QUICKIE WHEELCHAIR INNOVATOR, MARILYN HAMILTON IS ON A NEW ROLL NOW
I had planned to keep this secret. When I went through the experience I am about to share with you, I was determined never to tell a soul. Why? Because I was embarrassed and ashamed of myself. To a minor extent, I still am. But this column was named “Into the Light” for a reason: to bring things into the open that might otherwise be kept secret. And so, allow me to set embarrassment and shame to the side, and write.

I am sitting on the floor in the bathroom. The bathroom door is locked, and there is someone knocking on the front door of the house. I am terrified. I can't move. Intellectually, I know I am safe, and I know the person at my front door is my case manager, and I know my case manager is a truly caring and kind woman. But intellectually awareness has no influence at times like this; it simply doesn't count.

Other than moments of occasional trembling, I can barely move; standing up is, for the moment, not an option.

I had thought her home visit was at noon, and when she didn’t arrive I relaxed and figured something had happened, and she’d be calling to reschedule. When I see her car pull into my driveway shortly after three that afternoon, an internal switch flips on, and I am immediately in a state of terror.

More often than not, when I am caught off guard in life (someone arriving at my home unexpectedly being an example of this), fear kicks in. This time was no different. I rapidly locked the doors to the house and fled into the bathroom, locking the door behind me.

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Sitting on the floor with the half cup of coffee that was in my hand when she pulled into the driveway, I curse myself for not bringing a book with me. At least with a book I’d have some place to go, some place to hide. There is no way I’m opening the door.

Suddenly, the phone rings, and I know she must be calling me from her cell phone. The trembling increases.

Why the fear? a reader may understandably want to know. OK, I’ll explain. But understand: The explanation is not one that seeks sympathy or pity. The explanation, as you will see, is comprised of facts not of my making.
Wheelchair Innovator is On a New Roll Now

By Mike Ervin

Marilyn Hamilton was at the forefront of a quiet revolution. The Quickie-brand wheelchair is iconic today, but the first one manufactured in 1980 was hers. The lightweight frame was powder blue (she wanted it to be yellow) and was custom-built for her by two of her good friends who manufactured hang gliders. And the rest is history.

Before people such as Hamilton who rode in wheelchairs took a lead role in their design, wheelchairs were like those one-size-fits-no-one buggies that are used at airports. They were not intended to be pushed by the occupant. Imagine how much more burdensome life would have been for subsequent generations of wheelchair riders if that had never changed.

Maybe it’s inevitable that if Hamilton hadn’t revolutionized the wheelchair industry the way she did someone else would have -- or maybe not. Hamilton’s perpetually restless nature and deep curiosity are what propelled her through rehab and helped her adjust to a different kind of active life after her 1978 accident. She didn’t settle for making the best of limited wheelchair options.

The Quickie made her wealthy and celebrated, but she considers that chapter of her life to be well behind her now. At 63, she is ready to lead a new technology revolution of another sort.

She was injured on an August day when she stepped off a cliff in her hang glider in the Tollhouse Mountains in the California Sierras. She'd done it many times before, but this time she forgot to fasten herself in. She managed to cling to the bar of the glider, but that caused it to crash, and she broke her back (disc T12 of her spine).

But Hamilton had a distinct advantage that hastened her emotional recovery. His name was Bill Hamilton, uncle of her husband, Rick. Bill Hamilton had been in a wheelchair since he was injured in the 1920s.

“I was very grateful to have Uncle Bill in my life,” she said. He ran the packing operation of the Hamilton family’s lucrative fruit growing and packing business. “He went to work every day. He had family and help around him. You didn’t even notice his disability.” Bill was living proof for Marilyn Hamilton that even though she was a “jockette” in her previous life, there still could be many great days ahead.

“He said to me, ‘Hey, you’re bright, you’ve got a lot of energy. Find your passion. Don’t let anyone ever hold you back.’ I felt this enormous bond of hope because I really believe there are no coincidences,
Growing up, Sarah Triano was ashamed of having a primary immune system disability. "I tried to overcome my disability, to pass (as non-disabled), until my mom made me attend a California leadership forum for youth with disabilities," said Triano, who also has a mental health disability.

Today, Triano, 37, executive director of the Silicon Valley Independent Living Center, is glad that her mother insisted that she take part in that forum in 1992. "There, I was introduced to role models in the independent living movement," recalled Triano in a telephone interview with Independence Today, "and developed a sense of dignity and pride about myself and my disabilities."

During the next decade, Triano became the mother of what is now a burgeoning disability pride movement. In 2002, as a youth team leader with Access Living, a Chicago independent living center, she worked to recruit young people for a leadership program for youth with disabilities.

"We found that they were ashamed of their disabilities -- that the youth tried to avoid contact with people with disabilities."

From this experience, Triano said she realized that "one of the biggest problems that people with disabilities have is not being proud of a fundamental part of who they are."

If you have a disability, you're not taught in schools, in your church or the media to be proud of yourself, Triano said.

"You don't learn that disability is a natural and beautiful part of human diversity. The African-American civil rights movement couldn't have been what it was if black people had been ashamed to be black."

In 2003, Triano received the Paul G. Hearne Leadership award from the American Association of People with Disabilities. She used the $10,000 that came with the prize as seed money to fund the inaugural Disability Pride Parade, which was held in Chicago in 2004. The event succeeded beyond Triano's wildest dreams. "We were hoping 500 people would come," she said. "We had fifteen hundred people! We celebrated who we were and our shared history."

Janice Fialka and her son, who has a disability, were among those at the parade. In a poem titled "From Puddles to Pride," Fialka wrote about the parade: "On this street there are wheels rolling/lovely legs limping/ clenched fists raised high/ in the cloud-studded blue sky/.Our son, Micha/ whose label is not a source of shame to him/ who says...I meet the best people in the world."

In addition to Chicago, where parades have occurred annually, disability pride parades and ceremonies will be held this year in Philadelphia; Trenton, N.J.; Colorado Springs, Colo.; Mountain View, Calif.; and other cities in the United States, as well as in Norway, Ireland, Canada and other countries.

Curtis Cole, who has arthritis and glaucoma, is the executive director of the National Emancipation Association Inc., a Texas group that promotes the hiring of people with physical and mental disabilities. "Every year, we have a Juneteenth freedom festival and parade," Cole said in a telephone interview. "Disabled people said, 'Why can't there be a parade for us? We can enjoy it. We'll rock in our chairs.'" Organizers hope to hold a disability pride parade in Houston in 2013, Cole said.

Most disability pride festivities are held in July in connection with the anniversary of the Americans with Disabilities Act. There are a few exceptions. The New Jersey Disability Pride Parade will take place October 5th.

The first Philadelphia Pride event will be observed on July 28th. The festivities will include ceremonies at the National Constitution Center and a march to the Liberty Bell. During a special ceremony, the wheelchair that the late disability rights leader Justin Dart Jr. used when the ADA was signed into law will be unveiled. At the signing, Dart was flanked by then-President George H.W. Bush. Yoshiko Dart, Dart's widow, and Janine Bertram, widow of the late disability rights Evan Kemp Jr., will speak, and the photography of disability rights movement photographers Tom Olin and Harvey Finkle will be featured in an exhibition.

"Having 'Pride' in Philly, where there's so much history, is especially significant," Bertram, a disability advocate and writer, said in a telephone chat. "It celebrates us as part of our nation's history."

**Attendees at Disability Pride Parade**
We Remember...

Note: Fred Francis was the focus of a feature story in Volume 6, Issue 1 of Independence Today.

Frederick Lee Francis (November 12th, 1945 – June 13th, 2012), Francis, a longtime disability rights pioneer and activist, died peacefully at his home in North Scottsdale, Ariz. He was 66.

Francis was a dynamic force for change for people with disabilities, and his innovative ideas concerning both rehabilitation programs and centers for independent living greatly influenced many organizations across the country. His success with CILs in New York state was a model for people in the disability rights movement nationwide.

He was the youngest of three children born in Brooklyn, N.Y., to Ruth and Maurice Francis. After high school, he attended Long Island University, but “I didn’t apply myself,” he said in an interview with Independence Today earlier this year. “I was more interested in baseball than in studying.” He dropped out of college and worked with his brother at a Manhattan parking lot.

In 1965, he decided to return to school and enrolled at Brooklyn College of CUNY, the City University of New York. Two weeks into his first semester there, he was involved in a car accident on the New York State Thruway that resulted in the amputation of both of his legs.

He eventually resumed his studies at Brooklyn College, where he became acutely aware of a double standard. “People with disabilities were forced to go through medical examinations to show that they could not only do the work but survive,” Francis said. “There were no bathrooms for anyone in a wheelchair. Finals were held on the third floor of the gym, and there were no elevators. Blind students weren’t allowed to tape lectures (because) the professors were paranoid about being taped.”

Francis became so angered over the lack of rights and accessibility for people with disabilities that he cofounded a group called Student Organization for Every Disability United for Progress (SOFEDUP). When college administrators refused to seriously consider solutions to the problems that SOFEDUP had recommended, the group took over a faculty council meeting, Francis said.

“We wouldn’t let the faculty leave,” Francis said. “We had a meeting with the president of the college. Within six weeks, there were ramps. Blind students were allowed to bring tape recorders to class. They got rid of the medical examination requirement.”

In 1971, Francis graduated with a bachelor’s degree in psychology. In 1973, he earned a master’s degree in rehabilitation counseling from New York University. As part of his master’s program, he led a support group for people with disabilities, a new concept in that era. In 1977, he received a professional development certificate in rehabilitation management from the Rehabilitation Research Development Council of Cornell University’s School of Industrial Labor Relations.

During his undergraduate and graduate student years, he developed a reputation as “a militant activist,” Francis said. “I became involved in politics affecting the disabled outside the colleges and was asked to join a new organization called Disabled in Action (a group organized in 1970 by disability rights activist Judith Heumann).”

His first professional position, from 1971 to 1973, was as a vocational and career counselor at Hostos Community College in the CUNY system. He later worked at Abilities Inc., where he designed a national research and training program designed, he said, to “teach vocational rehabilitation counselors to be active and participate in finding their clients jobs.”

While at Abilities Inc., the New York State Education Department recruited him for an executive-level job as a division director in the deputy commissioner’s cabinet for Vocational Rehabilitation and Special Education Services. From 1978 to 1995, he served as the state Education Department’s division director for the bureaus of policy, evaluation, planning, research, interagency programs and independent living. From 1990-1995, he held the title of director of marketing and business and industry outreach.

As a New York state government official, Francis helped create and sustain centers for independent living by providing them with funds available from the Rehabilitation Act Amendments of 1973. The CILs, because of Francis, were able to provide housing aid, benefit assistance and other services to people with disabilities.

In later years, he taught at the CUNY graduate center’s Institute for Research and Development in Occupational Educational. He also taught and held research and development contracts at the U.S. Department of Education, New York state’s Office of Special Education and Rehabilitative Services, and the State University of New York at Albany, now known as the University at Albany.

In addition to his second wife, Julia, he is survived by his daughter, Ruth Taylor; sons Erik Myles (wife Susan), Brett Mitchell, William Wilkinson and Matthew Charles; granddaughters Amanda Marie, Madison Grace and Avery Brooke; sister, Barbara Cecil Kalt (nee Francis); and his nephew, Ronald Scott.

—Compiled from various sources
Confession: I’m an addict. If you flip on the TV remote or go on iTunes, you, too, will be hooked. What’s my obsession? “Push Girls,” a new TV reality show, featuring four hot women in wheelchairs, airing this summer on the Sundance Channel on Monday evenings at 10 Eastern and Pacific times, 9 Central time. (It’s also available on iTunes.) How to describe “Push Girls”? Think “Sex and the City” on wheels.

The 14-episode docuseries traces the lives of these outspoken and dynamic women who live in Los Angeles and, through accident or illness, became paralyzed. The title “Push Girls” doesn’t refer to people pushing the girls’ wheelchairs. These ladies push against stultifying boundaries. We see some of them drive and watch as some of the girls wheel themselves down steps. The slogan that they exuberantly shout out at the beginning of each episode says it all: “If you can’t stand up, stand out!”

As the series unfolds, we watch as the “girls”—Angela Rockwood, Auti Angel, Tiphany Adams and Mia Schalkewitz—date, dish about sex, navigate relationship drama and mother-daughter conflict; and contemplate whether to have children, job hunt, dance or shop. Along the way, they take 19-year-old wheelchair-user Chelsie Hill, who was paralyzed within the last two years, under their wings. I don’t dare leave out a dazzling ballroom dance competition or a high-heel buying expedition that would have made Carrie Bradshaw proud.

I don’t use a wheelchair. But being visually impaired, like many people with disabilities, I don’t see many TV shows (comedy, drama, scripted, reality—you name it) that feature characters like myself. When you see people like me on TV, they are usually either the butt of an insipid joke or depicted as living tragic lives. We’re sexless saints, grotesques or recluses who never see the light of day.

“Push Girls” is a breath of fresh air! When you imagine someone in a wheelchair, you think of somebody wearing dirty, “gross” sweatpants who doesn’t have sex, Tiphany says on the show. How refreshing to hear her add, “I have sex—lots of sex!”

Of course, life isn’t all dancing and sex for anybody, especially folks with disabilities, and the Push Girls don’t pretend that every day’s a day at the beach. Take Rockwood, who is quadriplegic, needs nursing care and is newly separated from her husband. Because of the separation, she’s dealing with financial issues (needing money to pay her mortgage) and health insurance concerns (her company won’t pay for her caretakers). To earn some money, Rockwood, who was a model before her injury, decides to try to beat the odds and get back into modeling. We watch and listen in as she calls modeling agencies. Yes, an agency is “wheelchair accessible,” a receptionist tells Angela, adding without a trace of irony, “there is a staircase.”

Tari Hartman Squire, CEO of Ein Sof Communications Inc., also is a fan of “Push Girls.” In an email to Independence Today, Squire, whose marketing firm specializes in disability-inclusive diversity and public policy, wrote that the show “illuminates critical issues facing millions of people with disabilities every day, such as personal assistance services … employment discrimination … diminished expectations … and mentoring.”

Fortunately, for our viewing pleasure, “Push Girls” isn’t the least bit didactic or boring. It deals with varied issues as part of the lives of women who eat, dance, celebrate and commiserate with each other. Viewers will see beautiful women and learn about the difficulties that many with disabilities encounter.

“But it is clear that the show is also just about four female friends who happen to use wheelchairs,” wrote Beth A. Haller, professor of mass communication at Towson University. “That is a disability narrative we haven’t seen on American TV,” added Haller, author of “Representing Disability in an Ableist World: Essays on Mass Media.”

I don’t normally like using the word “inspirational” in connection with people with disabilities because it has been so often used in a sappy, demeaning way. But I have to agree with Gay Rosenthal, the producer of “Push Girls,” who says in the press materials for the show that “watching the ‘Push Girls’ tackling life with spirit and confidence is not only inspiring but compelling.”

Rockwood and Adams, two of the Push Girls, took time out from filming the show to chat with me over the telephone. Unlike some reality shows, “Push Girls” isn’t cast or scripted, Rockwood said. “We really are best friends. It’s all about our stories. We shoot in real life. If someone walks in during a situation, they become part of the moment. Later, we’ll get clearance—ask the individual if we can use it (for the show).”
Product Review
Simplicity of ProxTalker Speaks Volumes for Users
By John M. Williams

One of my favorite educational philosophies is Keep It Simple Stupid! There is profound wisdom in the KISS philosophy. It implies that simplicity makes learning easy. I believe that making anything easy to learn is advantageous to individuals with intellectual disabilities. The ProxTalker (www.proxtalker.com) proves this.

ProxTalker.com LLC was founded in 2007 to design, manufacture and distribute the Logan® ProxTalker, a simple-to-use speech product that enables individuals to express themselves by simply placing a tag on a button and pressing down. The inspiration behind the development of ProxTalker was engineer Glen Dobbs’ son Logan, who is autistic. Dobbs’ goal was to help Logan express himself verbally. Dobbs knew that for his son to use the ProxTalker, Logan had to understand a cause-and-effect relationship between himself and the device.

Dobbs certainly had KISS seared in his memory when he and his engineer colleague Kevin Miller developed the ProxTalker. One can use it by simply placing a tag on a button and pressing down. A voice speaks the word on the tag. For example, if the word on the tag is food, “food” is spoken. If the tagged word is hello, then “hello” is spoken. It is as simple as that.

Before I received the ProxTalker for review, I was skeptical of its claims. But my skepticism was misplaced. I had it working in seconds: I was almost immediately hearing individual words, then phrases and then sentences.

The ProxTalker has five buttons that can be used individually or sequentially. All I did was pick a tag with a picture on it with an identifying word under the picture, place the tag on one of five buttons, and press. I had my choice of 80 tags. Initially, I picked food tags – apple, banana, chips, fish sticks and cookies. Each word was clear. I thought to myself, "Wow. This is easy." As I expanded my use of the tags, I saw benefits not only to people with intellectual disabilities but those with a range of verbal disabilities (such as stuttering, lack of articulation and voice disorders) and victims of traumatic brain injuries and strokes.

After a while, I started making sentences. My first was, "I want apple juice." Next was, "I want to take a walk." A third sentence was, "I want to play." And another was, "I...
and him being in my life was quite a blessing. I was able to make the switch early on and put all my anger and energy into how I can make it better."

She didn’t return to her previous job of teaching high school. She worked instead with Uncle Bill in the family business. She hated her clunky Everest & Jennings and Stainless wheelchairs. “It was hard to imagine me in this stainless steel dinosaur and being active.” So she approached her friends Don Helman and Jim Okamoto and said: “Come on! Make me a wheelchair. You’ve gotta help me. You can’t leave me here.”

She wanted a chair that was maneuverable, versatile and fashionable. The first Quickie was built in a Fresno, Calif., garage. When Hamilton hit the wheelchair sports circuit in her new device, she could tell by the tremendous enthusiasm it generated among others that the demand for a radical new chair would be enormous.

So Hamilton convinced her two friends to join her in business, and by 1986 they were doing $21 million in annual sales. That year, Quickie merged with Sunrise Medical.

Hamilton worked for Sunrise until 2006, but she wasn’t the same driving force in the company. Sunrise still makes Quickie, and it is still Hamilton’s chair of choice. “I’m forever indebted to Jim and Don for coming to my rescue,” she said. “I had a wonderful support group around me that allowed me to struggle. That was the foundation of what allowed me to think outside of the box.”

The wheelchair market was mired in a “slump of status quo,” Hamilton said, before she and other wheelchair riders shook things up with new designs. What made Quickie a different company, she said, was having their “ear to the ground” and letting the demands of active chair users drive innovation.

“For me, the excitement as an entrepreneur is change -- creating change -- and looking for what’s next.”

Today, she serves on the board of Ekso Bionics, a company that builds exoskeletons to help disabled people walk. “I wanted to take a look at what people needed in their lives today. Today, I think the challenge is helping people stay as healthy as possible immediately at the time of injury from a technology point of view.” She hopes that someday exoskeletons will help people in rehab become and stay active and healthy, just as the Quickie did. “Walking isn’t everything, but it is part of recovery. It’s just unacceptable to only exercise the parts of your body that work.”

Hamilton also has launched Stimdesigns, a company so fledgling it doesn’t yet have a website. The goal is to develop and bring to the U.S. market whole-body vibration technology. She thinks this technology also holds great promise for helping disabled people regain and retain maximum functioning and maintain good health.

“It’s important that we let people know that it is important to try to combat some of the things that come with aging. When trying to stay healthy, there is technology we could be using. It’s just a shame that we don’t have affordable technology that can help us. To me, it’s unacceptable. I’ve found that my real love is technology and doing things no one else would be willing to look at. The technology is here, and I want to be (in) the forefront of that.”

Hamilton has turned to a new chapter in her personal life, too. She divorced Rick, her high school sweetheart, many years ago. But seven
Bertram, who noted the depressed economy and the fact that many services for people with disabilities are being cut, said, “There’s so much that we need to protest that it’s important for us to celebrate and affirm who we are.”

Everybody either has a disability or has a family member or friend with a disability, Yoshiko Dart said in a telephone conversation, “yet in our consciousness is this feeling that disability is something awful – to be ashamed of.”

Pride events help people realize what her late husband always said, “that disability is a natural characteristic of being human,” Yoshiko Dart said.

The Alliance Center for Independence decided to hold its first New Jersey Disability Pride Parade in 2011 after the organization took two members of its young adult group to a conference, said the group’s executive director Carole Tonks. “There, they saw a video of the Chicago Disability Pride Parade,” she said. “The young men said, ‘Wouldn’t it be great if we had one?’”

There was no political agenda, Tonks said. “It was just like Italian Americans or any other group celebrating who they are. My 27-year-old son has autism. As his mom, I was proud to see him celebrate.”

Colorado Springs, Colo. held its first Disability Pride Parade in March 2012 as part of that city’s St. Patrick’s Day Parade. Seventy people with disabilities and their supporters marched as a group, Patricia Yeager, CEO of the Independence Center in Colorado Springs, wrote in an email. “It was the most fabulous thing … people who look, walk, talk and see differently being cheered for being ourselves,” she wrote. “Talk about a kick in the pants and being a part of the community for a group who often doesn’t feel like a part of the community.”

Byl Adam is a member of the Disability Pride Parade Planning Committee in Chicago. In 2010, Adam, a Street” actor Dustin Nguyen. “So I was used to being recognized,” she said. “But people in L.A. are respectful of celebrities.”

It feels good to be inspiring people, Rockwood said. “I definitely wanted to make the ignorance and stereotypes around women with disabilities fade away.”

If you know people watch you, you should embrace that, Adams said. “You get further by being sweet than by being sour. When you take off the masks, you see that all human beings are connected. You separate the superficial – the exterior – (from) what’s inside.”

Labels box people into categories, added Adams, who dislikes being defined by labels. “If I date a woman, society feels more comfortable putting me into (the) category ‘bisexual.’”

A good actor learns to listen in acting class, said Rockwood, who is trying...
However, I am responsible for managing their role in my life to the best of my ability.

I was shot in the head at point-blank range in 1984, and a bullet is lodged in the frontal lobe of my brain. The damage from the bullets hinders the very areas of the brain that are designed to help me (or anyone) manage fear, threat, and so on. I also deal with PTSD (post-traumatic stress disorder), which, in a nutshell, is an emotional disorder that results from a trauma out of the norm.

And so, in the bathroom I am flooding, meaning there is excessive neurological activity going on, and the part of my brain designed to calm this activity does not work because of the damage. The PTSD merely exacerbates the situation.

Sitting on the floor in the bathroom, I know all this. But as I said, knowing something does not, in and of itself, serve to free you from it. Knowing does, however, serve to remind me that I am not my enemy. In this moment, I am not my opponent. My opponent is the rather merciless tandem of brain damage and PTSD.

An hour has passed and, other then opening the bathroom door a sliver on two occasions, I can’t leave the room. By this point, I’ve come to fully recognize the emotional condition I’m in. I am feeling exactly what I was feeling when the kid held the gun against the side of my head moments before he fired.

I am frozen.

I wonder if my case manager will call the police, and will they break into the apartment and then break down the bathroom door and find me here, a quivering mass of fear and, needless to say, embarrassment and shame.

I decide I’ll wait until she leaves and then make up a lie so no one will ever know about this. For some reason I don’t understand (then or now), I believe people will be angry with me if I tell them about this.

And so, I decide, I will lie. Sure, my car is out front. But I’ll just say I was down the road helping a friend, or maybe I’ll say a friend dropped by and we’d gone out together. No way on earth will I tell a living soul what really happened.

Then I remember something. I remember reading that when someone is going through an anxiety or panic attack, the brain withdraws blood from the frontal lobe (exactly the place in your brain you’d want to have blood at a time like this) and gathers it in the brain’s center. If you engage in a cognitive task such as playing solitaire or conversation or counting out loud, you force the brain to move at least some of the blood back into the frontal lobe. While this might not fully free you of the hell you’re in, it may well prevent it from getting worse and maybe, just maybe, make things a little better.

And so, sitting on the bathroom floor, I begin counting out loud. After a while, I realize this must be helping me at least somewhat because I notice I am feeling foolish for counting out loud, and it is not lost on me that I’ll take foolish over terror-stricken any day.

More than two hours pass before I am able to leave the bathroom. My case manager is no longer outside. I sit down in my reading chair. As the terror finally lifts, a deep sadness takes its place, and, for a time, I cry. I don’t mind. There is comfort in it.

Slowly but surely, I grow back into feeling safe again.

The next day, my case manager called me. My plan to lie to her lasted a split second. Instead, I told her the truth and, in doing so, was met with understanding and compassion. She was not at all angry, just very glad I was OK. I received the same deeply welcome response from the few close friends I shared this experience with.

And so let me say to those of you who’ve had and have similar experiences: You are not alone. It is very likely that those who truly care about you will respond with kindness and compassion should you bring your suffering to their attention. I shared this experience from the few close friends I deeply welcome response to.

“Then they tried to back us into a corner and silence us by pretending we were similar to greedy corporate providers. If Bruce Darling had not been an absolute pit bull on challenging these regulations, we would have had no chance of amending these DOL rules. This is a David versus Goliath struggle, and we are challenging the power of the national labor movement.”

The Labor Department, Kafka continued, “is totally ignorant of how rate setting is done in state Medicaid programs. If there will be increased costs because of these rules, there is no guarantee that states will pick up these additional costs, and in all likelihood, (they will) cut services. The ultimate for instance involves overnight hours.

DOL is throwing a bone to the SEIU (Service Employees International Union), Professional Health Institute (PHI is the policy arm for most unions) and the Direct Care Alliance (DCA). ADAPT has been in discussions with SEIU for decades, and its national organizer, Bob Kafka, is on the DCA advisory board.

“OK. I received the same angry, just very glad I was passion. She was not at all understanding and comp-Received the same angry, just very glad I was passion. She was not at all understanding and comp-
Q: What is remote CART?

A: Remote CART is where we stream this text to the Internet. We do not need to be in the same room as the speaker. We could be listening via a telephone, a speakerphone or an online program like Skype. We establish our audio source, make sure I can hear appropriately, and then send the text to make sure the person can read it, and then we proceed. We have provided this service to people who were present at a convention in Africa! They received the text via the Internet and used a computer and projector to display the text to the room full of people. That helps everyone in attendance understand English spoken with different accents.

We do provide court reporting services to attorneys. This is the original profession from which the others were born. That is why we are so fast and accurate. We use the “funny little steno machine with no letters on the keys” that everyone may have seen on TV or if they had a chance to see one in a deposition or court. I specialize in real-time court reporting, which means the attorneys can read the words that are being spoken on laptops in front of them.

Q: How often are your services needed?

A: We fortunately are not on a 24-hour-a-day schedule yet, but we do not work a typical 9-to-5 schedule, either. We tend to work seven days a week, including holidays such as Christmas and Thanksgiving Day for our captioning customers. Think about it: Do TV stations shut down programming on holidays? No. Then their programs, especially live news, still need to be captioned. That means more opportunities for captioning!

Q: Who benefits from your services?

A: We have many different users of our services. First and foremost are those with hearing loss. From high school students with hearing loss who want to learn a foreign language -- we have provided Remote CART for French, Latin and Spanish classes -- to college or university students to senior citizens. The only requirement is that they can read, so our services would not be very helpful for children in preschool to probably third grade.

Our second audience tends to be those for whom English is not their first language. Research has proven that captioning helps ESL (English as a second language) learners improve their English by as much as 50 percent faster than those who do not use captioning.

Our third audience is people with normal hearing who appreciate having the transcript of the event or the captions as a “backup.” Sometimes rooms are noisy, people are rude and are talking while a speaker is addressing the audience, or a room has a poor sound system or acoustics. Captioning or CART helps people “hear” the message – or look back to the screen to see what they missed. Sometimes our mind wanders, and we can look back to the screen to catch up. We believe this service, therefore, will be helpful for those with ADD, ADHD or perhaps even autism.

Our fourth audience is usually someone who wants something transcribed in minutes rather than days. At 225 words per minute, we are at least twice as fast as the very fastest typists, and we can write for much longer periods of time due to the ergonomic design of our steno keyboard as opposed to the typical computer keyboard. We typically transcribe 60 pages an hour at normal conversational levels. As fast as you speak, we type. So we have helped quite a number of editors transcribe interviews for publication.

Q: What are your long-range plans?

A: With our app, we are going to expand our transcription business by making it even easier for the last group of customers to arrange transcription. We are going to expand and grow our court reporting side of the business to provide the most high-tech, real-time court reporting agency in northern Indiana. We hope to expand this side of the business to open offices statewide. Third, we aim to merge with or to purchase a couple (of) similarly aligned businesses to create a one-stop shop that offers all services related to our current service line. Fourth, we are in discussions with a company to become its first franchisee for the particular service it offers. Since nothing is finalized now, I cannot discuss it. It will create a brand-new line of business for us and enhance our high-tech court-reporting business.

Q: What potential clients would you like to have that you don’t?

A: Large, high-tech law firms that care about quality real-time court reporting services and, second, convention centers or convention planners who see the value in creating another line of profit for either themselves or their clients. For the second, we can provide transcripts, real-time streams of their speakers, captioning at the event, ADA accommodation – all for one service, but for which they can charge people or attendees separately. I most would like to work with people who think “outside of the box” -- high-tech people who could see applications of my services used in different, new ways. I would like to be the one who rides the beginning of the wave of new services rather than the one that only catches
the tail end of that wave. I would love a client who has a “Let's try this” attitude instead of a “It can’t be done” or “no one’s ever…” attitude.

And finally, I’d like to work with people who, instead of saying “We can’t afford to…” are willing to stop and say, “How can we…?" -- those who like to collaborate, who like to solve problems. Not having access to the spoken words that people with normal hearing take for granted helps level the playing field for those with hearing loss.

**Q: What are your greatest obstacles in getting new business?**

**A:** Lack of name recognition and not having a larger marketing budget, so we rely on the current word-of-mouth referrals that fuel our business.

And, sadly, many people with hearing loss do not even know about CART and how it can benefit them, especially as an ADA accommodation that they can request. So continuing to do demos of our service and get it in front of as many eyeballs as possible is challenging. And, third, many employers do not know that our service exists to help their employees with hearing loss. Hearing loss is the one disability we most likely will all experience as we age, so employers should know how to keep their best people performing at top levels, especially since an aging baby boomer generation plans to stay involved in some form of work for the long haul.

Last, the economy has not helped. Tight budgets affect behavior.

**Q: What technology do you use now, and how will it change in the future?**

**A:** All of my writers currently use steno machines. However, many people are now using our captioning software along with voice recognition (VR) software and using that as the “input device” to transcribing or captioning or providing CART services. However, very few have reached the same level of speed and accuracy steno writers currently are at. If this is perfected somehow, then we may be using VR more in the future. I also believe we will have many more apps to use and new ways to stream the captions to different devices. We currently can stream them to Smartphones and iPads. Who knows what the next decade’s devices will be? We use projectors and JumboTron screens. Technology could also change for the visual display of the CART text or captions. Hopefully, captions can be applied digitally soon and we can “retire” the old analog encoders most TV stations use today.

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**Pat and Tad: A Beautiful Defiance**

*By Peter S. Kahrmann*

I don’t know if the two men ever met. I do know I met each of them once. And I do know that each of them made an indelibly beautiful impression on me. I didn’t just like them both, I admired them both.

I also know that Patricio “Pat” Figueroa and Oakley “Tad” Hall III each lived with a disability and, like many others I’ve come to know over the years, each brought a beautiful defiance into play, not just in managing the disability they lived with but in managing a person or a society that sought to treat them as if having a disability diminished their worth and thus their equality. There is no such thing as freedom without equality.

I also believe both men died too soon. Pat died from complications from surgery on April 3rd and Tad died of a heart attack on February 13th, 2011. Pat was 63; Tad was 60.

First, some background:

Tad suffered a traumatic brain injury in 1978 when he fell from a bridge in Lexington, N.Y. At the time, the then 28-year-old playwright, director and author was the artistic director of the Lexington Conservatory Theatre and an emerging force in the New York theater scene.

Pat founded CIDNY (Center for Independence for the Disabled, New York), the first independent living center in New York state, in 1978, the same year that Tad sustained his brain injury. He was a fierce disability rights advocate and was the publisher of this deeply significant newspaper.

Pat was a wheelchair user -- the term wheelchair-bound needs to be permanently removed from the lexicon -- and although I couldn’t find the exact nature of his disability online, I don’t believe it is relevant anyway. What I will say is this: Pat was, like countless others, proof that one does not need to stand up to stand tall in life.

It doesn’t require an in-depth study of either man to quickly realize that both were tenacious in their commitment to their crafts. Tad’s brain injury did not stop him from writing and publishing “Jarry and Me,” a 2010 novel that blends the term wheelchair-bound needs to be permanently removed from the lexicon – and although I couldn’t find the exact nature of his disability online, I don't believe it is relevant anyway. What I will say is this: Pat was, like countless others, proof that one does not need to stand up to stand tall in life.

Writing a book is a herculean feat in and of itself. Writing one when you have a brain injury is herculean and then some.
ProxTalker
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want fluent speech." In all of those, the speech quality was first-rate.

To see if children could easily follow instructions and create their own phrases, I asked two boys, a 12-year-old and a 10-year-old, to do so. I showed them how to create the tags and asked them to create their own vocabulary. Following my instructions and then reading them, each boy created his own phrases and sentences effortlessly.

“This is no challenge,” said the older boy. He also said that the picture and the word underneath it helped him with his spelling. He was glad to know the ProxTalker could be adapted so he could carry it on his wheelchair.

“To easy,” the younger boy said. He thought the ProxTalker was too heavy to carry with him.

Both boys have mild learning disabilities. They told me they would use the ProxTalker in situations that required them to speak before their class. To them, the ProxTalker was a device that allowed them to communicate well and build confidence.

To learn how older adults would react to the ProxTalker, I took it to a senior citizen organization in Fairfax, Va., and demonstrated it before about 12 women and eight men. Women in their late seventies and older favored it more than men. They created tags dealing with medications, messages to their grand-

children, and messages that could be heard over the phone, such as, “Hello, Mary, this is Grandma.”

Eighty-one-year-old Miriam Gilliom said, “I love it because it’s so easy to use.” She uses a voice amplifier when speaking. She thinks she would not have to use the amplifier if she used the ProxTalker.

The women thought the ProxTalker was too heavy to carry. I told them it’s heavy because it was built to withstand being dropped on the floor, on the sidewalk or on other places with hard surfaces. It also is water resistant.

Many seniors recommended that the company print its materials in larger print. Nearly half of the seniors I spoke to said the ProxTalker could be useful to them.

To assist people with visual impairments, the ProxTalker provides large sound tags. To assist individuals with weak muscles, users can purchase a ProxTalker with light-touch buttons.

To expand my messages, I created my own tags. I placed a blank sound tag on a button and pressed and released the Record Programming tag on a button. I was prompted to record my thought. I did, and then I applied pictures to the tags.

ProxTalker’s simplicity does not end with the talking tags. The product is cordless. You do not have to turn the ProxTalker on or off. The power comes from four C size batteries that are easily replaced. A small Allen wrench accompanies the ProxTalker. A concisely written set of instructions accompanied by graphics shows how to replace the batteries. In fact, all the instructions are concisely written.

The ProxTalker has no dial to adjust the volume. To increase the volume on any ProxTalker button, press the Increase Volume programming tag; to decrease the volume, press the Decrease Volume tag. Most seniors did not like this feature. They wanted a volume control as part of the hardware.

Dobbs and Miller developed a unique and durable communication product to address the communication needs of Logan Dobbs. In doing so, they created a versatile, valuable, easy-to-use communication tool that can be used by individuals with a variety of speech disabilities of all ages. They have done the disability community and their families a tremendous service. Through ProxTalker, users are given the opportunity to experience the joy of expressing themselves.

The ProxTalker is available in German, Spanish, Danish and Swedish.

The ProxTalker’s price is $2,500. Over many years of usage, its benefits, I believe, would be more than justified. For those who want fluency, this is a product worth owning.

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Kathi Wolfe, a writer and poet, is a contributor to the anthology “Beauty Is a Verb: The New Poetry of Disability.”

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

Push Girls
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to get back into the profession. “You learn to let go and trust – to not focus on – (that) there’s a big camera in my face right now.” Fortunately, she said, the show’s production team won’t shoot anything from their lives that makes the Push Girls uncomfortable.

Acting training has helped Rockwood cope with being on “Push Girls,” where she’s under the gaze of the camera from when she wakes up until the lights are turned off at night. It’s freeing to just be herself on the show, she said. “But, when you’re playing a character, you’re worried about what would the character feel. On ‘Push Girls,’ it’s like being a little girl and your parent’s recording you. You’re just being.”

As with any friends, sometimes there’s tension among the Push Girls, Rockwood said. “But you want it to be honest. I don’t want my girlfriend to lie to me and say everything’s OK when it isn’t. How can you improve yourself that way?”

The Push Girls are crossing their fingers that the show will go on for another season, Rockwood said. “With all the (positive) reaction, how can we not go on (for a second season)?

Cross your fingers and stay tuned.

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Kathi Wolfe, a writer and poet, is a contributor to the anthology “Beauty Is a Verb: The New Poetry of Disability.”
Defiance
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Pat’s tenacity was on full display on November 21st, 1980, when he and more than 230 disability-rights activists -- all members of a group called Mobility Through Access -- took over the headquarters of the Metropolitan Transportation Authority of the state of New York. As if this act wasn’t quite enough to make their point, they trapped Richard Ravitch, the MTA chairman, in the building with them for more than 10 hours until he agreed to negotiate with the disability community.

Now, as I said at the outset, I met both men only once. I met Pat at a conference on disability and Tad at a conference on brain injury immediately after a showing of the remarkable 2004 documentary about him called “The Loss of Nameless Things.”

Tad and I talked outside privately for a bit while he took a smoke break. We talked about our writing, and we both exchanged what I’ve come to learn is a not uncommon and always heartfelt exchange between people who’ve had near-death experiences. (I’d gotten my brain injury when I was held up at gunpoint in 1984 and shot in the head.) We each said, “I’m glad you’re alive.”

Like many of us who live with brain injuries, it would take him time to readjust and develop ways of managing the injury’s role in our lives.

Managing life with a disability is no easy task and, given the fact that we live in a country that continues to treat us as second-class citizens (if that), the task of creating a manageable life is indeed a formidable one.

And there are a lot of us. Both the Centers for Disease Control and the National Institute on Disability and Research estimate that there are about 50 million Americans, about one in five, living with disabilities.

Both groups acknowledge that Americans with disabilities have poorer overall health in part because they have less access to truly adequate health care.

All this makes the beautiful defiance found in the likes of Tad and Pat and countless others all the more breathtaking.

Certain things struck me as true about both men. Both were kind. Both were focused on living their lives, and neither one allowed himself to be beholden or subservient to society’s penchant for asking people with disabilities to accept the role of being less than those without disabilities. (I happen to believe that perceiving another human being as being of less worth than you are is a disability in its own right.)

It takes a beautiful defiance to face down the odds, not just by people with disabilities, but by members of any minority who find themselves treated as less than -- a treatment that, if allowed to exist, denies equality and, therefore, freedom.

There are some high-profile examples of this beautiful defiance, for sure. Think about Rosa Parks. She brought a beautiful defiance to bear when, on December 1st, 1955, in Montgomery, Ala., she refused bus driver James Blake’s demand that she give up her seat for a white passenger. Think too about Nelson Mandela, who served 27 years in prison at the behest of a racist regime.

Why do I use the word “beautiful”? Beautiful is, in part, defined as something or someone pleasing to the senses. When I see a fellow human being like Pat or Tad or many, many others I’ve known and known of dare to defy what at times feels like insurmountable odds, it makes my senses soar with joy and admiration, which is why this defiance is, in a word, beautiful. So too were Patricio Figueroa and Oakley Hall III.

Peter Kahrmann is an advocate for people with disabilities. He resides in Massachusetts.

DOL
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If overnight time and a half pay is required, states will discontinue paying overnight hours. Those consumers who must have overnight assistance may have to go into nursing homes or other institutions.

While at this point, consumer-directed models affect only a third of people with disabilities who receive Medicaid services, those numbers will increase because the consumer-directed method is less costly than agency-managed services. In the end, states trying to reduce Medicaid costs will have to adopt consumer-directed models.

No one knows the struggles of home care workers better than consumers. No group wants its wages raised more than consumers. But many of us also struggle at the poverty level and cannot raise wages without Medicaid raising pay rates. The likelihood of the federal government and states raising Medicaid pay rates is slim to none, especially in this economic climate. While we may wish the Pentagon had to hold bake sales to fund bombers and those billions were funneled to Medicaid, the reality is that if DOL mandates overtime pay, the states will cut Medicaid hours. And that is not good news for anyone but the nursing home industry.

WRITERS WANTED

SEND INFORMATION TO:
independencetoday2@gmail.com
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In a call with the Consortium for Citizens with Disabilities (CCD), Darling represented NCIL. Afterward, Darling believed that PHI intentionally distorted his comments concerning a drop in PCA take-home pay with the overtime cap. In a memo issued by their director of governmental affairs, PHI claimed that PCA pay in New York would not drop with the issuance of fair labor standards, and that would not lead to institutionalization. Darling responded in a four-point memo that ended by stressing the importance of the SEIU principles.

"Advocates for this change can choose to ignore, minimize, or undercut our efforts to raise wages and resolve these issues, but I am concerned that their strategy unnecessarily polarizes this issue when we could be working together," Darling wrote.

"I go back to guiding principles signed by SEIU, ADAPT and others. The necessity to balance efforts to enhance workers' wages and benefits with the needs of people with disabilities was identified and addressed in those guiding principles. According to those guiding principles, signed ... on November 16, 2011, 'As a general principle, enhancements to workers' wages and benefits shall be paid for through increased funding.' The DOL proposal simply does not do this. I urge advocates for this change to work with the disability community to take a fair and balanced approach that supports the rights of both attendants and those they assist."

ADAPT's Patrick said: "This is a critical issue for interdependent living. As the value of PCA is raised to a level where we know it should be, so too is our value as people with disabilities raised.

"We need to work with worker organizers. We should constantly engage with them. Conflicts need to be discussed. We need to see through the lens of women who are not highly paid and women of color, and they need to see our perspective as people who live with disabilities in the community."

In their comments to DOL, NCIL and ADAPT stated: "Although the Department of Labor suggests that Medicaid and Medicare rates will increase and offset the additional costs associated with these changes, the Obama administration has proposed cutting Medicaid over the next decade and supported efforts by states to reduce their spending on the program through rate reductions. By increasing the cost of home and community-based services without addressing the funding mechanisms, these proposed changes will reduce the availability of home and community-based services that allow people with significant disabilities to live in the 'Most Integrated Setting.' Even if the administration and states were not actively cutting Medicaid, home and community-based services are most frequently structured in a manner that caps the available funding. Under this zero-sum model, increasing the cost of services will result in a reduction in hours of personal assistance and promote institutionalization."

Cathy Cranston, a longtime Texas home care worker, attended the first meeting at DOL. She is well aware of what it means to be a low-paid worker.

"I have been doing this for decades as an attendant who advocates for consumers and workers," she said. "Philosophically, overtime, travel pay, and minimum wage should happen because it is the right thing to do. My perspective is we consumers and workers are linked, and you cannot have one go forward without the other.

"Each state sets (its) own rates for Medicaid compensation, and Texas sets one of the lowest rates in the nation. We never get more than minimum wage. My perspective as a worker is that these changes sound great, but in practice, the Medicaid funds are not there."

Nikki McGinnis, a PCA in upstate New York, estimated that she will lose one-third of her income if DOL overtime standards become law.

"All my 56 hours are with one person," she said. "I work in the consumer-directed program, and we've been together for six years. Working for her isn't like working in a factory or hospital. I provide personal care, but we also hang out and have a good time together. This change won't help me. In fact, it will hurt me financially. I will lose 16 hours of pay each week. At $11.20 per hour times 52 weeks, I will lose $9,318.40, about one-third of my income.

"I am going to lose hours helping someone I am close to and will have to go work with someone else, probably several people, to make up for it. And my current hours are going to be given away to other people. That doesn't make any sense."

Advocates are asked to flood administration mailboxes with comments. For more information and a comment template submit form, go to www.adapt.org/main/dol. Advocates also can write to Special Assistant to the President for Disability Policy Kareem Dale at kdale@who.eop.gov.

Let the Labor Department and the Obama administration know they need to work with the disability rights community to solve this issue. Tell them that this or any policy that leads to institutionalization of people with disabilities is an important determinant for how you will vote in the November election.

Janine Bertram Kemp, a writer and activist, took refuge from Washington, D.C., in the wilds of Zigzag, Oregon. She is president of the Disability Rights Center and a member of ADAPT and Not Dead Yet.
pre absorbs teacher, was a volunteer at the pride pa-
role. “It was really nice! Kids with and without dis-
abilities were there – playing, dancing, doing crafts,”
said in a phone conversation.

He noted that is “incredible to see how hard people
work” to make pride parades happen. “You have to
fund-raise, get permits, arrange for Porta Potties. But
it means so much to so many people. I don’t have a
disability yet,” said Adam, who considers himself an
ally of the disability community, but “everyone has a
right to have pride in themselves.”

Our disabilities are only part of who we are, said Su-
san Aarup, a member of the Disability Pride Parade
planning committee for Chicago, which set its event
for July 21st. “My disability doesn’t define who I am,”
said Aarup, who has cerebral palsy. “It’s not so much
pride in our disabilities as pride in who we are as
whole human beings.”

Participating in disability pride festivities is a healing
process, said Johnny Crescendo, a musician, Adapt
member, and one of the upcoming Philadelphia Pride
event organizers.

As Crescendo’s song “Pride” says: “Pride’s the key
that unlocks the doors/ to the rooms where we be-
long./Pride is our destiny and where we all came
from/Turn around, embrace your pride.”

For more information, go to: www.svilc.org, www.dis-
abilityprideparade.org,

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Kathi Wolfe is a writer and poet. She is a contributor to the