Rights of Persons with Disabilities at United Nations headquarters.



A Tribute

Sen. Edward M. Kennedy: The Voice for the Voiceless is Stilled

Senator Edward M. “Ted” Kennedy (February 22nd, 1932 – August 25th, 2009) was one of the most influential leaders of our time, and one of the greatest senators in American history.

Known fondly as “the lion of the Senate,” he consistently used his powerful voice to speak out for the voiceless, the powerless and the poor. He could always be counted on to champion justice, fairness and compassion.

For nearly 50 years, virtually every major piece of legislation that advanced the civil rights, health and economic well-being of the

American people bore his name and resulted from his efforts.

Kennedy played a major role in drafting or passing: the Comprehensive Anti-Apartheid Act, the Americans with Disabilities Act of 1990, the Ryan White Care Act, the Civil Rights Act of 1991, the Mental Health Parity Act, the State Children’s Health Insurance Program (S-CHIP), the No Child Left Behind Act of 2001, the Immigration Reform and Immigrant Responsibility Act of 1996, the National Cancer Act of 1971, the Education of all Handicapped Children Act (the predecessor of the Individuals with Disabilities Education Act) and Title IX of the Education Amendments of 1972, which was designed to balance the amount of money colleges spent on men’s and women’s sports.

The most fitting tribute we could give Senator Kennedy is to carry on his fight for equal rights for all our citizens.

By Patricio Figueroa