

**IN SPAIN, A
DIFFERENT VIEW
OF I L**

**NCIL 2009
CONFERENCE
HIGHLIGHTS**

**POLIO SURVIVOR,
101 YEARS OLD,
GOING STRONG**

**Non Profit
US Postage Paid
Permit 490 Troy, N.Y.**

independence today

Volume 3

Issue 3



From left to right : Javier Romañach, Iñaki Martínez , William Loughborough, Alejandro Rodríguez-Picavea, Manuel López, in Madrid, Spain. Story on page 3.

**COMPASSIONATE
ALLOWANCE
SYSTEM TO SPEED
SSA BENEFIT
PROCESS**

**WHITE HOUSE
STANCE
FRUSTRATES ADAPT**

**WAYS TO EASE
SIDE EFFECTS
OF MENTAL
HEALTH MEDS**

**ASSISTIVE
TECHNOLOGY
HELPS CHILDREN
WITH AUTISM**

*Opinion***The Ideal Stimulus Package***By Patricio Figueroa*

Have you ever wondered why banks protect us from our money? To perform a simple transaction at a bank, you have to provide picture identification, your Social Security number, your mother's maiden name, and your blood type. Well, maybe not the latter. But government does the same thing, regardless of which political party is in office.

The Federal Reserve is responsible for this country's monetary policy, but even the savviest of us are hard-pressed to understand the gibberish that comes from there.

But it is our money. It is our tax dollars that keep government moving and spending. My question is simple: If it is our money, and we have an economic crisis, why can't we get it some of it back? Why is it that large banks, Wall Street firms, automobile companies and a giant insurance company can get bailouts totaling trillions of dollars, at no cost, and we're still struggling with foreclosure, high interest rates on credits cards, other bills and a low rate of return on our savings? And who cares about bailing out Fannie Mae and Freddie Mac, into which the Treasury has pledged to inject up to \$200 billion?

This whole stupid game is called "trickle-down economics" or "trickle-down theory." Both are political terms that refer to the policy of providing tax cuts or other benefits to businesses and rich individuals in the belief that the money will indirectly benefit the broader population. (It has also been called supply-side economics.) Will Rogers coined the term during the Great Depression when he said that "money was all appropriated for the top in

hopes that it would trickle down to the needy." This is like people on top urinating on us and hoping we get blessed.

The policies emanating from Washington are just "trickle-down economics," once referred to as "voodoo economics" by former presidential candidate George H.W. Bush in reference to Ronald Reagan's economic plan, known as Reaganomics. I know it doesn't rain up, but why is the economic forecast always "trickle-down golden showers"?

This rant is a prelude to my stimulus strategy, what I call the ideal stimulus plan.

Let me start by saying that I recognize this country's economy is in the tank, if it is not in the sewer already. I am feeling blessed to have a roof over my head, food on the table and money to pay my bills. But let's face it: We're in the worst fiscal crisis since the Great Depression of the 1930s -- you know, the one that the president with a disability, Franklin Delano Roosevelt, brought us through. This rant is about responsibility, greed, accountability, stupidity, arrogance, priorities and all the things that drive Americans crazy.

As we all know, Republicans did not support the stimulus package. If they have no interest in making our country better, maybe they should close their Washington offices, lay off their staffs and save taxpayers millions by going home. Now that the ban on using federal funds for stem cell research is lifted, maybe some scientists could take it upon themselves to grow some backbone for those who

Stimulus Plan
Continued on page 13

THIS DAY IN DISABILITY HISTORY

May 1st, 1956 -- The polio vaccine developed by Jonas Salk in April 1955 is made available to the public. Salk did not patent the vaccine, as he had no desire to profit from his discovery. He instead encouraged the vaccine to be manufactured and disseminated throughout the world. In 1963, he founded the Salk Institute for Biological Studies in La Jolla, Calif., now a leading center for medical and scientific research.

May 9th, 2007 -- Massachusetts Institute of Technology looks at the ways human beings augment their bodies. The MIT Media Lab conference, titled Human 2.0, featured technological innovations and lectures from luminaries such as Oliver Sacks, a British-born neurologist. Among other things, the conference showcased prosthetics that provide athletes with superhuman abilities and computers that provide emotional support. John Hockenberry, who joined the MIT Media Lab as a distinguished fellow earlier that year, demonstrated his upgrade from a regular wheelchair to a modified Segway. And Dan Ellsby, an individual with severe cerebral palsy, played a musical number; the software he composed the music on was developed at the media lab.

May 15th, 1995 -- Ed Roberts' wheelchair is donated to the Smithsonian Institution. Though Roberts died in March 1995, his memorial was not held until mid-May of that year, in conjunction with the NCIL conference. In 2000, the Smithsonian presented an exhibit on the disability rights movement.

May 19th, 2001 -- ADA Watch launches a campaign against Jeffrey Sutton. Hundreds of independent living activists from across the nation marched on the White House to protest the nomination of Jeffrey Sutton, an attorney who argued against the ADA in the Supreme Court. Sutton was nominated to the Sixth Circuit Court of Appeals on May 9th, 2001, by President George Bush. On April 29th, 2003, despite widespread outcries from many civil rights advocates, Sutton was confirmed to the court.

May 27th, 1995 -- Actor Christopher Reeve is paralyzed in an accident during the cross-country portion of an eventing (equestrian) competition in Culpepper, Va. After the accident, which made him a vent-dependent quadriplegic, he lobbied on behalf of people with spinal cord injuries and advocated for human embryonic stem cell research. He founded the Christopher Reeve Foundation and co-founded the Reeve-Irvine Research Center. Reeve died at age 52 on October 10th, 2004, from cardiac arrest caused by a systemic infection.

June 4th, 2008 -- Harriet McBryde Johnson dies. McBryde Johnson, disabled due to a neuromuscular disease and forced to use a motorized wheelchair, was an American author, attorney and disability rights activist. In 1990, she drew national attention for her opposition to the annual Jerry Lewis Muscular Dystrophy Telethon. In 2002, Johnson debated Peter Singer, challenging his belief that parents ought to be able to euthanize their disabled children. "Unspeakable Conversations," Johnson's account of her encounters with Singer and the pro-euthanasia movement, was published in The New

This Day
Continued on page 8

CoverStory

Commentary

In Spain, a Different View of Independent Living

By William Loughborough

As an “ugly American” who thought that our technology and social structures were models for the rest of the world, it came as something of a shock to discover that the Metro system in Madrid is not only the third longest in the world, but that the 30-year-old station looks as if it were freshly painted the day I first saw it. The platforms are being constantly swept and mopped (mostly brightly polished ceramic tile on the walls and floors) and the signage is extensive and effective – except for print-handicapped folks and those who don’t speak or read Spanish.

The older Metro stations and trains are essentially totally inaccessible, but the newer ones seem to be fully equipped with elevators and other conveniences, although I would still be concerned about being a hundred feet underground when the elevator was not in service.

One striking difference in cultures was the very extensive accessible infrastructure in business and residential areas, with the latter featuring curb cuts in the doorways.

INDEPENDENCE TODAY

JUNE 2009 Volume 3 -Number 3

Independence Today is a publication of the Independent Living Center of the Hudson Valley, Inc., or ILCHV, in partnership with the National Council on Independent Living, or NCIL. The newspaper is also available on the Internet at www.itodaynews.com. Published every other month, the deadline for advertising and articles is the 16th day of the month before publication. Advertising rates are available on request, and the price includes a hard copy and Internet ad.

ILCHV, Inc. reserves the right to refuse an advertisement for any reason. We do not imply or otherwise guarantee any of the information, services, products, or anything advertised in this or any issue of the publication or the Web version. The opinions expressed by the contributors do not necessarily represent the opinion of this publication, the organization or the board of directors. Copyright © 2009 by ILCHV. No portion of *Independence Today* may be reproduced without written permission from ILCHV, Inc.

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

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

If someone in a wheelchair (usually of the manual variety) approaches such a curb, he or she will almost always find somebody around to lift the chair. As Spaniard Javier Romañach noted, “The same guy who will help you in that situation might be the architect who removed a ramp from a building because he thought it ugly.”

Romañach is a prominent figure in the Spanish equivalent of the U.S. disability rights movement. The highlights of our conversations centered on how it came to be that Spain has, by law, established direct payments for personal assistance (home care) services, although so far on the usual limited basis of a citizen’s earning history rather than on current need. It only covers a few hundred people at this time, but expansion is likely.

Romañach has participated in organizing marches and actions, not unlike those held by ADAPT, and a notable takeover of a government building, not unlike the San Francisco “Section 504” demonstrations. He has produced several memorable videos that can be seen on YouTube celebrating the main thrust of his efforts on the theme of “Derechos Humanos Ya!” (Human Rights Now!), which is also one of the Web sites that preaches the message of independent living.

In addition to Romañach, I also discussed disability rights issues with Spaniards Alejandro Rodríguez-Picavea, another leader of the disability rights movement group, and his personal assistant.

In Spain, as opposed to the U.S., there is a completely different sector of opponents hindering progress to provide independent living services and opportunities because the non-governmental organizations (NGOs) are so firmly in control and so

completely out of touch with the desire of persons with disabilities (PWDs) to break away from the “medical model,” which considers PWDs objects of pity. The Spanish NGOs are so determined to remain in power that it makes them the rough equivalent of the U.S. nursing home lobby and Voice of the Retarded, groups that advocate for placing PWDs in nursing homes and institutions. In fact, the NGOs want to own and run the Spanish equivalent of nursing homes despite the fact that the concept of “putting grandma in a nursing home” is almost unthinkable in Spanish society.

Romañach was completely ignored or rebuffed by those who voluntarily provide services to the disability community. He found more open minds in the politicians and public officials, who questioned the leaders of the NGOs about personal assistance services and independent living only to discover that the NGOs weren’t even aware of those services.

During his often frustrating dealings in the matter, he had to resort to taking over a building to get an audience with the minister of labor, who finally helped initiate change. My favorite of Javier’s lines is, “Laws were meant to be written.”

There are only three or four independent living centers in all of Spain, and they are opposed by the aforementioned NGO hierarchy, which controls businesses, such as hotels, doing about €300,000,000 a year – among the 100 largest economic powers in Spain. (As of this writing, 1 euro equals \$1.40 U.S.) The NGO conglomerate is dominated by ONCE, Organización Nacional de Ciegos Españoles, an organization of and by blind folks funded largely on lottery ticket sales.

In Spain
Continued on page 10

Polio Survivor, 101 year old Still Going Strong

By Kathi Wolfe

Ann Dodes does her own cooking and housework. For the latter, she holds her walker with one hand while sweeping the floor with the other. She lives alone, keeps up with the news and reads magazine articles about health.

There is nothing unusual about this, except that Dodes, who lives in southeastern Florida and has post-polio syndrome, is 101 years old. Born in New York City in 1908, Dodes is believed to be the oldest polio survivor in the United States.

In a series of telephone interviews, Dodes related the story of her life. In wide-ranging conversations, Dodes reflected on topics from polio to the "secret" of her longevity to the Great Depression to her marriage.

Dodes' parents, Russian Jews who immigrated to the United States in 1908, had six children: five girls and one boy. (All of Dodes' siblings are deceased.)

At birth, "I was a normal baby," Dodes said, "but as the years went on my feet wouldn't walk." Her parents took her to doctors and hospitals, "but they didn't know what was wrong with me."

After trying fruitlessly to determine the cause of her difficulty walking, Dodes' parents became discouraged. In 1913, Dodes traveled with her sisters and her mother from their home in New York to her grandfather's home in Russia. "They hoped that Russian doctors would figure out why I couldn't walk," Dodes said.

But it wasn't a safe time for Jews in Russia. "We heard screaming in the streets," Dodes said. "We were in the middle of a pogrom

(an organized massacre of Jewish people). For our safety, my grandfather took us to a nearby convent (of Catholic nuns)."

Her grandfather booked passage for Dodes and her family to return to the United States by ship. "When we arrived (at the dock), we were told the boat had left, so we returned to the convent," Dodes said. Days later, they learned that the boat had been torpedoed and everyone aboard had drowned. "The First World War was beginning," she added.

Dodes, along with her sisters and mother, stayed at the convent for two years until it was safe to return to America. "The nuns were very kind," Dodes said. "They treated my feet with heat, and as time passed my feet felt stronger. I started walking without help."

In 1915, after the family returned to the United States and resettled in New York, her mother took Dodes, then age 7, to a podiatrist. "I was able to walk, but not able to skip, skate or jump," she said. "I tried to roller skate and fell on my head."

The podiatrist told her mother that Dodes had infantile paralysis, now called polio. "He advised her to take me (when it was warm out) to the ocean and wash my feet with the mud that comes on (shore) with the sand." The podiatrist also advised Dodes to wear a specific pair of shoes.

"Coward was a brand of shoe that he thought would help my feet," Dodes said. "I don't know what it was – maybe it was bathing my feet in the mud, maybe it was the Coward shoes -- but as the years passed I walked like everyone else. I

never ran – but who needs to run?"

Dodes walked without using crutches, a walker or a brace until she developed post-polio syndrome 14 years ago. At that time, she began using a walker.

From the time Dodes can remember, she said, "I've been good at math." Dodes went to high school at a Hebrew technical school in the Bronx that was supported by a philanthropist. "You had to do well in math to go to it." Dodes said she can't remember the name of the school (which has closed) or the philanthropist (who is deceased) but recalled that she graduated in 1927 or 1928. "I never went to college, but I took some courses later in life."

Soon after graduating high school, Dodes put her math skills to use, working as a secretary to an accountant. (Throughout much of her life -- before her marriage and after her children were in school -- Dodes worked for accountants.) "I was riding on the (the subway). I picked up The (New York) Times and saw a job ad for an accountants' secretary. When I got off the train, I went into a candy store and bought a sheet of paper and an envelope, and sent a note in green ink saying I wanted to work for them."

Dodes always carried pens with green ink in her pocket. "My father (a grocery salesman) wrote his grocery orders in Russian. I used the pens to translate them into English for him." The next day, the accounting firm called her in for an interview. "I went to the office and I saw all of these unopened envelopes on the desk. I asked, 'Why did you pick me for the job?' They said the green ink made my letter stand out!"

Securing that job in 1928, which she held for four years, was a stroke of luck for Dodes. It meant that she had work when the Great Depression

began in 1929. During the Depression, "so many people were out of work!" Dodes said. "I saw men selling apples for a nickel on the streets – people stood in line for bread."

In August 1929, Dodes met her husband Harry (who died at age 87 in 1995). "We were on vacation in the mountains and eating in the dining room," said Dodes, who noted that, at that time, young women and men sat at separate tables. Observing a good-looking man sitting across the room, "I said to my girlfriend next to me, 'You see that handsome guy? I'm going to marry him!'"

The couple fell in love, but because the times were so tough they couldn't get married until September 1933. "My husband studied engineering, but (because of the Depression) he couldn't finish college," Dodes said. He instead worked in his family's restaurant business. Because of her husband's job and her father's work in the grocery, "we had food, but so many people didn't."

Harry and Anne Dodes were married for 61 years and had three children. "We had a great life together!" Dodes said. At age 66, Harry Dodes was diagnosed with cancer. "The doctors said he had only a year to live, but he lived for 21 more years," she said.

When Harry Dodes was told he had cancer, Ann Dodes retired from her job, and the couple moved from Queens, N.Y., to Florida. "Our kids were married. We went out with friends," Dodes said, "We had a wonderful time!"

Although her husband had taught her to drive, when she got to Florida, Dodes decided that she wouldn't do it any more. "It was so funny!" she said. "I was 65,

Polio Survivor
Continued on page 9

Assistive Technology Providing Help for Children with Autism

By John M. Williams

Out of the more than 100 one-on-one interviews I have done as a journalist, the toughest was with an 11-year-old autistic boy. He would not respond to my questions until I condensed them to four words, and he heard them asked through my tape recorder. His answers were then clear and concise.

Throughout my 31 years in the disability field, I have talked with people of all ages with autism. Whenever I used text-to-voice technology in communicating with them, I have been successful. I did not start out knowing that autistic children respond to artificial voice commands. About 20 years ago, I watched two autistic boys, about 10, play Pac-Man, the classic arcade game. They responded well to the digitized voice. I took notes about the experience and then wrote an article about it.

Since the summer of 2008, I have received more than 100 e-mails from parents of children with autism and teachers who have autistic children in their classrooms. Most are like Mary Kelly of Chicago, Ill., whose goal is "creating the opportunity to give my son Terry a future." Terry, 7, was diagnosed with autism when he was 3 years old.

For Kelly, giving her son a future is her life's mission. She has been searching for a year for technology that can make a difference in Terry's life. Using the Internet, she has found some companies that manufacture technology specifically developed to benefit autistic individuals. In her search, she discovered Accelerations Educational Software (www.dttrainer.com).

Jim Ellison of Houston, Texas, has a similar story. His 9-year-old son Michael

was diagnosed as being autistic three years ago. Other disabling conditions prevented a diagnosis of autism until Michael, who is in the second grade, was 6. "Michael's teachers need to know about the technology that can build a future for him," Ellison said.

Michael's teacher, Kathryn Hays, said, "I need to know more about technology's benefits to my students with autism." She said she notices that Michael responds to voice instructions from a computer better than oral commands from her.

Many teachers are baffled by how to teach a student with autism and have asked me what it is.

Autism is a brain development disorder that is characterized by impaired social interaction and communication, and restricted and repetitive behavior, which begins before a child is 3 years old. About 300,000 American children have been diagnosed as having autism, according to the first comprehensive national surveys of the developmental disorder. Autism, sometimes called "classical autism," is the most common condition in a group of developmental disorders known as autism spectrum disorders (ASD).

Autism is characterized by distinctive behaviors. Autistic children have difficulties with social interaction, display problems with verbal and nonverbal communication, and exhibit repetitive behaviors or narrow, obsessive interests. These behaviors can range in impact from mild to disabling.

According to his mother and teacher, Terry Kelly

exhibits nonverbal communication and repetitive behavior (such as rocking in his seat) and is obsessive about his possessions.

Autism varies widely in its severity and symptoms and may go unrecognized, especially in mildly affected children or when more debilitating handicaps mask it. Scientists aren't certain what causes autism, but it's likely that both genetics and environment play a role.

There is no cure for autism. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that target the core symptoms of autism: impaired social interaction, problems with verbal and nonverbal communication, and obsessive or repetitive routines and interests. Most professionals agree that the earlier the intervention, the better.

For many children, autism symptoms improve with treatment and with age. Some children with autism grow up to lead normal or near-normal lives. Children whose language skills regress early in life, usually before age 3, appear to be at risk of developing epilepsy or seizurelike brain activity. Michael Ellison has seizures. During adolescence, some children with autism may become depressed or experience behavioral problems.

Kelly, Ellison and the teachers of their children are looking at video modeling as a teaching tool. Video modeling is a form of observational learning in which desired behaviors are learned by watching a video demonstration and then imitating the behavior of the model. In video self-modeling (VSM), individuals observe themselves performing a behavior successfully on video and then imitate the targeted

behavior. Video modeling has been used to teach social interaction and skills, including communication, daily living, recreation, academic and athletic. Accelerations Educational Software is one of the country's leading developers of software for individuals with autism and other learning disabilities. The company incorporates behavioral methods that allow even very low functioning individuals to become independent learners. The company's first product, the DT Trainer, was created by its founder, Karl Smith, for his autistic son.

"My son is an inspiration behind our mission to create effective and affordable educational software for individuals with autism and other learning challenges," Smith said. The software motivates individuals to perform tasks that they may not want to or may find difficult to learn. There are hundreds of colorful, interesting and fun reinforcing agent to pick from that engage even difficult-to-motivate individuals. The program breaks down learning into the appropriate steps for low-functioning to high-functioning students. The program is for learners who:

- Are developmentally between the ages of 2 and 9 .
- Are easily distracted or overloaded.
- Are not self-directed or self-motivated.
- Have difficulty following directions.
- Require moderate to substantial repetition.
- Need maintenance of previously learned materials.

"Using assistive technology, children can learn and function productively given the appropriate educational plan and technology," said

Autism
Continued on page 15

Compassionate Allowance System to Speed SSA Benefit Process

By Brenda Brown-Grooms

The Social Security Administration (SSA) has initiated a plan to speed up the disability benefits approval process for people with the most severe disabilities and illnesses.

The Compassionate Allowance (CAL) system is designed to quickly identify diseases and other medical conditions that invariably qualify under the government's "Listing of Impairments" based on minimal, but sufficient, objective medical information. If the condition does not meet these strict criteria, it will not be designated as a CAL case. All CAL-identified conditions are entered into the predictive model and are selected for CAL processing based solely on the claimant's allegations listed on the SSA-3368 (Disability Report--Adult) or SSA-3820 (Disability Report--Child).

Like quick disability determinations (QDD), CAL cases will receive relatively fast reviews. CAL cases are similar to terminal illness (TERI) claims, although not all CAL cases involve terminal illness. For example, a person with a spinal cord injury could qualify as a compassionate allowance, even if he or she is expected to live for many years.

An initial list of 50 disabilities and diseases has been established as a starting point (with brain injuries soon to be included). That list includes the following rare diseases and cancers:

- Leukemia
- Adrenal cancer
- Alexander disease (ALX)
- Amyotrophic lateral sclerosis (ALS)
- Anaplastic adrenal cancer
- Astrocytoma (Grade

- III and IV)
- Bladder cancer
- Bone cancer
- Breast cancer
- Canavan disease (CD)
- Cerebro-oculo-facio-skeletal (COFS) syndrome
- Chronic myelogenous leukemia (CML)
- Creutzfeldt-Jakob disease (CJD)
- Ependyoblastoma
- Esophageal cancer
- Farber's disease (FD)
- Friedreichs Ataxia (FRDA)
- Frontotemporal dementia (FTD)
- Gallbladder cancer
- Gaucher disease (GD)
- Glioblastoma multiforme (brain tumor)
- Head and neck cancers
- Infantile neuroaxonal dystrophy (INAD)
- Inflammatory breast cancer (IBC)
- Kidney cancer
- Krabbe disease (KD)
- Large intestine cancer
- Lesch-Nyhan syndrome (LNS)
- Liver cancer
- Mantle cell lymphoma (MCL)
- Metachromatic leukodystrophy (MLD)
- Niemann-Pick disease (NPD)
- Non-small cell lung cancer
- Ornithine transcarbamylase (OTC) deficiency
- Osteogenesis imperfecta (OI)
- Ovarian cancer
- Pancreatic cancer
- Peritoneal mesothelioma
- Pleural mesothelioma
- Pompe disease
- Rett (RTT) syndrome
- Salivary tumors
- Sandhoff disease
- Small cell cancer
- Spinal muscular atrophy (SMA)
- Stomach cancer
- Thyroid cancer

- Ureter cancer.

This list of compassionate allowance conditions was developed using information received in public outreach hearings, public comment of an advance notice of proposed rulemaking, comments received from the Social Security and Disability Determination Service (DDS) communities, and through the counsel of medical and scientific experts. The SSA also considered which conditions already met their current definition of disability. The list will expand over time.

A QDD case is an initial electronic disability collect system (EDSC) case identified electronically by a predictive model as having a high degree of probability that the claimant is disabled, evidence of the claimant's allegations is expected to be easily and quickly verified, and the case can be processed quickly by the DDS.

According to the SSA, the QDD process goes beyond TERI and presumptive disability/blindness (PD/PB) criteria to identify applicants who are clearly disabled and whose medical evidence is easily available. These applicants should receive disability status in the DDS-recommended time frame of 20 days or fewer. Quick disability determination cases are:

- Identified electronically and cleared from a field office by the EDCS once received and processed by the DDS's automated case-processing system.
- Assigned to designated disability examiners who have been trained to carry out the QDD process.

- Processed using the CAL guidelines for expediting cases.
- Able to be simultaneously designated as TERI, PD/PB or CAL to ensure continued priority status if the case is removed from the QDD process.
- Processed in field offices.

Differences in the predictive model for CAL cases are supposed to be simpler than those for QDD cases.

The government notes that:

- CAL cases are identified solely when an applicant claims to have a disease or other medical condition that matches a disease or medical condition loaded in the predictive model. There are no scoring or threshold criteria.
- Designated employees in the DDS, Office of Quality Performance and Office of Disability Adjudication and Review can manually add, remove or reinstate a CAL indicator to a case not necessarily included in the QDD process. Field office employees

Benefits
Continued on page 14

Commentary**Sotomayor Would Do Justice to the U.S.***By Kathi Wolfe*

I don't have Type 1 diabetes. Yet this disease is intimately connected with my life. My mother, a Type 1 diabetic, died at age 39 in 1971 from complications of the illness. (She was diagnosed with Type 1, often known as juvenile diabetes, at age 6.) I am legally blind because of retinopathy of prematurity, and I likely would not have been born three weeks prematurely if my mom hadn't had diabetes.

I loved my mother dearly, but diabetes is never far from my mind -- especially in the wake of Judge Sonia Sotomayor's nomination to the United States Supreme Court. Sotomayor, a judge of the U.S. Court of Appeals for the Second Circuit, was diagnosed with Type 1 diabetes at age 8. She recently turned 55.

Barring something unforeseen, at press time it appears highly likely that the Senate will confirm Sotomayor as a Supreme Court justice.

If confirmed, she would be the third female and the first Hispanic justice to serve on the Supreme Court. I'm not a lawyer, so I won't pretend to analyze Sotomayor's opinions. According to news reports, however, she has had much legal experience, and even critics who disagree with her decisions are hard-pressed to say she is unqualified to sit on the Supreme Court. Sotomayor has sat on the Appeals Court for 11 years, served as a New York federal district judge for six years, been a prosecutor with the Manhattan district attorney's office for five years and worked as a private-practice lawyer.

I'd never pass a pop quiz on the fine points of the law. But I do know that it's time for the Supreme Court to

start looking like the United States (an increasingly multicultural country, where women make up more than half of the population). Given that Sotomayor is a woman and Hispanic, if she is confirmed, it would go a long way toward injecting some much-needed diversity into the Supreme Court, a predominantly white, male-dominated institution.

Equally important to me and, I'll bet, for many of us with chronic illnesses and disabilities, is the fact that Sotomayor has Type 1 diabetes.

According to the U.S. Census Bureau, nearly one in five Americans has a disability. Yet, we who have disabilities have rarely seen someone with our experience on the Supreme Court. Justices make decisions based on their interpretation of the law. But it's hard to believe that they leave their personal lives behind when they sit on the Supreme Court bench. This is one reason why having Sotomayor on the Court would matter to disabled people.

There have been other past and present Supreme Court justices with illnesses. Former Chief Justice William Rehnquist died after being ill with thyroid cancer. Justice Ruth Bader Ginsburg received treatment for colon cancer in 1999 and disclosed this year that she had undergone treatment for pancreatic cancer. Justice John Paul Stevens has had open-heart surgery. But many of these justices did not live long periods of their lives with disabilities, and they often kept their diseases under wraps or weren't very forthcoming about their illnesses. What sets Sotomayor apart is her openness about living

nearly all of her life with Type 1 diabetes.

When she was a child, doctors told Sotomayor that because of her diabetes she couldn't be what she wanted to be when she grew up: a police detective. "If I couldn't do detective work as a police officer, I could do it as a lawyer," she told the *New York Daily News*.

Like many of us with disabilities and chronic illnesses, Sotomayor learned early on to develop the inner strength to stick to one's dreams and career goals in the face of sometimes daunting odds and lowered societal expectations.

Despite the reality of potential workplace discrimination if they disclose their disease, many people with Type 1 diabetes work successfully in numerous fields, from entertainment to sports to medicine to law. Yet even so, people with Type 1 diabetes, like folks with other illnesses and disabilities, run into prejudice and stereotyping. Recently, a federal jury ruled that the FBI had discriminated against Jeff Kapche, a police officer, when it wouldn't hire him as a special agent because he has Type 1 diabetes, despite the fact that he managed his illness with insulin injections.

According to the U.S. Census Bureau, the unemployment rate of people with disabilities is about 70 percent. In light of that, I can't help but see Sotomayor as a role model, not only for people with Type 1 diabetes, but for all of us with disabilities. I don't mean that all of us should agree with her judicial philosophy or want to be like her, but her rise to prominence, despite run-ins with naysayers and having to deal with a stigma, encourages us to work to be the best that we can be in our chosen field.

My mother, in the late

1940s, worked as a technician in a medical lab. "I never told anyone I was a diabetic where I worked," she said to me when I was a teenager. "If I did, I wouldn't have had the job."

Thinking back, I don't recall my mom telling many people at all that she had Type 1 diabetes. I doubt if even some of her best friends knew. "It's just not something you talk about," she said one night.

Deciding when to disclose a disability or illness is a personal and sometimes difficult decision, and I'm not advising people on whether to be open about their health condition to their prospective or current employer. But I'm glad that we talk about diabetes now.

Ultimately, Sotomayor's success, if she reaches the Supreme Court, will depend on her qualifications, not on her diabetes. Whether she will be a champion for disability rights will depend on her interpretation of the law and the Constitution and not on her illness.

The disability community appears to be cautiously hopeful about Sotomayor.

"Based on our preliminary analysis of Judge Sotomayor's extensive record on the bench, we are encouraged that she may be the champion we have been looking for," Andrew J. Imparato, president and CEO of the bipartisan American Association of People with Disabilities, wrote in a statement. "Her jurisprudence in the disability area shows that she has a good understanding of the real-life implications of her decisions and sees the important connection between disability rights laws and other civil rights laws.

"Her personal experience

Sotomayor
Continued on page 12

Injured Poet's Memoir Takes

Healthy Approach

By Amy Halloran

Peggy Shumaker is a poet and teacher who lives in Fairbanks, Alaska. In June 2000, she and her husband were riding on a bike path when a teenager driving an ATV hit them. Shumaker wrote a memoir of her accident and recovery that meditates on her childhood and her family's history.

We spoke by phone nearly nine years after her accident and two years after the publication of her memoir "Just Breathe Normally" (University of Nebraska Press, 2007), which will be issued in paperback this fall. Shumaker has also written six books of poetry. She is retired from teaching creative writing and English at the University of Alaska at Fairbanks but still teaches at the Rainier Writing Workshop, a low-residency MFA program at Pacific Lutheran University.

Q: Your book tackles the topic of recovery from an interesting angle, lacing vignettes of your accident and healing with stories about your ancestors, your childhood and your adult life, too. As you were recovering, did you digest your childhood in your mind?

A: Well let me just explain that just after the wreck happened, I was injured, and I couldn't see well, and I couldn't physically write. There was a great urgency in me to be able to read and to be able to write, and what I was doing at first was simply trying to write my way out of a bad place -- and write my way toward a life that might be a life that I wanted to lead. So I guess what I'm saying to you is, my memory was pretty fragmented, and as my memory began to repair, some of the memories were my own, of childhood, some of

them were even of the very recent past, because I have trouble hanging on to what's happened since breakfast. Some were ancestral, and some were communal memories, and some were quite old. In fact, I ended up thinking a whole lot about memory in the aftermath of this, and I have a bunch of questions I use when I teach classes.

Q: Do you see your story as a parallel narrative, of healing your body and healing your idea of your childhood?

A: It didn't start out that way but I think the parallels are pretty undeniable. I was very near to death, and I had to think a lot about what matters, what would I want. Part of it involves being honest because, as you know from reading the book, a lot of my upbringing was chaotic and not especially pretty. Part of it deals with resilience, and part of it deals with figuring out, "OK, so this is what happened in my life. What next?" And I was just trying to be healthy in both of those endeavors, in dealing with the early things and also with the most recent upheaval.

Q: Was the trauma of your childhood not so much in the front of your mind until the accident?

A: We all live with what we've come through. When I was laced with self-doubt, I would think, "Who would want to read this stuff?" And it took me a long time to realize everybody experiences tremendous loss, everybody has grief, everybody has physical limitations, everybody has times when memory is unreliable or damaged. It happens in every life, and so it turned out to be my take on things that are present in just about every

life.

Q: You write about your mother hitting you and your siblings. Did you compare the unpredictability of living with a parent who couldn't control her anger to the randomness that put you in the path of the ATV?

A: That's interesting because I had thought more of the carelessness of my father and the carelessness of this boy and neither of them being able to make connections between their own actions and the consequences of those actions. Now that you bring it up I don't think the boy was motivated by anger, but I can see his lack of control and my mother's lack of control have a similarity.

Q: In the section titled "Ice River," you call each spring "a recovery." Did you think this way before your accident, and if so, how did your experience of recovering deepen that sense?

A: (Alaskan) winter is very, very long, and, by the way, when I lived in Arizona I had no concept of winter. In Alaska it was the first place that I realized break up is something really to look forward to. When the ice goes off the river there's a tremendous sense that everything is possible. The birds are going to come back, the grass is going to sprout, the bears are going to come out of hibernation. The world is going to renew itself in a way that is extremely dramatic. Yes, I did see that every spring is a form of renewal, a form of recovery. I did see that before the accident. I think it was more emotional for me after the wreck.

Q: How long was the process of your recovery?

A: In some ways it continues. It took three months and three days for my eye to open again, and it took some time after that before I could read clearly. It was probably a year before I could do

things without assistance, meaning there was pain and there was lack of balance and that kind of stuff. At this stage. I can pretty much live the life I want to live, but my eyes go different directions, and one of the things I don't like to think about is when you have head trauma you're more susceptible to have Alzheimer's. So there may be consequences I don't know about yet. I can ride a bike again. I can no longer scuba dive; that's a pain, but it's not the end of the world. I can snorkel. They have a hyperbaric medicine center at Duke University, and I went through all the tests, and I passed all the tests except the last one. The last one showed that even when I exhale there's scar tissue blocking some passages of my lungs, so the doctor said, "You'd be fine going down, but coming up could be a problem." I'd really like to come up. So I can't do that anymore.

Q: While you were injured and recovering, did you identify yourself as disabled?

A: I think very definitely, especially when you consider that term to mean I didn't have the capacity I once had. I went from being fiercely independent to needing help with everything. At the very beginning I needed help to breathe. And then I needed help to turn in bed, and then I needed help to sit up, and I needed help to make it to the bathroom. So it's a very sobering experience, and it's also an opportunity. I got to allow a lot of other people to give to me.

Q: Was it hard for you to ask for help?

A: I didn't have any choice. (She laughs) I was deeply lucky that there were a lot of people around willing to help me -- most especially my husband -- but many relatives, many friends. I

*Poet
Continued on page 10*

Polio Survivor
Continued from page 4

but I saw these old people, and they walked so slowly. I thought, 'I don't want to drive. I might kill them!'"

When Harry Dodes died: "I was so sad! I'd never felt old before, but then I felt my age for the first time." But, "how long can you mourn?" she said. "You're not born together and you don't die together."

Today, Dodes leads a full life -- maintaining her home, paying attention to current events and keeping in close touch with her family. Her son lives near her, and she frequently visits her family outside the state. In addition to her son, she has two daughters, six grandchildren and 12 great-grandchildren.

During her lifetime, Dodes has thought a great deal about health, disability, justice and longevity.

She advises people to pay attention to their bodies. "If you exercise, use common sense. With my post-polio, I don't overdo it. I use my head. If I'm tired, I stop."

To what does she attribute her longevity? "I don't smoke. Someone gave me a cigarette once. I threw it away. It tasted like garbage!"

Although she occasionally eats chicken, "I'm mostly vegetarian," Dodes said. She first read about the benefits of a vegetarian diet as a teenager. "I loved to go to the library, and the books said vegetables were good for you," she said. "Everyone laughed at me for eating so many vegetables, but here I am: 101 years old!"

Dodes has asked her doctors why she has lived so long. "They laugh and say, 'You're lucky and you have good genes!'"

What advice does Dodes have for living a good life?

"Be kind to people!" she said. "Never rush or leave anyone in pain alone. I'm not in pain. So I can be alone -- even for a couple of weeks -- and find plenty to do. But if you're in pain, it's too hard to be alone."

Dodes' thoughtfulness and intelligence is well-respected by her family and friends. "I learn so much every time I speak to you, and just from observing your everyday life," wrote Dodes' great-granddaughter in the April 2009 edition of "Second Time Around," a publication of the Boca Area Post Polio Group of Boca Raton, Fla.

"Other than using a walker, my health is good for my age," Dodes said. "I don't know if anyone is listening to our conversation, but I've never taken a physical in my life."

Dodes fiercely values her independence. "I don't want to ever go into a nursing home," she said. "You can't be yourself there. Here in my home, if I want to have a sandwich at 3 a.m. or eat dinner in a housedress, I can!"

Life continues to surprise her. Nearly a century ago, when she was 7 and returning to America, the nuns at the convent in Russia gave her a brown dog named Maslik. "I loved him -- the little dog. But one night on the boat (to the U.S.), there was a storm. Maslik got scared, jumped overboard and died."

Dodes was so saddened by Maslik's death that "for years and years, I don't know why, I couldn't go near any dog," she said. Two years ago, however, "I don't know why, but I suddenly became friends with my son and daughter-in-law's little dogs. Do you know what? I'm the most friends with the ugliest one!"

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

Ways to Ease Side Effects of Mental Health Meds

By Joely Johnson

The first time I took Prozac, I thought I was going to die. A few hours after swallowing one 20-milligram capsule -- the standard starting dose -- I experienced a pounding heart, sweating, tremors and confusion. I know now those are all the classic symptoms of serotonin syndrome, a potentially life-threatening adverse reaction that may occur following therapeutic drug use.

After a few hours of deep sleep, however, I actually sensed a tiny break in the crushing depression I had been suffering from. I found myself thinking that the drug might actually work for me, but I could not imagine taking another dose the next morning.

Lowering the dose to what my doctor referred to as a "subtherapeutic" amount did the trick. To manage this, however, I had to open the capsule and dilute the powder into juice that I then measured out and drank each morning. I was able to keep taking Prozac and benefited greatly from it. To this day, I continue to take substandard doses of my mental health meds, which seems to work for me while keeping side effects to a minimum.

According to the U.S. surgeon general, about 6% of Americans suffer from a serious mental illness such as schizophrenia, bipolar disorder, severe depression, panic disorder or obsessive-compulsive disorder. A smaller group, 0.5% of the population, is considered severely disabled by their conditions and receive Social Security benefits for mental health-related reasons.

Many, if not most, of those with serious or severe mental illness take

prescribed psychotropic medication. It is common for people to experience problems associated with their medications, such as tremor, nausea, diarrhea, confusion, insomnia, sedation, sexual dysfunction, weight gain and even high cholesterol and glucose-control issues. Understandably, these distressing effects can lead people to skip doses or quit their drugs (what is called "noncompliance"), which can result in the worsening of symptoms or relapse.

History shows that overly high doses may be responsible for some of the side-effect trouble, at least in certain individuals. "The now-extensive experience for treatment of schizophrenia showed that doses were far too high, causing major adverse drug events," said Julie Zito, Ph.D., pharmacy professor at the University of Maryland in Baltimore. In addition, years ago, the few available psychotropic medications were offered in limited dosage strengths. For example, you might have had only the choices of a 50-mg pill or a 150-mg pill, making overly high dosing more likely.

Drug side effects may also have a genetic link, causing some people to be more sensitive than others and more likely to develop adverse effects. Age also can play a role, making medication side effects more common in the elderly and in children. This is because body weight, metabolism, kidney or liver function, and digestive health can all have an effect on how much of and how quickly a drug is absorbed into the body.

Side Effects
Continued on page 14

Poet
Continued from page 8

was really lucky that I wasn't on my own. I'm thinking now about the word "disability," and in some ways it means you cannot do things, and that was true. There were many things that I could not do. There are still a few that I cannot do. I felt kinship with other people who were limited in mobility. I felt definite kinship with people who couldn't bring words to their conversations when they needed them. I felt real kinship with people whose minds didn't let them pull up what they wanted at a particular moment.

Q: Do you still feel connected to the disability community because of your experience?

A: Absolutely. No doubt about it.

Q: When you couldn't read, did you listen to recorded works and ask people to read to you?

A: At that stage, I was not really alert very much, so even though I wanted to read I was not staying awake enough to do those things. I couldn't concentrate enough to do those things. I did have one niece who was willing to sit with me and read things, but it would be a matter of a couple of poems before I was out again.

Q: How was the experience of being read to different from being able to read to yourself?

A: I think it's really intimate the relationship between a reader and a book, and I think it's a very different thing when you hear another voice. That's an intercession, and that person whose voice you're hearing gives inflections and pacing and turns of phrase that may not be the ones that you would hear in your imagination. I'm

glad that those books exist -- in fact I used to read for the blind in Arizona. I'm glad that those books and services are available for people who need them for books and commutes, but I prefer by far my own pace and my own relationship with the word on the page.

Q: How did you rebuild your life as a writer?

A: In the doing. I was at a book club the other day, and somebody asked me, "So, did you find your way back to the world through words?" I've been doing that since I was a little kid, trying to apprehend the world through words. So of course, that was my natural inclination, to try to write.

Q: And when you tried, did you have difficulty getting words on the page?

A: Well, it wasn't simple. When I first began there were physical impediments. Later, I was having all these little fragments, little shards. People have suggested different metaphors for collections of brief non-fiction like a mosaic, or maybe they're beads on a string, or maybe they're like pieces of a quilt, but I think mine's like a kaleidoscope, where there are all these shards, all these little pieces, and if you tilt it just a little, then they rearrange themselves. It's not nearly as organized as beads on a string.

Q: While you are not sweet in the book to the person who hit you, you don't seem malicious to him, either. You are frank about stating he changed and almost took your life, and yet you don't seem vindictive. Did you edit your feelings about him?

A: I didn't have a lot of anger toward him because, frankly, that took energy I needed for other things. I did have somebody ask me the other day if I knew what happened to him, so I Googled him, and the most recent buildup is he

was arrested for drunk driving last October. So he's still being dangerous. I wanted, of course, for him to be a better citizen. I wanted for him to have some acknowledgement that his actions were deeply destructive, but I really didn't feel angry toward him. I was frustrated by him, and it was distressing to me that he could cause such harm and not recognize that he'd done it.

Q: Did you have anger at your situation?

A: Well, there were lots of times I was impatient. There were lots of times that I wanted things to be different, but I wouldn't say angry is the word. That's not the way that I operate in the world. You know something? I think that has to do with the fact that it was the way my mother operated, and I saw its limitations.

Q: I can see where that becomes a conscious choice.

A: It didn't get her what she needed.

Q: How did the project of writing this book differ from other books you've written?

A: There was a great sense of urgency because if I could do it, if I could write, it meant I could get well. If I could get stronger, it meant that I could do things on my own. So in some ways it was a series of steps, and not back toward who I used to be but toward who I was going to be from then on. I think there was a greater sense, too, of not knowing what I was doing because I didn't go into it thinking it was a book. I didn't go in thinking it was anything except a way to get out of being utterly helpless.

Q: Is there anything else you'd like to say to this audience?

A: I would say to the disability community that very often during the



Peggy Shumaker

aftermath of a wreck there will be people who think they're acting in your best interest, and they will focus on what you cannot do. Sometimes they're attempting to lend aid, and sometimes they think they're preventing you from reinjuring yourself. Whatever their motivation, there's a lot of people who focus on what you can't do, and I needed to be around the people who would focus on what I could do. I just hope that the people that get energy from the kind of exercise that writing a book this book was will recognize that surrounding yourself with people who focus on what you can do is a good thing.

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

In Spain
Continued from page 3

On the positive side, ONCE employs about 100,000 people with disabilities, mostly in menial tasks like selling lottery tickets. The president of ONCE makes about €750,000, a salary that may well be worth that from a corporate point of view but far from those paid directors of not-for-profit voluntary agencies in the USA.

William Loughborough is a frequent contributor to Independence Today currently living in Madrid, Spain. He has been involved in the Web Accessibility Initiative since its inception.

White House Stance Frustrates ADAPT

By Mike Ervin

The long line of ADAPT marchers slithered toward the White House. Everyone took his position along the front fence, facing the White House main entrance, across from Lafayette Park. It was the first day of ADAPT's first national action against the Obama administration.

It was a sweltering morning. The lucky ones were those whose positions put them in the scattered patches of shade cast by trees. An announcement came over the bullhorn: A contingent of ADAPT leaders was going inside for a prearranged meeting with White House staff to discuss the Community Choice Act and everyone should remain in their positions. What would happen next would depend on how well things went inside.

Meanwhile, it was Henry Claypool's first day on his new job as director of the Office on Disability of the U.S. Department of Health and Human Services. Claypool is a spinal cord-injured wheelchair user who once relied for support on Medicare, Medicaid and SSI. He was well-known in disability political activist circles before his appointment. He began his career working at a center for independent living and went on to work as a disability policy advisor for the Centers for Medicare and Medicaid Services and the Social Security Administration. Claypool is a noted advocate of people who depend on public supports like he once did and has attempted to change what he sees as injustices in programs such as Medicare.

The first thing on Claypool's "To Do" list that day was to attend the meeting with the ADAPT leaders, which he had encouraged. "It was my advice and assessment that it would be good to talk

to ADAPT early to make sure we were building a relationship so that we could move the agenda forward," he said.

Also in attendance for the administration were Nancy-Ann Min DeParle, director of the White House Office of Health Reform, and Jeff Crowley, director of the Office of National AIDS Policy and presidential disability policy advisor.

Claypool said that, when he saw so many ADAPT members gathered outside the White House, he had a sinking feeling that this wasn't going to be the harmonious summit he envisioned. "I saw that this was going to be an opportunity for people to make an impassioned plea. I didn't anticipate, and I probably should have, that ADAPT would place demands on the administration."

ADAPT member Randy Alexander of Memphis, Tenn., said that he also feared things would go wrong before the meeting even started. "In retrospect, the tone was set upon entering the back service entrance (of the Eisenhower Executive Office Building next to the White House) and having to use the service elevator with the construction and cleaning crew."

ADAPT's agenda, Alexander said, was to learn if the Obama administration had any intention of including the Community Choice Act or any significant reform of long-term care in the upcoming health care proposal.

"Our agenda was to express that the Community Choice Act is clearly a civil rights issue, and that we had expectations set forth

from what we heard and saw during Obama's presidential campaign," he said. "Three of us in the room had faced state-sanctioned segregation by being forced into institutions. One individual was headed back to her state at the end of the week only to have to go back to the nursing facility she currently resides in.

"I truly hoped it would be a meeting where they would say or be convinced to say, 'OK, we don't know if it will happen now, but let's lay out a plan to try.' Simply 'try' is what I hoped for."

According to Alexander, the White House had no plans to address long-term care, include the CCA in its health proposal or push the CCA as a stand-alone bill anytime soon.

According to Claypool, DeParle expressed Obama's eight principles for health reform, which are "intentionally broad." Claypool said there was no flat-out rejection of long-term care.

Alexander said that, upon hearing no specific plan or time frame for addressing the issues important to them, ADAPT members who had been in institutions told their stories to DeParle and the others and then angrily stormed out of the room.

Outside the White House, Bruce Darling of Rochester, N.Y., another ADAPT leader, announced via a bullhorn that nothing had been accomplished and the community had been "betrayed." Many of those assembled then blocked the main entrance. Some chained or cuffed themselves to the fence. Police arrested 96 people, issuing arrestees citations on the spot and releasing them.

"I felt like a failure," Claypool said. "I felt like I'd let both sides down. My brothers and sisters in the community were left really frustrated and wanting, and

the administration that I'm trying to serve kind of got burned."

Claypool blamed himself for underestimating how the understandably high emotions of this issue were likely to supersede any meeting agenda. "I need to pay more attention to how the community's feeling." But he also said he thought that ADAPT members entered the meeting with unrealistically inflexible expectations.

"Our community has a lot to learn as well about how politics work and how things move forward," Claypool said. Progress, especially on far-reaching issues, is often slow in Washington, he said. When those pushing for change on the outside get meetings with those on the inside, he said, they should seize the opportunity to make whatever progress they can. He saw this as an opportunity lost.

Alexander said of the meeting, "I felt they were very insulting with comments of, 'You don't understand the complexity of the issue.' If we want a chance for freedom we had 'better be patient' was the message!"

A few days after the meeting, there was a change on the disability issues page of www.whitehouse.gov. The reference to the administration's support of CCA was deleted.

Alexander said that the deleted reference looked like the administration was retaliating by abandoning ship on the CCA. Claypool said when he was made aware of it, "I put my head in my hands." He said he, too, was concerned that the implication and timing might fan the flames of unrest.

But, he said, as far as he was able to ascertain, the White House Web site was

ADAPT
Continued on page 15



Dear Advocates and Friends,

As you will read below, the 2009 NCIL Annual Conference was a huge success, thanks to our incredible membership and generous sponsors. I would like to take this opportunity to thank the NCIL Board and staff for their tireless efforts to make this event happen! I would especially like to thank top sponsors Purple Language Services, Pride Mobility, Johnson & Johnson, Amerigroup, HealthSouth, The Center for Disability Rights, Verizon, Q90 CIL Management Suite, Invacare, NCART, IndependenceFirst, HSC Foundation, AdvaMed, Arizona Bridge to Independent Living (ABIL), Living Independence Network Corporation (LINC), Sunrise Medical, Vehicle Production Group LLC, and Edison Electric Institute, though every contribution to this year's Annual Conference has been critical to the event and is very much appreciated by NCIL and its members!

Sincerely,

Kelly Buckland, Executive Director

Annual Conference Summary: Activities of the Week

The 2009 NCIL Annual Conference was an incredible success! Despite the current economic crisis and the callous inaction on distribution of Independent Living stimulus funds by RSA, advocates came from all over the country to demand civil and human rights for people with disabilities, attend workshops and plenaries on the Independent Living Movement, and organize national and grassroots plans of action.

On Friday, the Conference opened with a keynote from Dr. Connie Garner, staff to Senator Edward Kennedy. Dr. Garner spoke passionately on the need to pass the CLASS Act in conjunction with the Community Choice Act in order to create real change in healthcare and civil rights for people with disabilities. Attendees then participated in one of three events designed to educate both NCIL and its membership on the importance of diversity in our Movement. Throughout the week, NCIL's Diversity Committee hosted a plenary session, a town hall forum, and a reception to expand dialogue on this important topic.

That evening, Conference-goers attended a reception hosted by the International Committee. At this powerful event, advocates were delighted to hear rousing speeches from Judy Heumann and Marca Bristo. They spoke about the need to ratify the UN Convention on the Rights of Persons with Disabilities. The room was entirely packed and their calls to action and the response of the crowd echoed loudly throughout the hotel.

Annual Meeting: Elections

On Saturday, attendees enjoyed the Exhibit Fair, Awards Banquet Luncheon, and Annual Meeting. The membership was very involved at this year's Annual

Meeting, at which several important votes were scheduled. Up for election this year were the positions of President, Treasurer, Representatives of Regions I, III, V, VII, and IX, and Members-At-Large. The results of the election are as follows:

- President: Daniel Kessler
- Treasurer: Phil Pangrazio
- Members-At-Large: Bruce Darling, Jeff Hughes, and Frank Shible
- Region I Representative: Mary Margaret Moore
- Region III Representative: David Burds
- Region V Representative, Regional Representatives Chair: Brenda Curtiss
- Region VII Representative: Vacant
- Region IX Representative: Kent Mickelson

When Vice President Dan Kessler won the Presidency, the position of Vice President (and Chair of the Legislative and Advocacy Committee) became open. Lou Ann Kibbee ran unopposed and was elected by unanimous consent.

Awards

A vital tradition of our Annual Conference is taking the time to thank and congratulate individuals who have worked tirelessly for the advancement of Independent Living and the rights of people with disabilities. These people have made outstanding efforts and achievement. There is not enough space to outline the tremendous accomplishments of these individuals in the WhAM! (Weekly Advocacy Monitor), as a full account of their contributions could hardly fit in a book. We offer our highest congratulations and appreciation for the unyielding labor and leadership of the following outstanding advocates.

This year's Regional Advocacy Award winners were recognized by their peers and honored at our Opening Plenary Session.

NCIL
Continued on page 13

Sotomayor
Continued from page 7



as a woman with childhood-onset insulin-dependent diabetes gives her additional insights that can inform her approach to disability issues."

Diabetes is covered under the Americans with Disabilities Act and the Americans with Disabilities Act Amendments Act. For information about diabetes and the ADA, go to www.eeoc.gov (U.S. Equal Employment Opportunity Commission) and www.jdrf.org (Juvenile Diabetes Research Foundation).

Assuming that she is confirmed as expected, I hope Sotomayor's jurisprudence will respect and protect the civil rights of people with disabilities and all Americans. Her nomination process has been a "teachable moment" for this country, showing yet again that someone with a chronic illness can reach the height of her profession.

For a lawyer, what could top serving on the Supreme Court? Though most of us with disabilities don't expect to reach such prominence, we'd like to crack the disability "glass ceiling." Sotomayor offers hope that this is possible.

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

Stimulus Plan
Continued from page 2

did not support the stimulus plan.

Let's look at disability priorities, keeping in mind that we cannot hope for much progress on many of our legislative goals as some expected under an Obama administration. To my dear colleagues in the disability rights movement, let's be frugal and accept whatever we get because, after all, we're part of this great country.

My stimulus plan is simple. Here is what I would like to see:

Because we're drowning in debt, let the government bail us out. If it is truly our money, then give it back to us. Based on 2005 statistics from the U.S. Census Bureau, there are approximately 120,000,000 households making less than \$550,000 a year in gross income. Let's start by giving those households a \$1 million grant.

Tax the grant at 28% or 34%, the average rate for most households in that income range; that comes to about \$280,000 in federal income taxes. That leaves \$720,000 for family expenses. With this balance, let's pay the family's mortgage, typically \$300,000 (a figure higher than the median). That should leave \$420,000.

Now pay any medical bills, college loans, credit card debt, auto loans and any other bills the family has (such as the state income tax, city taxes or real estate or property taxes). That should leave the typical family with about \$90,000. With this balance, the family would pay for a health insurance plan for two years, at \$12,000 a year. The remainder is around \$66,000. Let the family keep this balance for savings, investing, vacationing, home improvements (ideally

green improvements), buying another automobile, life insurance or for long-term-care insurance.

Now let's see who benefited. First and foremost would be the banks. The money would stop foreclosures and credit card defaults. Bankruptcies would be virtually wiped out. Slumping auto sales would be reversed. Retail sales would increase, both at Macy's and Wal-Mart stores. Wall Street, health insurance companies, the travel industry and even small businesses would all feel the ripple effects as the economy would start humming. Jobs would not only be saved but huge numbers of new ones would be created.

How much would such a plan cost? It would be much, much less than the current stimulus plan, the Troubled Asset Relief Program (TARP) and the auto industry bailout. The pricetag for the current recovery act has been placed at nearly a trillion dollars.

Under my plan, no TARP money would be given to banks, mortgage firms or those who work on Wall Street. I would estimate the net cost to be around \$86,400,000. (That's 86.4 million dollars.) And every sector of the economy would benefit, not just those who gambled with derivatives, swaps and other forms of voodoo economics out of greed, irresponsibility and arrogance.

The current stimulus plan reflects a poor sense of priorities, based on fiscal policies that have proved to be ineffective and outdated. And don't worry about inflation -- that's what the Federal Reserve is for: to create a financial policy that will protect us.

Patricio Figueroa Jr. is the editor and publisher of Independence Today.

NCIL
Continued from page 12

Region 1: Janet Dermody, Region 2: Chris Hilderbrant, Region 3: Maureen Hollowell, Region 4: Scott Renner, Region 5: Maureen Ryan, Region 6: Dennis Borel, Region 7: Dawn Francis, Region 10: Von Elison

This year's National Advocacy Award winner was selected by NCIL's leadership and recognized at the Annual Awards Banquet. The award was renamed the Corey Rowley National Advocacy Award in honor of Corey Rowley, who passed away recently. Newly-elected NCIL President Dan Kessler and Secretary Ann McDaniel spoke movingly about Rowley's many contributions to the Independent Living Movement and of NCIL's desire to honor her memory by naming the award after her. The Award was presented to Lee Perselay, counsel to Senator Tom Harkin, who has made major inroads for the disability community in the Senate.

The Frank Harkin Memorial Award was awarded to the honorable Anthony Coelho, and the President's Award to the honorable David R. Obey.

The Diana Vietz Award for youth leadership was presented to not just one but two outstanding youth this year, Eddie Rea and Micah Fialka-Feldman.

Last, but certainly not least, Denise Figueroa, the fourth president of NCIL, was recognized for her lifelong commitment to NCIL and the Independent Living Movement as she accepted the Max Starkloff Lifetime Achievement Award.

Senate HELP Committee Press Briefing: Panel discusses the inclusion of Long-Term Care in Healthcare Reform

Following the Rally, NCIL

Executive Director, Kelly Buckland, along with Policy Fellow Jason Beloungy, attended a Press Briefing held by the Senate Health, Education, Labor and Pension Committee (HELP) on Monday, June 8 in the Russell Senate Caucus Room (SR-325). The Press Briefing was a way to get the topic of long-term care reform into the spotlight of healthcare reform. Dr. Connie Garner from Senator Kennedy's office started off the event by explaining the purpose of the event and introduced Senator Harkin, the author of the Community Choice Act. Senator Harkin gave a passionate talk to those in attendance about the logic and necessity to include long-term care reform in healthcare reform. Senator Harkin's speech excited the crowd, which was full of orange shirts and blue shirts worn by advocates and ADAPTERs who attended the NCIL Conference.

Senator Harkin got the enthusiastically supportive crowd fired up for the remainder of the briefing. Following Senator Harkin, Dr. Garner introduced Dana Torres. Dana is well known as the 41 year old Beijing Olympics silver medal swimmer. Dana took part in the briefing to share her personal story of her experiences with her aging father and disabled coach. The panel included a very moving presentation by John Henry Douglas, a member of the Florida SILC who was awarded two purple hearts in Vietnam.

John Henry spoke movingly in tears about his father being forced to die in a nursing home, as well as his own fight to get out of a nursing home. John Henry's discussion was selfless in the way he talked about how the VA has benefits that allow him to live at home independently, and that these same benefits should

NCIL
Continued on page 15

Side Effects
Continued from page 9

Despite all the reasons side effects can happen, there are ways to manage your mental health medication and minimize side effects without sabotaging your treatment. If you are having trouble with your meds, consider the following suggestions:

Talk to a good doctor. Finding a doctor or nurse practitioner willing to work with you is a big first step to establishing a personalized medication regimen. You want someone who will ask questions and explore all treatment options. "Sometimes the right drug for you is an older drug," said Josh Meyers of San Diego, who takes Remeron (mirtazapine), a tetracyclic antidepressant that is less commonly prescribed than newer drugs.

Consider switching drugs. We now know that side effects from one drug may bother one person but not another, and that someone who reacts negatively to one medication may do fine on a slightly different one. Fortunately, doctors and patients today have literally hundreds of mental health drugs to choose from. "If you are experiencing a major side effect, we might have six other medications that do the same thing but have a different side-effect profile," said Dale Archer, MD, founder of the Institute for Neuropsychiatry in Lake Charles, La.

Try a lower dose. The goal of psychotropic drug treatment should be to find the smallest effective dose of medication that can still control symptoms, Dr. Zito said. If you are having side effects from your current dose, it makes sense to try lowering it. If you and your doctor go this route, it is helpful to monitor yourself closely for both mental health symptoms and side effects from the drug. You may even want to keep notes that you can share with your doctor so you

can determine your optimal dose.

Change the timing. If sedation is a problem, try scheduling your medication just before bed, when you can take advantage of the slowdown. Similarly, if you find your nighttime dose keeps you up, take your pill in the morning when the stimulating effect may not be as noticeable.

Ask about gradual dose reduction. If you suspect that you or a loved one may no longer need a particular mental health drug, talk to the doctor about trying a gradual dose reduction. This is often done in long-term-care facilities, where elderly residents may eliminate their need for antipsychotics after receiving appropriate care for other health issues. People who are put on antidepressants or anti-anxiety drugs during a crisis situation may also find their need for medication changes over time. This can be particularly true if they are engaging in treatments that were not in place before the crisis, such as talk therapy or increased physical exercise. "You don't just suddenly take it away, however," says Brian Wolstenholme, PharmD, certified geriatric pharmacist at MediSort Medication Consultants in Fort Lauderdale, Fla. "The body is still expecting the drug to be there." Like any of the changes mentioned here, gradual dose reduction is best done with the help and supervision of a doctor who knows your history.

Joely Johnson is a health and science writer in upstate New York. She is also a certified yoga instructor.

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

Benefits
Continued from page 6

cannot do the same.

- There are very few reasons to remove a case from CAL (unlike QDD, a CAL case can be followed through to a denial determination).
- A case that is identified as CAL can be processed quickly under QDD guidelines, even if the DDS removes the case from QDD's processing.
- CAL cases can be identified and started at the initial, reconsideration, and hearing and appeals council levels.

It is worth noting that the recommended 20-day time period for QDD cases starts when the DDS accepts jurisdiction of the case. Further, the time period for CAL cases is not limited to the 20-day processing period, even though expedited processing procedures remain in effect for CAL cases.

For more information, go to <http://www.socialsecurity.gov/compassionateallowances/conditions.htm> and click on "Compassionate Allowances Home."

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

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

This Day
Continued from page 2

York Times Magazine in 2003. She wrote "Too Late to Die Young" in 2005 and "Accidents of Nature" in 2006. During her career as an attorney, she specialized in helping people who couldn't work obtain Social Security benefits.

June 14th, 1965--Dr. Jesse H. Meredith performs the first hand re-implantation on Robert Pennell, a prison inmate whose hand was severed during an accident. When the ambulance arrived, the hand was packed in ice and transported to North Carolina Baptist Hospital in Winston-Salem (now Wake Forest University Baptist Medical Center), riding next to its owner. Two years earlier, TIME reported on the successful operation by Chinese surgeons who had been the first ever to reattach a man's hand. Meredith was well-aware of these ground-breaking surgeries and he and his surgical team were in the position to become the first in the United States to reattach a human hand. When the procedure was completed, a cast was put on the patient to keep the bones from shifting. All told, the operation lasted eight hours. (<http://www.dotmed.com/news/story/9130/>)

June 18th, 2008 – Heavy Load, the world's first disabled punk rock band, plays its first gig in the United States. The United Kingdom band is composed of three men with learning disabilities and two non-disabled men who also provide guitar support. The band was the subject of a documentary, HEAVY LOAD: A FILM ABOUT HAPPINESS, that was featured on the Independent Film Channel. A short video of the band's New York City gig can be viewed on www.hulu.com

-- Compiled from various sources by Mike Reynolds

NCIL
Continued from page 13

be awarded to all people with disabilities – not just veterans. Following John Henry, Mike Oxford used his in-depth knowledge of the issues to make a strong case for both the Community Choice Act and the CLASS Act. Following Mike’s presentation at the briefing, Barbara Manard, Ph.D. vice-president of long-term care/health strategies for the American Association of Homes and Services for the Aging (AAHSA), talked about the research that supports the need for the CLASS Act.

Compiled by NCIL staff

ADAPT
Continued from page 11

being updated, and the deletion was unintentional and a bad coincidence that would be rectified. As of mid-June, the CCA reference was still missing.

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

Autism
Continued from page 5

special education teacher Sharon Tate of San Diego, Calif. Tate has been teaching autistic children for five years. Because she has seen video modeling get results in the classroom, she supports using that method, along with text-to-speech technology, to educate autistic pupils. Tate has a 5-year-old daughter who was diagnosed a year ago as being mildly autistic. “Tammy responds or learns when she sees herself on screen,” said Tate, who “strongly believes” her daughter can have a future

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

Product Testing
Most Like What They See of These Binoculars
By Opal Shelton Colvin and Kimberly R. White

This review is of a product available through Independent Living Aids Inc. in Jericho, N.Y. It is product item # 4090, Far View Spectacle Binoculars with 2X magnification.

The binoculars come boxed and in a nice black case about the width of a cigarette pack and the thickness and length of two cigarette packs. The case has two slots in the back so it can easily be attached to ~~a belt and carried hands-free~~ if desired. The entire package is very lightweight, weighing less than 0.5 lbs.

The binoculars are black plastic with two sets of clear lenses. They look more like glasses with an extra set of lenses than binoculars. They have a good quality black cord attached to each earpiece that can be adjusted to fit the user. There are discrete lens adjusters on each side of the glasses.

One of our testers, an elderly lady named Dale, resides in an assisted-living facility. Her vision is very limited, but she said that with the binoculars she could now watch a ballgame. She also said that, with the product, she could now identify a person nearby. Before, she could only make out the shape but not see features. She had to wait until the person spoke to her to know who it was. She was extremely pleased with the binoculars.

A mother and father of a 10-year-old with very limited vision said that their son, Erick, loved the binoculars because he could wear them instead of holding them at a racetrack. The parents and son were also happy that Erick could see more of what was going on than he could

before. Erick and his parents also liked the binoculars because other people at the racetrack thought the binoculars “were cool.” Erick received lots of positive attention, which made him and his parents very happy.

Independent Living Aids clearly specifies that the binoculars are for viewing, not reading. They may be used to look at a computer monitor, but they are not designed for reading words on a computer screen. They are also not made for doing close needlework or cross-stitching. Even though the distributor did not say they could be used for that purpose, some of our testers do cross-stitch, so they decided to try. The binoculars didn’t work well for them.

The one thing that some people did not like about the glasses/binoculars was that when someone is looking at the person wearing them, the wearer’s eyes look huge. Several of the testers and their friends commented on that. Only one, however, said that that would keep him from using the product. He is a man in his forties who also later admitted that he does not always use his prescription glasses because he thinks he looks better without them.

The cost (about \$65, depending on shipping location) did not seem to bother any of the testers. Most of the people who tested the product said that they thought the cost was either good or reasonable based on its performance.

A few of our testers are disabled college students. Several other students saw the product while our tester was evaluating them. The

college students who were exposed to the binoculars were ecstatic about them. They were thrilled with the idea of a group of them ordering the binoculars and wearing them at ballgames. Several of them agreed that if a bunch of them wore the binoculars and all their eyes looked huge, the sports channels might show them in the stands. They also agreed that the possibility of being seen on television nationwide was well worth the cost of the binoculars. Some of them stated that the thrill of the possibility of seeing them on television would surely make their parents happy to purchase this product for them.

This product does what it was advertised to do. The majority of our testers were well pleased with it, and some were delighted with it.

Opal Shelton Colvin is an advocate for people with disabilities and works with domestic abuse victims. Kimberly White is a registered nurse and advocate for the disabled.

Advocates for the Blind Sue Arizona State U. Over Kindle Use

The National Federation of the Blind (NFB) and the American Council of the Blind (ACB) are suing Arizona State University for its use of the Amazon Kindle DX to distribute electronic textbooks to students, alleging the device cannot be used by blind students.

The national advocacy organizations say the Kindle has text-to-speech technology that reads books aloud to blind students, but that the device’s menus do not offer a way for blind students to purchase books, select

Blind Sue
Continued on page 16

Indianapolis wins Accessible America Award

By Mike Reynolds

The National Organization on Disability announced in April that Indianapolis, Ind., has won the Accessible American Communities prize for 2009.

The city is being heralded as a national model for its focus on disability issues and successful design of programs, services and facilities that are accessible for citizens and visitors who have a wide variety of disabilities. The 2009 Accessible America Competition, administered by NOD, was sponsored by a generous grant from AARP.

Other 2009 contest finalists were: Alexandria, Va.; Denver, Colo.; Louisville, Ky.; New Haven, Conn.; Sioux Falls, S.D.; and Surprise, Ariz. Since 2001, more than 150 cities from across the nation have competed for the award. Indianapolis will be presented with a \$25,000 cash prize for winning the award.

“Indianapolis is honored to be recognized with the National Organization on Disability’s Accessible America Award,” said Mayor Greg Ballard. “A commitment to make our city more inclusive for people with disabilities and the aging population has spanned generations, and I am pleased (that) our collective efforts are benefiting both our residents and visitors.”

Indianapolis was judged by an independent group of experts who not only focused on accessibility in the traditional sense but also on promoting employment opportunities and emergency preparedness issues, as they affect people with disabilities. Both initiatives were critical in the scoring of the applicants.

Indianapolis incorporated universal design in several of its local city projects, including the new Cultural Trail, a bike and walking trail that connects several areas of the city to other neighborhoods and cultural districts and entertainment facilities. The city actively incorporated suggestions for making the trail accessible throughout its development, such as adding audio signals at intersections that are frequently used by blind people.

The focus on accessible design is also apparent in the recently renovated home of the Indiana Pacers, Conseco Fieldhouse, which is considered a national model for inclusive design for indoor sports arenas. Indianapolis also made the inclusion of individuals with disabilities and senior citizens a priority in its winning bid to host the 2012 Super Bowl at Lucas Oil Field. The city’s zoo and museums have also done extensive planning to make exhibits not only accessible but designed with the intent that a person with a mobility or sensory impairment can fully interact with the exhibits or appreciate the dolphins from the land or in the water.

Governor Tom Ridge, chairman of the National Organization on Disability and former Secretary of Homeland Security said: “Communities that compete for the Accessible America Award demonstrate that people with disabilities can contribute meaningfully to solving today’s challenges. The city of Indianapolis exemplifies a successful model of enriched civic life through the full participation of all citizens, including those with disabilities.”

“The National Organization on Disability is dedicated to recognizing best practices through which communities offer people with disabilities major footholds to an independent lifestyle, such as education and employment,” said Carol Glazer, NOD president. “We commend Indianapolis as a city that has worked hard to achieve a vision where opportunities are available to people of all abilities.”

The panel of nationally recognized disability advocates and experts who served as Accessible America Competition judges chose the winner based on comprehensive accessibility and opportunities for people with disabilities. Accessible America applicants demonstrate an exceptional commitment to offering their citizens with disabilities full and equal opportunities to participate in the life of their community, including access to jobs, education, voting, transportation, housing, emergency preparedness planning, and services. The Accessible America Competition promotes nationwide replication of these best practices.

This year’s award also had a strong emphasis on outreach to potential cities by using social networking sites such as Facebook and YouTube to capture the unveiling of the award, remind people of deadlines and generally create awareness about the award.

A formal event at which the award will be presented to the city from the National Organization on Disability is tentatively scheduled for July. For more information on the Accessible American Communities Award, go to www.nod.org.

***** *

Mike Reynolds is a writer, activist, and filmmaker diagnosed with CP at birth. He is a graduate of UMaine.

Blind Sue
Continued from page 15

a book to read, or even to activate the text-to-speech feature, according to a joint statement by the two organizations.

In a lawsuit filed, a journalism student was named as a plaintiff. “While my peers will have instant access to their course materials in electronic form, I will still have to wait weeks or months for accessible texts to be prepared for me,” said the student, Darrell Shandrow, in a statement. “These texts will not provide the access and features available to other students.”

In a statement to the *Library Journal*, a university spokeswoman did not answer any specific questions pertaining to the lawsuit.

In addition, the national organizations have filed complaints with federal agencies against five other institutions using the Kindle DX in a pilot project to assess the role of electronic textbooks and reading devices in the classroom. Those schools are Case Western Reserve University, the Darden School of Business at the University of Virginia, Pace University, Princeton University and Reed College.

The lawsuit and complaints accuse the schools of violating the Americans with Disabilities Act and the Rehabilitation Act of 1973.

Organizations for the blind previously used litigation to win concessions from other companies. Target Corp. was charged with a Web site deemed inaccessible to blind shoppers, prodded the retailer into making improvements to its site and paying over \$10 Million. Last fall, the Massachusetts attorney general’s office and the NFB reached an agreement with Apple Inc. under which it agreed to make its iTunes accessible to the blind.

Source: Associated Press