LONG-TERM CARE PANEL HOLDS OFF FINANCING

STUTTERER’S CHALLENGES NOT OVER YET

WEB DESIGNER USES TECHNOLOGY TO GREAT EFFECT

TERM OVER, BAILEY STILL FIGHTING INJUSTICE

WE REMEMBER...

Former Senator Robert Dole
It’s Time for Term Limits

When keeping your job becomes more important than saving lives, we’ve got a problem. One need look no further than Washington, D.C., to see this being played out in the worst possible way. With rare exceptions, members of all political stripes put keeping their seats in Congress ahead of those they are elected to serve.

“I’d like to help you and support you, and I know what you’re saying will save lives, but if it means I’ll lose my job, too bad so sad.” Essentially, that’s the mind-set of members of Congress and many on the state and local levels as well. But let’s focus on Congress for the moment.

In 1947, Congress approved the 22nd Amendment to the United States Constitution setting term limits for the presidency, and the country has not fallen apart as a result. When George Washington chose not to run for the presidency after serving two terms and returned to private life, King George III of England said, “If he does that, he is the greatest man on earth.”

The idea of anyone voluntarily giving up power was unheard of in those days. Until there are term limits for every level of government -- federal, state and local -- nothing will change. We will continue to be governed by men and women who believe that their re-election is more important than not only the quality of your life but your ability to keep your life.

Thomas Jefferson recognized the dangers of not having term limits: “(I)f some termination to the services of the chief Magistrate be not fixed by the Constitution, or supplied by practice, his office, nominally four years, will in fact become for life.” The same reasoning applies to members of Congress and, by the way, every elected position in this country of ours.

The idea of anyone voluntarily giving up power was unheard of in those days. Until there are term limits for every level of government -- federal, state and local -- nothing will change. We will continue to be governed by men and women who believe that their re-election is more important than not only the quality of your life but your ability to keep your life.

Here’s a perfect example of the damage done (and lives lost and savaged) by the lust for power rather than the desire to serve those who elected you.

Everyone knows that the absence of universal background checks and the failure to close the gun-show loophole will cost thousands of lives, among them innocent children. And 89 percent of the American people support background checks, including a majority of the NRA members. But because the NRA leadership is be-

Carson

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Stutterer’s Challenges Not Over Yet

Thirty-two-year-old Tommy Carson says with a pinch of bitterness: “I remember that morning as though it was this morning. I dressed and went into the kitchen for breakfast. My brother, Andrew, who was 7 and a half, was eating Cheerios. I sat next to him. He passed me the Cheerios.”

“Good morning, Tommy,” my father said.


Carson, who was about 4 or 5 at the time, said his family looked at him rather strangely. He felt strange.

“Tommy, tell your mother what you want,” his father said. “But don’t repeat yourself.”

“Ah. Ah. I. I. I want or, or, orange juice.”

His father said: “Say it again. Take your time and think about what you are saying.”

(Carson said he was to receive advice like that from scores of adults for decades.)

“I did what my father asked, but I still stammered,” said Carson, who was born in Reno, Nev. “The situation was the beginning of my life’s nightmarish struggle with stammering or stuttering.”

Over the next two years, Carson said, his stuttering became more prominent. Everywhere he turned, people were advising him on ways to speak. He started speech therapy when he was 6. For three years, he took speech therapy classes once a week. He said the speech classes did not help him at all. During those years, often he was laughed at when he stuttered. When he did not see any progress with speech therapy, his family decided to end it.

“My son was getting worse rather than improving,” Jim Carson said.

Tommy agreed with his father’s assessment. Throughout Tommy’s years in grade school, he struggled with his stuttering. Often, he was denied opportunities to become involved in school activities that involved speaking. At least three times, he was given nonspeaking roles in plays. He said he became a hermit and did not develop

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Disability Equity Still Passion for Dole

By Kathi Wolfe

On April 12, 1945, when former U.S. Senator Robert Joseph (Bob) Dole led a 10th Mountain Division platoon up Hill 913 in Italy’s Po Valley and was injured while trying to help a wounded soldier, his comrades thought he’d died. Luckily for him, after being hospitalized for more than three years and going through extensive rehabilitation, he pulled through. (Today, he can move his right arm a little and has feeling in just two fingers of his left hand). At age 90, Dole, a lifetime disability rights advocate who represented Kansas in the U.S. House of Representatives from 1961 to 1969 and in the Senate from 1969 to 1996, is still going strong.

For decades, he played a crucial role in drafting and securing passage of disability rights legislation, from the Individuals with Disabilities Education Act (IDEA) to the Americans with Disabilities Act (ADA). Currently, Dole is tirelessly lobbying the U.S. Senate to ratify the United Nations Convention on the Rights of Persons

Q: Thank you very much for talking with us!
A: OK.

Q: Would you talk about the legislation that you’ve worked on, such as the ADA?
A: Let me start with the ADA. It was ... a very contentious debate on the ADA. But, finally, a majority of senators changed their minds. It was bipartisan. It’s been a big help. I went to the signing ceremony on the White House lawn. With wheelchairs, gurneys, visually impaired people, hearing impaired -- we had them all there! Justin Dart Jr. [the late disability rights leader] was there -- along with President George Bush the first -- No. 41. It was a great ceremony! To see all the people! I don’t think [anything like it] has happened since.

Q: You said it was a contentious debate about the ADA. What do you think changed their minds?
A: All of us persuasive supporters! I had a lot of personal contact [with them], and the White House was involved,
Twenty-seven-year-old Anthony Meyer Edwards sees every day as a challenge -- a challenge he meets with gusto and determination.

On a recent day in Toronto, Canada, Edwards sat in front of a computer looking at a prospective client’s website. He had been asked if he could liven it up. He shook his head again and again, but he kept his comments to himself. He made some handwritten notes and then spoke into his handheld digital tape recorder.

“Lunchtime,” he said as he wheeled himself away from the desk. “Who here is hungry?” he asked.

No one answered.

He nodded and said: “Lunch is on me. We’ll go to the historic district. I know a good Italian restaurant.” His assistant then got behind Edwards’ wheelchair and started pushing.

Ninety minutes later, Edwards was back at his prospective client’s office. “It will take me a month, maybe six weeks, to do what I want, and then two to four weeks to train your staff,” Edwards said without a smile.

“How much will it cost me?” he was asked.

Edwards cited a price and stressed that a $4,000 retainer must be in his pocket before he left the building. His prospective client was silent for a moment and then said, “Agreed.”

Edwards and his new client shook hands, and the latter told his secretary, “Draw a $4,000 check for Mr. Edwards and give it to him immediately.”

Minutes later, Edwards had his check. To the secretary, he said: “I’ll be in on Thursday. I’ll need an office only. My assistant and I will bring everything I need.”

When Edwards was 16, he was involved in a serious car accident. A drunk driver slammed his Jeep into Edwards’ car. The results were devastating. Edwards lost the use of both legs. A piece of glass that lodged in his left eye resulted in a 70 percent vision loss. His left hand was partially paralyzed. It took him nine months to recover from other injuries. A financial settlement in the high six figures was reached between Edwards and the driver’s insurance company and between Edwards and
you’ve chosen to read my words at all fills me with gratitude and helps me manage life.

There is real intimacy in the relationship between writer and reader. When joined, the connection is complete. There are no others present save for the life of the words on the page. It’s pretty miraculous if you consider the fact that reader and writer, with rare exceptions, have never met. Yet, when I think about the writers I’ve read, some on a regular basis, I stretch no truth when I say I have a relationship with them. I do. Very much so.

I don’t know what this past year was like for you and your loved ones. A good one, I hope. I hope this new one is an even better one for all of you.

Without question, there are always losses and gains to be digested from the year just past: People leave the world, new ones arrive; jobs are lost or gained; friendships stagger through changes in which some survive, some don’t; health issues rise and fall; people fall in and out of love; goals are met and missed. Life goes on.

I can promise you that in this new year, I will keep writing and look forward to meeting you back here down the road. I don’t have any profound advice for you when it comes to your life in this new year. Certainly, Oscar Wilde had it right when he said, “Be yourself; everyone else is already taken.”

And when it comes to managing life itself, the late Nelson Mandela was spot on when he said, “A good head and a good heart are always a formidable challenge.”

My thoughts? Be safe, take care of you, and remember to live. And may 2014 be a wonderful year for you and your loved ones.

Peter S. Kahrmann is a writer and an advocate for people with disabilities.

Term Over, Bailey Still Fighting Injustice

By Janine Bertram Kemp

Michael Bailey, whose four-year term as president of the National Disability Rights Network ended on Oct. 22, went out with a bang.

Bailey, the first parent in the organization’s history to serve as president, initially became involved with NDRN when it was still called the National Association of Protection and Advocacy Systems. NAPAS was largely seen as a trade association. He paid his dues, joined the board of directors and worked his way up to the position of president because he had a dream. He wanted to change NDRN from primarily being perceived as an association of lawyers practicing disability law to a real and dynamic network of disability rights organizations.

And if the audience reaction to his final speech as president was any indication, Bailey successfully turned that dream into reality. After he outlined a history of civil rights struggles in the United States and placed disability rights and NDRN squarely in that context, he received a five-minute ovation. (Bailey will serve one more year, in the role of past president, on the organization’s board of directors.)

NDRN defines itself as “the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP).” Collectively, the P&A/CAP network is the “largest provider of legally based advocacy services to people with disabilities in the United States.” These member agencies advocate for the enactment and vigorous enforcement of laws protecting civil and human rights of people with disabilities.

Under Bailey’s leadership, P&As have moved from what was viewed as having an almost caretaking legal approach to being rights based. (While most P&As were paternalistic, there were a few that had a person-cen-
Term Limits

We remember...

holden to the gun lobby, which is bought and paid for by the gun manufacturers, members of Congress know they might lose their seat if they go ahead and save lives.

As for the sequester drama, consider this: It is pulverizing Meals on Wheels programs, cancer patients are going without treatment, and food stamp programs and housing subsidies are being slashed across the country. Even so, members of Congress rolled silken sleeves and passed a bill (some of it was handwritten) that brought air traffic controllers back to work because their absence was causing long lines at the airports. And here’s the kicker: Congress passed the measure two hours before they all left for a week’s vacation – two hours!

Without term limits, the carnage and greed and lust for power will continue on all political fronts. The greediest among the wealthy (with the backing of big business, big unions and other special interests) will continue to run the country.

Take a moment to consider the following four quotes; the authors will be identified at the end.

“It is to be regretted that the rich and powerful too often bend the acts of government to their own selfish purposes.”

“Experience demands that man is the only animal which devours his own kind, for I can apply no milder term to the general prey of the rich on the poor.”

“Nearly all men can stand adversity, but if you want to test a man’s character, give him power.”

“I tell you the truth, it is hard for a rich man to enter the kingdom of heaven. Again I tell you, it is easier for a camel to go through the eye of a needle than for a rich man to enter the kingdom of God.”


One need look no further than the recent vote on universal background checks (it would have passed with flying colors if members of Congress put the safety of the American people ahead of their lust for power) and the coming of the sequester to realize members are willing to sacrifice American lives so they can stay in office.

Imagine what would happen if members of law enforcement, firefighters and other first responders took that approach to their jobs.

Adrienne Asch (Sept. 17, 1946 – Nov. 19, 2013). Asch, an internationally known bioethicist, scholar and leading voice in the disability community, died in Manhattan. According to Randi Stein, a longtime friend, the cause was cancer. She was 67.

Asch was director of the Center for Ethics and the Edward and Robin Milstein professor of bioethics at Yeshiva University in Manhattan. She also held professorships in population health and epidemiology and in family and social medicine at Yeshiva’s Albert Einstein College of Medicine.

Asch was trained as a social worker, philosopher, clinical psychotherapist and social psychologist. Her work transcended many fields, including bioethics, disability studies, reproductive rights and feminist theory.

“She certainly was one of the pioneers in disability studies,” Eva Feder Kittay, a distinguished professor of philosophy at Stony Brook University and a colleague of Asch’s, said in an interview. “She was a very strong voice, always bringing in the disability perspective, trying to change the view of disability as some tragedy that happens to someone, rather than just another feature and fact about human existence.”

Professor Asch’s scholarship centered on issues of reproduction and the family. In an age of advancing reproductive technologies, she found that those concerns dovetailed increasingly with issues of disability rights.

She maintained that the lives of disabled women should be as much a feminist concern as those of able-bodied ones. Disabled women, she argued, had long been doubly marginalized: first because of their sex, and again because they failed to conform to a collective physical ideal -- an ideal to which at least some able-bodied feminists subscribed.
When I was 10, my best friend Carla and I spent a lot of time in the branches of a favorite tree. Sometimes, we carried snacks with us as we climbed. Sometimes, Carla brought a book.

On those lovely summer afternoons, I remember her reading to me “The Story of Helen Keller,” a child’s version of the life of the renowned deaf and blind woman who had become a writer, speaker and humanitarian.

The manual alphabet, finger spelling, was in the back of the book and, together, we learned to form the letters. When school resumed that fall, we had a secret language.

My exposure to deafblind individuals in real life has been minimal. I have met many deaf people and many blind people, but rarely have I encountered anyone possessing both disabilities.

I have recently become more than a little immersed in the world of deafblind culture. In large part, that is due to my having become involved in teaching people to use the technology provided to them through the National Deaf-Blind Equipment Distribution Program, also known as iCanConnect.

There are an estimated 2 million Americans with this dual sensory disability, and because of one of the lesser publicized but truly remarkable components of the 2010 Communications and Video Accessibility Act, many of those individuals are finally being connected with the rest of us.

The CVAA mandates that the Federal Communications Commission allocate $10 million annually for the purchase of and training in the use of equipment to qualified deafblind individuals that will enable them to communicate with others. Qualifications are simple: A person must verify medically that he or she is both severely hearing and visually impaired and prove an income of less than four times the poverty level, currently about $45,000 annually for single-person households. Equipment purchased includes laptops, iPhones, iPads, amplified phones, signalers indicating the ring of a doorbell or phone, and more.

If this just sounds like a lesson in statistics to you, please read on. Even those of us who think we have a solid grasp on what it means to have a disability probably have something to learn. Let me introduce you to a few individ-

Before the final report of the federal Commission on Long-Term Care was even released, it was being criticized for taking a pass on the essential question of financing.

The legislation that contained the provision creating the 15-member commission (the American Taxpayer Relief Act of 2012), was signed into law Jan. 2, 2013. The commission’s charge was to develop a plan “for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals in need of such services and supports.”

But the commission was only given six months from the time it was empanelled to issue a plan.

Nine members were appointed by Democratic Party congressional leadership and the White House, and six members were appointed by Republican leaders. All members agreed that millions of Americans who need LTSS to live independently in their homes and communities don’t receive the help they need because they can’t afford it. Panel members agreed that the service-delivery system, with its heavy reliance on Medicaid, needs to change. But when it came down to financing, the members could reach no consensus on how to pay for it all.

Before the full report was released on Sept. 30, a summary of the final recommendations was released by the commission on Sept. 13. In a statement expressing appreciation for the efforts of the commissioners, Nancy LeaMond, AARP executive vice president of social impact, said: “Regrettably, agreements on comprehensive long-term-care financing could not be reached in the short time the Commission had to do its work … Every night, families are discussing these tough issues at their kitchen table. It’s time to bring that conversation into the spotlight and take action.”

Sen. Jay Rockefeller (D-W.Va.) also issued a statement in which he said: “We have a moral obligation to make sure that all people who need access to good, quality health care and supports can obtain the services they need that are both affordable and sustainable. So I must express my disappointment that the Commission was not able to more broadly address a key issue of affordability … Because this system must work for everyone. That must be the focus of future deliberations.”
too. We had a lot of help. A lot of them weren’t for it [the ADA]. Many of them were on the fence. They had heard from some people back home -- about elevators and other problems, [people] who didn’t have access. That’s a principal part of the bill. If I’m in a wheelchair and can’t get into a restaurant, then that’s a problem. We were contacting these undecided people personally. That made the difference.

**Q:** You were going to talk about the other legislation that you worked on?

**A:** Just generally. I was in the Senate for 28 years. I supported IDEA and a bill to provide an aide to totally disabled persons. That is what I remember specifically. Because I have a disability, I did a lot of work for people with disabilities.

**Q:** Why is disability a bipartisan issue? It seems to affect everybody and their families.

**A:** I was determined to make it bipartisan. You’re right. It affects not just the disabled person, but families, the workforce -- whatever he’s [or she’s] involved in. I think more Democrats than Republicans voted for it [the ADA]. But [the ADA] was still solidly bipartisan.

**Q:** Why should the United States ratify the United Nations Convention on the Rights of Persons with Disabilities?

**A:** In the first place, every other major country has done it. We’re in the process now of getting ready for a second try at it. We’re five votes short. Again, we have a lot of undecideds.

**Q:** So you’re working the undecideds?

**A:** Oh, yeah! I think the two Georgia senators who voted no are now voting yes. We’re picking up two votes, but we still need five. We think we have nine that are possible. If we could get five of those nine! The homeschoolers have this theory that if we [ratify] this, the U.N.’s going to take over the children or the school curriculum -- which is certainly not the case. Harry Reed, the Majority leader, said he would bring it up when he had the votes. He’s been very cooperative.

**Q:** The opponents feel that if we ratify it, the U.N. will take over the schools.

**A:** It’s the sovereignty issue. [But] all it would do is protect Americans with disabilities when they travel overseas. It wouldn’t cost anything. We wouldn’t have to change any laws.

**Q:** Would you talk about the Affordable Health Care for America Act?

**A:** I don’t know what’s going to happen to Obamacare. I think it’s in real trouble. But any [health care plan] should have a provision to take care of pre-existing conditions and people with serious disability.

**Q:** How can we help the veterans with disabilities who’ve come back from Afghanistan and Iraq?

**A:** We’re doing pretty well helping the veterans. Their families need help. Particularly, they need somebody to care for the veterans. My wife is working on a project to provide caregivers to seriously disabled veterans.

**Q:** Do you have any advice for young people with disabilities?

**A:** Never give up. Because you never know when something’s going to come along that could be ... helpful. You gotta check state, local and federal laws to see if you qualify [for programs or services]. If not, you need to contact both your congressmen [or women] and your senators to see if they can draft legislation, because there may be a lot of people in that category.

**Q:** Have things changed for people with disabilities since you were injured in the war?

**A:** In the last 50 years, there’s been tremendous advances in medicine -- they treat someone with a disability as soon as they can instead of keeping you in the hospital for months and months.
Professor Asch supported a woman’s right to an abortion. But in her lectures, writings and television and radio appearances, she argued against its use to pre-empt the birth of disabled children. She argued likewise for prenatal testing.

In a 1999 article in The American Journal of Public Health, Professor Asch laid out her philosophy.

“If public health espouses goals of social justice and equality for people with disabilities -- as it has worked to improve the status of women, gays and lesbians, and members of racial and ethnic minorities -- it should reconsider whether it wishes to continue the technology of prenatal diagnosis,” she wrote. “My moral opposition to prenatal testing and selective abortion flows from the conviction that life with disability is worthwhile and the belief that a just society must appreciate and nurture the lives of all people, whatever the endowments they receive in the natural lottery.”

She also was a highly sought-out speaker.

“We were privileged a couple of years ago that she participated in our Jacobus Ten Broeck Disability Law Symposium” concerning ethics, said National Federation of the Blind’s director of public relations Chris Danielson. “(Professor Asch) was debating another ethicist named Dan Brock about the morality of bringing a disabled child into the world. Dr. Asch was always firmly on the side of disabled people, including unborn disabled children, having full rights and dignity. We respected her point of view and supported her point of view.”

At the National Disability Rights Network’s annual meeting in 2012, Asch was invited to comment on the case of a 6-year-old girl with multiple cognitive and physical disabilities whose parents had removed her sex organs and stunted her growth with hormone treatments. The practice is commonly called the Ashley Treatment, after the first known child to undergo this procedure.

“Some ethicists said it was OK to abort a baby with disabilities,” said Curt Decker, NDRN executive director. “(Professor Asch) took a strong stand on protecting the integrity of children with severe disabilities.

“Adrienne took this position that this is not something that could be supported through a discussion of ethics. She was someone who would make sure the disability community would view these disability cases in the proper light.”

In an interview conducted in 2006 by Anna Kirkland at the University of Michigan, Professor Asch said: “My parents taught me to think for myself and to be comfortable with who I was, even if people around me weren’t entirely comfortable with who I was, either as a left-wing type or somebody who loved classical music, or someone who was Jewish, or someone who was blind. So they just taught me to be myself.”

Adrienne Valerie Asch, born in New York City, was a premature baby who lost her vision to retinopathy in the first few weeks of her life. When she was a girl, her family moved to New Jersey, then one of the few states that let blind children attend school with their sighted peers. She attended public schools in Ramsey, in Bergen County.

After high school, she attended and graduated from Swarthmore College with a bachelor’s degree in philosophy in 1969. But she found employers unwilling to hire her -- an experience, her associates said, that made her keenly aware of disability as a civil rights issue.

In 1973, after earning a master’s degree in social work from Columbia, she spent much of the rest of that decade and the next working for the New York State Division of Human Rights, where she investigated employment discrimination cases, including those involving disability.

She was trained as a psychoanalytic psychotherapist in the 1980s and maintained a private psychotherapy practice throughout that decade. In 1992, she received a Ph.D. in social psychology from Columbia.

Before joining the Yeshiva faculty, Professor Asch taught at the Boston University School of Social Work and at Wellesley College. Her publications include two volumes of which she was a co-editor: “Women With Disabilities: Essays in Psychology, Culture, and Politics” (1988, with Michelle Fine) and “Prenatal Testing and Disability Rights” (2000, with Erik Parens).

Professor Asch is survived by a brother, Carl, and a sister, Susan Campbell.

Bill Porter (Sept. 9, 1932 -- Dec. 3, 2013). Porter, an Oregon door-to-door salesman who plied his trade for decades despite having severe cerebral palsy and whose story inspired an Emmy-winning television film starring William H. Macy,
the family of the driver who slammed into Edwards. Currently, Edwards has some movement in the two smallest fingers of his left hand, but he has begun to lose some vision in his right eye.

“I take painkillers every day,” he said. “I spend about $1,200 a year on pain medications. In the United States, I would spend more than ten times that much. That’s criminal.”

Edwards, born in the Binghamton, N.Y., metropolitan area, lives in Toronto and is considering becoming a Canadian citizen. From the day he was given his first computer, Edwards has been fascinated by how websites are designed. When he was 19, he enrolled in Sessions College in Tempe, Ariz. He graduated when he was 22 with a degree in Web page and website design.

While in college, he earned money designing websites for his classmates. “I earned thousands and thousands in cash,” he said.

He familiarized himself with database design and scripting, programming, Web page and website design, graphic design, and digital media production and publishing.

“Web development is a growing field that will only grow larger as the Internet continues to expand,” Edwards said.

Edwards believes the Web is increasingly touching new areas of our lives -- from online shopping to entertainment and social media. He believes that Web development is challenging and will help designers improve their visual creativity and multimedia communication skills.

Edwards estimates that in six years, he has built more than 100 websites. His clients, all of whom learned of his skills through word of mouth, include hospitals, restaurants, schools, small businesses and law firms. His annual income exceeds $150,000.

Edwards uses a variety of technologies daily for his work, including a handheld digital tape recorder for his meetings. He likes the voice quality, its 500 hours of recording time, its smallness and the fact that he can have a minimum of five interviews on it -- each one under its own folder.

To remotely view his clients’ websites, he uses a TV with a 44-inch screen. “The large screen compensates for my vision loss in both eyes.”

That is quite a legacy for Bailey. Yet leadership is never about one person. Sometimes it means someone with strong values who is in the right place at the right time to guide a community into actualizing an idea whose time has come.

When it was known as NAPAS, NDRN was often seen as doing little more than raising funds to perpetuate itself because so many state P&A groups acted in a paternalistic or ineffective manner. NAPAS became NDRN in 2005, and Bailey became its president in the fall of 2009. Around the same time, there was a dramatic change in the strength and forcefulness of NDRN’s investigations and reports that has remained consistent throughout Bailey’s tenure.

Bailey was a successful defense attorney in Portland, Oregon, who had been part of the legal team for the American Indian Movement (AIM) at and after the Wounded Knee encampment in 1973. He had a long history of progressive politics and supported the principles of Native American sovereignty, coupled with a commitment to due process and peace.

Fifteen years later, when Eleanor, his first child, was born on April 2, 1988, with a diagnosis of Down syndrome, he wrapped up his law practice and stayed home with her. (Eleanor Bailey, now 25, is a respected advocate in her own right.)

“Eleanor’s birth was presented by others as a tragedy,” Bailey said. “I knew nothing about developmental delay. We had a great year together. I had a wonderful time. Because I knew nothing about developmental disabilities, I thought nothing was wrong with her. I still feel that way. All the difficulties in Eleanor’s life had nothing to do with Eleanor and everything to do with discrimination, unfairness and the tyranny of low expectations.

“I have to fight unfairness and discrimination. It seems evident. I did not have to read the great disability scholars like Paul Longmore to learn this -- it was just common sense.”

When Eleanor was “3 or 4, … I started to see her as part of the disability industrial complex, and that was just ass backward. It’s truly wrong that the industry has all the power.
any lasting friends in grade school.

“I thought I was a freak. I hated my stuttering. I hated being laughed at. I became my own best friend. A strong bond developed between my brother and me.”

High school initially was worse than grade school. His freshman year was one that he will always remember. He was picked on by students in higher grades. Upperclassmen, he said, would walk up to him, stutter on purpose and then laugh.

“My stuttering was atrocious,” Carson said. A major hurt occurred when he tried out for the debating team. “The debating coach looked at me and asked: ‘Are you serious? Get out of here. Don’t waste my time.’”

As a sophomore, two events happened that affected his life. The first was when he met Janice Martin, a speech therapist who agreed to work with him. With reluctance, he agreed. She worked with him until he graduated from high school.

“Tommy’s attitude about his stuttering changed for the better,” Martin said. “During his last year, he started to get control of his stuttering, and that produced the major change in Tommy.”

Tommy started studying harder and showed an aptitude for math and science. He began stuttering less.

The second event was the development of his athletic ability. His sophomore, junior and senior years, he played mostly left and right field for his varsity high school baseball team.

His batting average was .325, and he hit nine home runs each year. The biggest thrill of his career was when he helped pull off a triple play in his junior year. It was the first and only triple play in his high school team’s history.

One of his regrets in high school was never going on a date. He was too embarrassed to ask a girl out.

When he entered Washington State University in 2001, he was unsure of his future. He found college life much different than high school; he was more accepted. When he stuttered, people did not laugh. When he tried out for the debating team, the coach encouraged him and pointed out that many successful people who stuttered achieved great things in life.

While in college, Carson made many presentations before his classmates. One of his classmates who went to high school with Carson said: “Tom was a different guy in college recently served. Names have been changed to protect privacy.

Maria, in her early thirties, has been both deaf and blind since age 10. Extremely fluent in braille and signed English, she had no experience with contemporary connectivity until the delivery a few months ago of her Braille Sense U2 through the iCanConnect outreach program.

I explained her new device to her through the interpreter. The method of communication is called tactile interpreting, because interpreter and deafblind individual are in constant tactile contact throughout the conversation.

I told Maria that by typing on the U2 and reading on its braille display, she can send emails, browse the Web, conduct Internet searches, read and write documents and more.

By the end of the first session, her unit was connected to her wireless network, and we launched her first Google search. I told her to click on one of the resulting links that leads to Wikipedia because it looked to me as though it would contain the information she sought.

“Wow!” she said. “A free encyclopedia! I want that!”

Her delight was palpable, as was mine, as I explained to her that she owns it, along with everyone else, and along with every other imaginable bit of information to be found on the Internet.

Before long, she was sending and receiving email messages to everyone she knows and driving me to distraction with her request to get a Facebook page established. We did, and she now posts constantly.

Then there is Michael. Born deaf, he always knew that someday his vision would fail as well because he was diagnosed in adolescence with Usher syndrome. Now 63, he has been blind and deaf for seven years. He only reads minimal braille (single letters with one finger), but it is now his link to the outside world.

Through the generosity of many, Michael received a braille device five years ago. Called the DeafBlind Communicator, it links a braille display with a simple cell phone and has en-
Henry Claypool, a wheelchair user who currently serves as executive vice president of the American Association of People with Disabilities, was a member of the commission. In an interview with Independence Today, Claypool said: “I was real dubious, and I didn’t think it was going to go anywhere. But this is one of those issues that isn’t going away.”

Claypool was one of the five commissioners who refused to go along with the majority view on financing. Those five issued separate recommendations.

“We really felt strongly that there’s a public responsibility,” Claypool said. “Instead of pressing the issue and losing support from Republicans that were not going to sign on to anything that clearly meant new spending, the majority just kicked that can down the road.”

The final report outlined two differing financing philosophies of the commissioners.

The first philosophy took pretty much a total market-based approach, calling for deregulation, changes in tax laws and other measures to make it easier for individuals to purchase insurance and to save to pay for their own future LTSS costs. For example, one idea called for allowing seniors to use reverse mortgages to fund their LTSS needs.

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We Remember Continued from page 9

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A successful door-to-door salesman must be able to drive, walk and, especially, talk. Porter did not drive and had great difficulty walking and talking. But because of his friendliness, tenacity and charm, he was for many years Watkins’ top salesman in the region that encompassed Oregon, Washington, California and Idaho.

Porter came to wide attention in 1995, when he was the subject of an article in the Portland newspaper The Oregonian. A profile on the ABC newsmagazine “20/20” soon followed, and Macy, who saw it, was moved to start work on a biographical screenplay.

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William Douglas Porter was born in San Francisco to Ernest and Irene Porter; a birth injury left him with cerebral palsy. When he was a youth, the family settled in Portland, where his father sold signs to local businesses.

After graduating from high school, Porter was deemed unemployable by the state. Although it offered him disability benefits, Porter declined the money.

Encouraged by his mother to pursue a sales career, he applied to the Fuller Brush Co. but was turned away. The Watkins company also turned him away, until Porter, making his first successful pitch, persuaded them to give him their most inhospitable territory in Portland.

He covered it by foot, taking the bus as close as he could get before disembarking to walk his route — eight to 10 miles a day. He had the use of only one hand; in it he carried a briefcase filled with pictures of his products. A traditional sample case would have been too heavy.

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Working on commission, he put up with countless slammed doors and braved all kinds of weather. Slowly, the orders came, for soap and spices and dog biscuits. When the products arrived, his mother delivered them by car. When his mother could no longer handle delivery duties, Porter hired Brady.

According to Brady, who had worked for Porter since 1980, her boss might bring in $300 or $400 in his best weeks. In 1997, after being hit by a car while headed out to his rounds, he began to sell his products by telephone.

Once, in the late 1990s, Brady was witness to Porter’s sales skills. The two were attempting to fly to a speaking engagement in Canada, but Porter had no photo ID and was barred from boarding. Porter, eager to make the next flight, had Brady drive him home, where the two searched for and finally found his baptismal certificate and then raced to the Department of Motor Vehicles. A clerk, who recognized Porter from local news coverage, fast-tracked his application for a nondriver ID. In a matter of minutes, Brady said, Porter had his ID card and had sold the clerk a large tin of cinnamon.

Porter, a longtime resident of Gresham, near Portland, had no immediate survivors. He had long considered Brady, her husband, and the couple’s six children and six grandchildren as family.

-- Compiled from various sources
Deafblind

abled Michael to send and receive email and text messages. Because the equipment is old and degrading, iCanConnect has provided him with a more current technological combination of an iPhone and Braille Sense U2.

There is a steep learning curve with iOS devices for anyone. (iOS stands for iDevice operating system, the primary control program in the Apple iPhone, iPad and iPod touch.). But it is even harder for someone who can’t see the screen or hear the voice prompts. The user is instructed to type certain combinations from the keyboard and trust that they will appear on the phone. Another set of keystrokes sends the message. But when it fails – and technology will always fail sometime – you are without communication with the outside world until you understand how to remedy the situation.

Some of the people I teach have enough vision to read magnified text on large computer monitors. Some have enough hearing that they can hear my voice explaining how to use the equipment.

Like all disabilities, in other words, each individual is as different as the proverbial snowflake – different in terms of identity, and different in terms of the nature of vision and hearing difficulties.

The individuals served by this program are children, teenagers, young adults, baby boomers and the elderly. Their technological needs and abilities vary, as do their communication and information aspirations.

For one woman, her greatest joy was finding that, with her new braille equipment, she could read the weather status before setting foot outside. Simple, perhaps, but if you can’t see the sun out your window or hear the rain on your roof, reading about weather conditions from the safety of your own living room is incredibly liberating.

Another recipient is returning to college and will be using her equipment to communicate with professors and fellow students.

The interests of those served by the program range from Native American history and folklore to baseball, from early childhood education to law, from the environment to politics.

Two million is a big number and, as I stepped into this fairly unfamiliar circle, I reflected that I had not previously encountered deafblind individuals at other cross-disability conferences or meetings.

The reason is clear enough. If you are both deaf and blind, your greatest obstacle to independence may well be communication, and your greatest danger may be isolation.

The 2010 CVAA and iCanConnect are changing that—and the life transformations that are resulting are wonderful to observe.

Deborah Kendrick is a newspaper columnist, editor and poet. She can be reached at Kendrick.deborah@gmail.com.

Bailey

People in the business purport to believe ‘nothing about us without us,’ yet they violate that principle continually and put their own interests first. The loyalty is generally to the funding, not to the civil and human rights of persons with disabilities.”

“As his daughter Eleanor grew and progressed through school and into the world of work and adult life, Michael always partnered with her to see that she had the life she wanted and deserved,” said Marsha Rose Katz of Montana ADAPT. “As a team, they have been shining examples of what’s possible, and they have taught so many others, definitely ‘leading on,’ as Justin Dart would say.”

Katz is a longtime disability rights activist who has worked extensively in both the developmental disabilities and independent living worlds.

Before he joined the NDRN board in 1994, Bailey was hired as a temporary community organizer for the Oregon Council on Developmental Disabilities, which morphed into a full-time position that lasted until 2004.

During the period that he worked on the DD council, Bailey became active with TASH (formerly known as The Association for the Severely Handicapped).

“I met Tia Nellis, Marsha Forest, Jack Pierpoint, Steve Drake and Diane Coleman,” Bailey said. “And though I was a baby TASHie with no connections to anyone, all those people took a big interest in me. They went out of their way to connect and help me. Then I understood that I was part of a bigger movement than Oregon. I joined the federal interagency coordinating council for early intervention. At a meeting in D.C., I met Marsha Katz, who went out of her way to mentor me, to be kind to me.”

“I first met Michael at a TASH conference many years ago
Edwards uses voice recognition to produce reports, write emails and control the appliances in his office and apartment. He uses a low-vision product for reading. “Without a range of assistive technology products, I would be unemployed.”

It takes Edwards about four hours to build a home page and 80 minutes per page to build other Web pages. The work involves installing WordPress, uploading its theme and plug-ins, modifying its theme, configuring plug-ins, creating a custom header, creating and posting original content and managing ad placement. Additional time is needed for submitting the site to search engines, ping-ing, directory submission, social bookmarking and article marketing.

Edwards has two personal care attendants who are with him eight hours a day. One man works from 7 a.m. to 3 p.m., the other from 3 to 11 p.m. Edwards is in bed by 10:30 every night.

When developing a website, Edwards said, “The site must reflect the mission and activities of my client.”

For example, when building a website for a law firm, Edwards used videos showing the firm’s lawyers in court, in meetings and teaching. In building a website for a hospital, he used videos showing a vast range of medical procedures. In building a website for a church, he used videos and pictures to show its range of ministries.

Edwards, though, believes videos are not enough: Editorial content is extremely important to bring people back to the sites. He stresses the need to post content three to four times a week. As he builds each page, content includes text, videos, images, logos, emails and links.

Depending upon the client’s needs, Edwards always adds four weeks or more to the time frame to complete a job. This gives him time to run myriad tests and root out all the kinks.

Edwards has a dream of walking again, although he knows that will never happen. He is designing a website in Toronto for a company that sells wheelchairs. He intends to show several people beginning to use wheelchairs and later getting out of, and walking away from, them.

“I love science fiction, and showing people walking away from their chairs is pure science fiction. Still, we made it to the moon, and getting there was at one time science fiction.”

when I worked for a wonderful progressive ARC in Michigan,” Katz said. “I was immediately struck with the fact that we had the same values and fire and righteous anger. We are both a good deal older now, but we still often hear from others that we continue to possess those qualities.

“Over the years, Michael and I have realized that despite spending most of our lives on opposite sides of the country, we had a great many parallel experiences. I feel honored to know him and fight the good fight alongside him.”

Bailey left his position with the Oregon DD council when he realized it was using advocates as voices to perpetuate their own careers and budgets.

“After leaving I asked ‘advocacy for what?’ There is a difference between being busy and affecting social change. We spent a lot of time ‘educating’ parents. But that was very self-serving. The goal was not so much to create new and independent leaders as it was to create worker bees, as my boss called them.”

The goal was for families to come to the legislature and tell their stories, but the effect was unexpected. The state budget officer would make a projection on revenue, and the state Office of DD Services would announce the cuts and service reductions that the projection meant.

“We acted to protect the current budget and restore or prevent cuts,” Bailey said. “Bringing parents and a few self-advocates to the legislative table to talk to strangers about their most personal things and then weep copiously in public worked wonders. We always protected the programs. That meant that we had the same crappy system we started with.

“Oregon still lacks a cadre of advocates who know how to do selected confrontation, apply pressure and make changes,” Bailey said. “In my time in Oregon, there have been two strategic changes. One was the closure of Fairview, and the other was the Medicaid wait list (Staley) lawsuit.”

(The Fairview Training Center was a state-run facility for people with developmental disabilities in Salem, Oregon, administered by the Oregon Department of Human Services. It opened in 1908 and closed in 2000. The Staley Agreement settled a federal class-action lawsuit filed in 2000 by Medicaid-eligible adults with developmental disabilities who had spent years on long wait lists for services. The agreement was reached on September 11, 2000.)

“Both are the result of Disability Rights Oregon litigation,” Bailey said. “No one else at that time had challenged the system. My point is that the whole time, the DD council lacked a strategic focus that really would result in change. It took
Carson was accepted as one of the guys. His stuttering did not bother anyone. As a result, he stuttered less.

As a junior and senior, Carson played for the varsity baseball team. He hit .310 both years and had 12 home runs his first year and 14 his senior year. He was not, however, offered a professional contract. He did not blame his stuttering on that fact. “I was an average player and nothing else,” Carson said.

While in college, Carson had his first of many dates and his first of many kisses. And he resumed speech therapy. “The therapists worked well with me. They understood how damaging stuttering can (be) on a person’s ego.”

When he started therapy in college, he was stuttering 60 percent to 70 percent of the time. Sometimes his speech “blocks” lasted four to five seconds. Other times, they lasted 30 seconds or longer. Even so, Carson said he had an “I can do it” attitude.

“When he graduated from college, Tom was stuttering less than half as much as he was when he started,” said Marion Collins, a speech therapist from Boston.

“I knew that if I was going to make something of myself, I had to control my stuttering all the time,” Carson said.

College was a challenge for Carson. He wanted to be the No. 1 student academically in a class of about 2,000 students. He wanted to be a class leader. When he graduated in 2005, he ranked 170 in a class of 1,857 and majored in environmental science. He wasn’t a class leader.

While in college, he tried various methods of speech therapy. The methods consisted of speaking in a rhythm, hypnosis and then self-hypnosis, prolonging words as he started to speak, avoiding words he knew he would stutter on, singing some words, and memorizing his presentations. Though these efforts were successful with others, he still had problems. When he graduated, he was still stuttering, still angry, but still determined to succeed.

After graduation, he faced a major hurdle: He was jobless. During his last two years in school, he had more than 40 interviews but no job offers. He was convinced that he was being discriminated against because of his stuttering. But he was determined to find a job and be successful. Sixteen months after he graduated, he was hired to do research on the environment.

“I love my job, but I still feel discriminated against.” He claimed that he has not been given the same opportunities as his coworkers. “I am never asked to be a lead investigator on any project.” He blamed that fact on his stuttering.
approach “small ball.” “We took a stand that personal responsibility and just allowing people to save wasn’t really a financing strategy. We think a public option is an essential component.”

The alternative philosophy stated that a social insurance program must be “at the core” of any effective strategy for financing LTSS. This could be achieved, the report stated, either by expanding Medicare or by creating a new LTSS benefit program beyond Medicaid, which has harsh income and asset limits.

“We’ve got to stop punishing people by taking away their services when they make money,” Claypool said. “It’s un-American.”

ADAPT issued a statement criticizing the recommendation on other fronts. “We are deeply disappointed with the recommendations the Commission has released, which fail to address,” among other things, “Medicaid’s institutional bias in any substantive and actionable way” and “the need for affordable, accessible, integrated housing, which forces people to remain in institutions.” ADAPT’s statement went on to say, “If it doesn’t do anything else, this report reaffirms the need for fundamental change in the systems that provide long-term services and supports and demonstrates that people with disabilities cannot rely on others to advocate for such change.”

Nevertheless, Claypool feels that the commission’s work served a very useful purpose in rallying groups and individuals who care most about the issue to “push the conversation forward.”

In this regard, the commission’s report recommended that a national advisory committee be created to pick up where the commission left off and that the next White House Conference on Aging include discussions of LTSS.

If it reaches the point at which any significant federal legislation or policy transforming LTSS service delivery is put forth, the partisan debate in Washington as to how it should be structured and financed will probably reflect the debate among the commissioners.

Mike Ervin is a writer who lives in Chicago. His blog, “Smart Ass Cripple,” appears at smartasscripple.blogspot.com.

Q: Do you think people look at us differently now? Are they less afraid of people with disabilities?

A: Seventy years ago, a person would see somebody with a disability coming, [and] they’d cross the street. They didn’t know how to handle it. Now we treat people with disabilities like we treat everyone else. A lot of people praise people with serious disabilities for the fact that they’re working. They’re doing many things that a nondisabled person would do. I don’t see any discrimination. But the ADA, if there [were] any [discrimination], took care of it. They’re good people in the [disability rights] movement.

Q: Thank you, senator.

A: Goodbye.

Kathi Wolfe, a writer and poet, writes frequently on disability issues. Her most recent poetry collection, “The Green Light,” was published by Finishing Line Press.

When building a website, Edwards works with employees of his employer. He teaches them what he knows about building websites. “When the site goes up, they have to manage it. My job is done.”

Edwards wants to see people with disabilities employed as website builders. He sees thousands of job opportunities for them, and whenever he can, he encourages them to get a degree in Web building.

“If I can do it, anyone can.”

John Williams is a regular contributor to Independence Today. His website is www.atechnews.com.