We Remember...

Larry Allison
How I Cope with Stuttering, Parkinson’s

By John Williams

John M. Williams has stuttered most of his life and recently was diagnosed with Parkinson’s disease. This is his account of the challenges he faces.

I was not born stuttering, nor was I born with Parkinson’s disease. I can pinpoint with 99.9% accuracy when I started to stutter. I started to stutter in April 1952.

Psychologists, a psychiatrist and half a dozen speech therapists point to a singular incident that occurred on Saint Valentine’s Day in 1952. On that fateful day, my second-grade teacher repeatedly smacked my left hand with a steel ruler. She wanted to change me from writing with my left hand to writing with my right. She severely damaged my left hand.

Shortly after that incident, I got shingles. Shortly after I got shingles, I started stuttering. I am nearly 70 years old, and I have been stuttering for 62 years. It has not been easy dealing with stuttering.

Parkinson’s is a progressive disease of the nervous system marked by tremor, muscular rigidity, and slow, imprecise movement, chiefly affecting middle-aged and elderly people. It is associated with degeneration of the basal ganglia of the brain and a deficiency of the neurotransmitter dopamine.

When I was a child, my stuttering was severe. It embarrassed me to take 10, 20, 30 seconds or longer to say a word. Many of my peers were not allowed to play with me because I stuttered. Their parents were afraid that my stuttering was contagious. This isolationism hurt a lot. Over six decades, I experienced scores of situations in which I was shunned, laughed at or singled out as someone unworthy to be hired.

Stuttering is speaking in such a way that the rhythm is interrupted by 1) repetitions, blocks or spasms, or 2) prolongations of sounds or syllables, sometimes accompanied by contortions of the face and body.

As a person with Parkinson’s, I have been embarrassed at being picked up when I have fallen. I have been embarrassed by slurred speech and when I have forgotten to do something. I have been embarrassed when I have failed to meet deadlines for articles. The situations associated with stuttering stiffened my resolve to control my stuttering and to succeed. The trials that accompanied stuttering prepared me to deal with the multiple gut-wrenching challenges associated with Parkinson’s disease.

Shining a Needed Light on Hypocrisy

By Peter S. Kahrmann

I love the fact that Alabama State Representative Patricia Todd, in late January, threatened to drag her colleagues’ hypocrisy into the light.

Todd, a Democrat, was referring to those elected officials in her state who, on the one hand, oppose same-sex marriage because, they declare, it violates “family values,” while at the same time, engage in affairs behind the backs of their spouses and significant others.

The fact that she had to step back from her plan to expose the hypocrisy on the advice of her attorney is, it seems, rooted in the fact that she received death threats over it. No doubt that some who leveled the threats would say they are advocates for family values.

Whether Todd follows through with her plan or not, she has shed a harsh and needed light on those who, on the one hand, claim allegiance to family and traditional values, while on the other hand, wade about in the sewage of hypocrisy.

U.S. District Court Judge Callie Granade recently ruled that Alabama’s ban on same-sex marriage is unconstitutional. In late January, she issued a two-week stay on her ruling, which gave the 11th U.S. Circuit Court of Appeals until Feb. 9 to decide whether the delay should be lengthened. That court did not seek to extend the postponement. And when the Supreme Court again refused to delay lower courts’ rulings in favor of same-sex marriage,
We Remember...
By Barbara “Bobbi” Linn

Larry Allison (Sept. 11, 1943 – Dec. 16, 2014). Allison, a staunch figure in New York City disability politics and city politics in general and a popular radio-show host, died at Mount Sinai Hospital in Manhattan after a long illness. He was 71.

Allison, a Bronx resident, was an employee of the New York City Mayor’s Office from 1973 to 1991, including a stint with the Office for People with Disabilities, where he served as deputy director. He also worked at the city Board of Elections from 1991 to 1995, as well as the NYC Department of Information Technology & Telecommunications from 1995 to 2001, serving as assistant commissioner.

Allison served in both Democrat and Republican administrations in NYC government. At the city’s Board of Elections, he spearheaded the task of making polling places handicap accessible, strategies that were utilized throughout the state of New York.

He was a fixture in New York’s politics – managing, advising and assisting in the campaigns of a number of candidates. According to his obituary, whether a candidate was Republican or Democrat did not matter to Allison. If he felt the candidate was sincere, had good ideas, and would follow the ideals that made the nation great, he would help.

A former assemblyman, Steven Kaufman, said that Allison worked on a number of his campaigns.

“The man was absolutely brilliant and had a phenomenal sense of humor,” said Kaufman. “He was very knowledgeable about every subject you could think of, and he always laughed.”

Allison was co-host of the Vernuccio/Allison Report, a weekly show that discussed issues of national affairs and policy. The program was launched on a Westchester Country radio station and expanded into national syndication.

Allison had a wonderful relationship with his co-host and close friend Frank Vernuccio. “Larry truly lived for that radio show; it was the joy of his life,” Vernuccio said.

Last year, Allison told an old friend that being on the radio made him come alive. As a child, when his mother worked in movie theaters, he was able to see countless movies and got the acting bug. He confessed that he had come to New York to become an actor, although that never panned out. In a way, working on his radio show, he came full circle.

Allison worked for NYC’s Office of Emergency Management beginning in 2001 and, after the 9/11 attacks, he volunteered to work at the World Trade Center site. He died due to complications from an illness he developed at Ground Zero.

He was born in Corning, N.Y., to the late Lennart and Edithel (Littlefield) Allison, the first of three children, including twin boys. He first began working with people with disabilities as a counselor at Camp Oakhurst in New Jersey. In 1965, he followed Jack Birnbaum, one of his mentors, to Camp Jened high atop Hunter Mountain in New York.

He later became director of Camp Jened, and his goal was to give those under his charge as normal a teen experience as possible. To this day, his campers and staff recall a passionate, caring individual with an irreverent sense of humor, who, even without a disability, saw the injustices facing people with disabilities, understood it to be wrong, and resolved to assist in changing society.

Camp Jened was one of the few camps that hired people with disabilities for its staff. Employment at Camp Jened also gave campers something solid to put on their resumes, as well as hope for the future.
Commentary

ABLE Act Not Empowering People

By Mike Ervin

At first glance, the Achieving a Better Life Experience Act seems too good to be true.

It’s a serious attempt to address the serious problem of people with disabilities being trapped in lifelong poverty because of the asset limits that are part of the eligibility requirements for programs such as Medicaid and Social Security. The ABLE Act sailed through the House and Senate with overwhelming bipartisan support and was signed into law by President Obama on Dec 19.

But the closer one examines the ABLE Act, the more its many shortcomings become evident. It will indeed help some people accumulate some assets while still remaining eligible for public programs. But it’s so watered down that it will be of no benefit at all to millions of people with disabilities (PWDs).

The legislation was pushed by more affluent families of children with disabilities, and the final version mostly serves that population. The segment it abandons the most are disabled adults who are poor.

The final version was called the Stephen J. Beck, Jr. ABLE Act, named after a man from Burke, Va., whose daughter was born with Down syndrome. Beck is credited with convincing the legislature, pushing to get the bill introduced for the first time in 2006 and rallying community support for its passage. The House passed the bill by a vote of 404-17on Dec 3. Five days later, Beck died unexpectedly.

The central feature of the ABLE Act is that it allows PWDs or their families to create tax-exempt bank accounts in which they can save up to $14,000 annually and $100,000 in total without having that money count as an asset.

Anything that enables people with disabilities to break free from the harsh and antiquated $2,000 asset cap for recipients of SSDI and Medicaid is a big step forward. But only people who become disabled before age 26 can create ABLE accounts. Kelly Buckland, executive director of the National Council on Independent Living (NCIL), was one of many disability leaders who objected vociferously when that provision suddenly appeared in the bill just before the House vote.

“The age 26 cutoff was simply arbitrary,” Buckland said. “They used it to get the cost down, and that was the only rationale. NCIL supported the ABLE Act for years. We worked (Capitol) Hill to get it passed, then in the 11th hour Congress put in the age restriction without talking with us.

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Book Review

‘Blue-Eyed Boy’ Authentic and Powerful

By Kathi Wolfe

Recently, on a train, my seatmate told me that her husband had sustained a head injury while he was deployed in Iraq. A service dog, she told me, was helping him cope with post-traumatic stress. “He’s doing better, but it’s slow,” the woman said.

Aside from such chance encounters, I don’t think as often as I should about war or the wounds it inflicts. For years, I’ve heard the news of our wars in Iraq and Afghanistan, and I’ve interviewed disabled veterans from former Sen. Minority Leader Bob Dole to veteran’s rights advocate Robert O. (Bobby) Mueller for Independence Today. Being legally blind from birth, serving in combat has never been an option for me. Like many of my friends, I want to support our troops even when I oppose war, and I hope the disability community steps up to advocate with and for vets with disabilities.

Yet, few veterans, able-bodied or disabled, are in my social or family circles, and the trauma of war injury hasn’t hit my solar plexus – until I read “Blue-Eyed Boy: A Memoir” by Robert Timberg (Penguin Books. 304 pp. $27.50, hardback. Available on Kindle and other E-book formats. Due out in paperback in July. $17.)

On Jan. 18, 1967, Timberg was a young Marine lieutenant in Vietnam. It was fewer than two weeks before he was set to end his 13-month tour of duty in the Vietnam War and return home to his first wife Jane (stopping along the way in Okinawa, Japan, for some R&R and to check out bargain-rate stereo equipment for their apartment in California).

Though trained in the infantry, on that day, Timberg went to distribute combat pay to five officers and 80 enlisted men “deep in the boonies” of Vietnam. En route, his vehicle was hit by a Vietcong land mine. “I felt myself lifted as if in the eye of a hurricane, except in place of wind and rain I was being carried aloft by flames,” Timberg writes.

The land mine disfigured Timberg’s face so horribly that it was nearly completely covered by third-degree burns. “What remained looked like steak before you throw it on the grill,” he writes.

“...he was a handsome man/and what I want to know is/how do you like your blueeyed boy/Mister Death,” wrote poet e.e. cummings in an untitled poem -- it begins “Buffalo Bill’s defunct” -- that Timberg chose for his memoir’s epigraph.

Cummings’ poem is an apt choice for an epigraph. Timberg was so badly wounded that he nearly died. His face was so severely damaged that he had to have more than 30 surgeries. One surgery, a full-thickness graft done without anesthe-
**Sometimes, Little Things Mean a Lot**

*By Peter S. Kahrmann*

Snow, much like death and taxes, is one of life’s great equalizers. Cars and trucks, old or new, battered or pristine, are equal in their white-cotton beauty. So too houses, whether they are well-kept Victorians or run-down A-frames. Same with sheds, garages or buildings, commercial or private. No matter their age, condition or design, all are equally beautiful in their powder-white coats right after a snowfall.

The same can be said for streets and sidewalks, paved or pitted. They are beautiful just after a snow, before the trampling and disruption of humankind’s daily life takes place.

I am an early riser. I am up around 2:30 or three in the morning and enjoy walking Charley, my black Lab mix, first thing, before the world is awake.

Recently, we began a walk about quarter to three. It was brutally cold, the kind my father used to say was “I-fail-to-see-the-humor cold.” It was windy, and the wind-chill made it feel like 15 below zero.

Charley and I completely agree that “brief” is the code word for walks in conditions like this.

After about 15 minutes, the time Charley needed to relent and make his more substantial morning donation, we headed back home. As we approached the building we live in, off to my left, I heard a faint but desperate, “Help me!”

I looked and a saw an elderly woman on the ground a few feet from the front door of her modest-sized house. Though I didn’t know her name at the time, I knew she lived alone. She was nothing but a nightgown and a light cotton bathrobe and ankle-high white snow boots. Bathrobe and nightgown had ridden up to mid-thigh as a result of her fall.

There was no time to tie up Charley. I was somewhat concerned about him because his usual mode of behavior when meeting people is to lick them to smithereens and

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**Robot a ‘Social’ Teacher for Students with Autism**

*By John M. Williams*

The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children (or 14.7 per 1,000 8-year-olds) in multiple communities in the United States has been identified with autism spectrum disorder. ASD is characterized, in varying degrees, by difficulties with social interaction and verbal and nonverbal communication as well as repetitive behavior.

Autism has its roots in very early brain development. The most obvious signs and symptoms of autism tend to emerge between 2 and 3 years of age.

ASD can be associated with intellectual disability, difficulties in motor coordination and attention, and health issues such as sleep difficulties and gastrointestinal disturbances.

Some people with ASD excel in visual skills, music, math and art. With the May 2013 publication of the “Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5),” all autism disorders were merged into one umbrella diagnosis of ASD.

Teachers are confronted with the herculean task of preparing students with autism for success after graduation. With the number of students with autism rising, schools are struggling to find the tools and personnel to meet their academic, social and functional needs.

What tools are available to help students and teachers achieve their goals?

One company, RoboKind, believes it may have an answer in Milo, an intelligent, interactive, humanoid robot that delivers research-based lessons that teach social behavior.

“This revolutionary robot is an exciting and affordable tool for educators and therapists,” said RoboKind’s founder and chief executive officer Fred Margolin.

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Milo “bridges the gap between technology and human interaction for kids on the autism spectrum.”

Pamela Rollins, Associate professor of communication disorders, Callier Center for Communication Disorders, Dallas

Using Robots4Autism’s research-based curriculum, Milo
My Life as a Canvas

By Shameka Andrews

This year, the Independent Living Center of the Hudson Valley received a grant from the New York State Council on the Arts, through the Arts Center of the Capital Region, to sponsor a photojournalism course that enabled people with disabilities to write about and photograph aspects of their disability experiences. ILCHV hired Lee Anne Morgan, a nationally known photojournalist, who guided us in our writing and picture taking. The class was part of ILCHV’s commitment to Pat’s Place, a program named after the late disability advocate and artist Pat Figueroa, who believed that participation in the arts was a method to empower people with disabilities.

The class included 8 individuals with all types of disabilities. The youngest was 18, the oldest mid 60’s, both male and female. The class provided an opportunity for us to share our experiences, and support each other’s creative struggles. The result is a catalogue of essays and pictures by artists with disabilities, speaking to each of our own personal experiences.

Independence Today will periodically publish one of the eight essays from this project. Below is the next in the series.

I would describe my story as a dark, black canvas with swirls of bright colored paint. I was born in 1978 with spina bifida. Spina bifida is the incomplete development of the spinal column where a piece of the spine is exposed. During the first few years of my life I had a number of operations to correct secondary conditions such as hydrocephalus and clubfeet caused by spina bifida. Because of my disability I have been in a wheelchair my whole life.

“One Step Past the Pain”/Shameka Andrews

During childhood my disability created barriers in my life and in my relationships with other people. Lack of accessibility in my neighborhood caused me to be isolated and depressed the majority of the time. There were many nights I cried myself to sleep. I remember I loved going to school and school events because that was usually the only time I was able to paw at them with childlike glee. I kept him on the leash as I went over to the woman, lifted her to her feet and brought her into her house. She told me she’d fallen down trying to retrieve her morning newspaper.

I asked her if she needed me to call anyone or wanted an ambulance, but she said no.

I asked if she’d like me to sit with her for a while, and she said yes. Had she said no, I would have insisted on staying for a few minutes, falsely claiming I needed the time to gather my wits, when, in truth, I wanted to stay and make sure she was OK.

We talked for a little while. She told me her husband had died 20 years ago, and that they’d been together 39 years.

I asked her if she’d like me to make her a cup of coffee or tea. She declined the offer, saying she just wanted to sit a bit and warm up. She nodded at Charley.

“He’s a nice dog. Lab?”

“Lab mix,” I said.

“My husband had two: one boy, one girl. Nice dogs.”

When I got up to go, I asked her if she’d accept my phone number, given we were neighbors. She nodded. I gave her my phone number and asked her to please feel free to call me if she needed anything.

Charley and I went home.

When I got into my house, it hit me that if I hadn’t found her, she would have died given the weather conditions. It then occurred to me that I’d been given a truly precious gift, the chance to help someone and perhaps save a life.

And then I realized something about Charley that astonished me and brought me to tears. Charley is normally the answer to what happens when a cup of espresso is turned into a dog. But from the moment we went to the woman’s aid, he was calm and attentive and gentle. His focus was solely on her. At one point, he sniffed her hands and licked them with what seemed to me to be gentle care.

Every once in a while, life sends us a reminder that we make a difference. We would be wise to keep our eyes peeled to notice it when it happens.

Later that morning, I and others made some phone calls to make sure our neighbor was being looked out for.
One such trial happened during my seventh-grade year. Several of my classmates started making fun of my stuttering. I was irate and started a fight with the biggest of the boys. I lost the fight, but I won the respect of my classmates. For the rest of the year, my classmates never again made fun of my stuttering in front of me. I resumed speech therapy that year determined to control my stuttering.

Then there was the jobs issue. During my last two years in college and for one year after I graduated, no one offered me a job that I applied for. The interviews concluded with the same refrain, “We will not offer you a job because you stutter.”

After people learned that I had Parkinson’s disease, many writing assignments went to someone else. I have been told, “Since you have Parkinson’s, we did not think you could do the job.”

My stuttering conditioned me for such rejections. Circumstances such as the ones cited above affected me deeply. They made me feel as though I were a pariah, an outsider, unwanted, a contagious plague.

It has been about four years since I was told I had Parkinson’s disease. I believe I have had it for 10 years. I have had to make many adjustments in my life to cope with the daily obstacles Parkinson’s throws at me. The adjustments have been hard but necessary.

One of the biggest adjustments for me regarding stuttering was accepting the fact that I was never going to be on stage. I was a ham at heart. I had tried out for plays in grade school, high school and college only to be rejected because I stuttered. I was never asked to read lines of dialogue.

A comparable incident concerning my Parkinson’s was voluntarily surrendering my driver’s license. A year ago, when my legs started freezing on me for 30 seconds to as long as several minutes, I realized that I could have a severe accident, and the results could be my death, someone else’s death, multiple deaths or multiple serious injuries. I could not live with myself if someone was killed or injured in any way because of my vanity. And so I told my friends and family I was through driving. I have kept my promise.

As I was recovering from the steel ruler incident and the shingles, I was in a lot of pain. I was stolid in dealing with the pain. Today, parts of my body are in pain all the time. Sometimes the pain is unbearable, and I cry. Sometimes I scream. When I can keep quiet regarding the pain, I do. It is important to me to bear the pain silently. I do not want people around me 24 hours a day. They have their lives to lead, and I want them to deal with their problems without my intrusion.

When I was taking speech therapy, I had to remember to practice daily. This was not easy because many of the therapies I did turned out to be useless. When I did practice speech therapy, it was always for 30 to 45 minutes. I was not as committed to speech therapy as I am to the therapies that help me deal with Parkinson’s.

Daily and religiously, I do from 35 to 55 minutes of physical therapy. I see a physical therapist twice a week for 45 minutes. Because Parkinson’s attacks the muscles, it is important that I keep the muscles moving, and so my daily regimen consists of exercising my fingers, wrists, arms and legs.

I have an exercise bike on the patio. When weather permits, I ride the bike for 20 minutes. Sometimes, I exercise twice a day. By exercising daily, I am told that I am slowing down the spread of the disease within my body. I would not dream of losing even one day of exercise.

When I stuttered severely, I was my worst enemy. I blamed...
Allison’s commitment to his campers was lifelong. He stayed in touch with many and expressed almost a parental pride over their accomplishments. Many of his campers grew up to become leaders in the disability rights and independent living movements. Many have speculated that Camp Jened was a breeding ground for leadership in the disabled community.

Camp photos document Larry’s elaborate outfits, which he styled for the various masquerade balls over the years. Perhaps the one remembered best was his “Larry of Arabia” outfit. For that, he wore white sheets covered with lots of white toilet paper.

He said that people with disabilities were treated as “second-class citizens.” Among the stories he would tell was the one about going to a bar with a man in a wheelchair, about 30 years old, who had a speech disability. Allison became enraged when the bartender refused to serve the guy with the disability while serving everyone else in the party.

In 1963, Allison graduated from Corning Community College, and in 1966, he received a bachelor’s of arts degree from New York University, where he majored in political science and history. He earned a master’s degree from NYU in 1970.

Much of his retirement, when he was able, was spent discussing politics in a loud voice for which he was well known, working on various campaigns, watching Fox News with Jocelyn, his cherished wife, planning a camp reunion or two, and exchanging hilarious emails with the late Pat Figueroa, founder of Independence Today.

Survivors include his wife, Jocelyn; two daughters, Amanda and Alynda; two brothers, Ronald and Donald; many nieces and nephews; and many godchildren, stepchildren and grandchildren.

Barbara “Bobbi” Linn has been involved in the disabled civil rights movement for more than three decades. She is the founding executive director of Bronx Independent Living Services.

Milo costs $3,000; the accompanying educational software is $2,000 more.

The curriculum was developed by Dr. Pamela Rollins in conjunction with the Callier Center for Communication Disorders at the University of Texas at Dallas. It includes social stories, visual support, video modeling and principles of applied behavioral analysis.

Rollins has more than 30 years of research, teaching and clinical experience in the ASD field. She is familiar with how autism intervention programs support teachers and help children with autism by teaching critical social and emotional skills.

Rollins teaches graduate-level courses on the assessment and treatment of children with autism. She received her doctorate in human development and psychology from the Harvard Graduate School of Education and was the recipient of the American Speech Language and Hearing Foundation’s First Investigators Award to study the relationship between early pragmatic accomplishments and vocabulary development in children with autism. Her recently published book is titled “Early Communication, Language &
sia, was so painful that the doctor was nearly overcome by observing Timberg’s pain.

Timberg, a career journalist who worked for years on The Baltimore Sun, is best known for his 1995 book “The Nightingale’s Song,” a 1995 account of John McCain and other prominent Vietnam-era Naval Academy graduates. His style in “Blue-Eyed Boy” is an example of what renowned writer and journalist Ernest Hemingway called “grace under pressure.”

Take one scene that so many of us with disabilities who have been treated as objects rather than as human beings will recognize. As Timberg is lying in pain, depressed, in the hospital, he hears a nurse walking by call him “The Burn.” Seething inside but feeling powerless, “The Burn just lay there, uncomplaining, a pathetic slab of helpless protoplasm,” Timberg writes.

Over a long life and prestigious career, “...my actions wrecked both (of his two) marriages. Along the way, though, I also did some good things,” Timberg writes. “...I was a junior partner in raising four kids...I was a newspaper editor...I was editor-in-chief of a prestigious military journal.”

Timberg decided to write “Blue-Eyed Boy” to recount how he rebuilt his life after he was severely wounded. “I somehow reclaimed my future after a life-altering event that threatened to lay waste to the rest of my days,” he writes.

get out of the house on a regular basis. One of my favorite elementary school memories is reading to my friend Michael. He was visually impaired and his classroom was next to mine. Michael and I are still friends today. We still occasionally read together when he comes over once a month. In middle school I joined the Big Brother, Big Sister program as a ‘little sister.’ I loved going out with my big sister, Sharon.

I don’t think about my childhood, mostly because it is filled with memories of sadness, anger and depression. As the years go by, I remember less. But writing this has caused me to think about the bad times and remember the good times too. When I was ten and in the hospital for one of my last surgeries, my Big Sister, Sharon, brought me a plush, soft stuffed hippo. It was a kindness I’ve never forgotten, for her act brought me comfort. The hippo too, which I used as a pillow!

As an adult, I am often haunted by the memories of my child-
This violated the ‘nothing about us without us’ mantra! The young person who gets in a car accident at age 26 or after, who just graduated college and started a career, trying to pay off student loans, will not be eligible!”

Buckland said that after the age restriction was added, NCIL sent a letter to ABLE Act sponsors withdrawing its support.

Of the 17 representatives who voted against the ABLE Act, 12 were Demo¬crats and some were quite politically progres¬sive. Some said they objected to another last-minute provi¬sion that slipped in a Medicare cut.

The provision discontinued Medicare coverage of vacuum erection systems “until such time” as Medicare covers erectile dysfunction drugs under Medicare Part D. These devices, commonly known as penis pumps, are used to help men with erectile dysfunction achieve erection. Proponents of this provi¬sion estimated it will reduce Medicare spending by $444 million. Creating ABLE accounts would increase the deficit by $2.1 billion over the next decade, according to the Congres¬sional Budget Office.

The American Association of Retired Persons sent a letter to all House mem¬bers that read in part, “…establishing the ABLE program should not be achieved by tapping into Medicare savings ... We urge you to remove Medicare offsets from the ABLE Act.”

All this prompted Rep. Debbie Wasserman Schultz, D-Fla., to reluctantly vote no. In a statement, she said, “I am a cosponsor of the ABLE Act, a laudable piece of legislation meant to help people with disabilities set up tax-free savings accounts. However, I decided not to vote for the bill once Republicans insisted on funding it by making permanent cuts to Medicare. I cannot in good conscience support Medicare cuts that will have a direct impact on the care that some seniors receive. At a time when we are concerned about the long-term solvency of Medicare and looking for ways to strengthen the program, cutting it is bad policy. I believe there were plenty of other pay-for options the Congress could have considered to fund the ABLE Act.”

Rep. Jim McDermott, D-Wash., said: “Mark my words, when it comes time to offer another tax break, my colleagues on the other side will come after Medicare again. And the next time, the cut will be deeper and easier because we did it today.”

Rep. Xavier Becerra, D-Calif., said in a speech on the House floor: “Using Medicare savings to offset non-health related programs sets a dangerous precedent. While there are elements to this bill that both sides can agree on, this bill takes one step forward and two steps back.

“It’s a laudable and worthy goal to incentivize savings and ensure that families of individuals with disabilities have access to the resources they need. But Congress has a responsibil-

"I am...
Devoted
Intelligent
Successful
Ambitious
Beautiful
Educated
Determined

Shane Slay
Celebrating the abilities of people with disabilities.

Created by Shameka Andrews in 2006

Independence Today is online at:

www.itodaynews.com
www.ilusa.com
www.ilchv.org
As anyone with a disability knows, adapting to life after an injury is the farthest thing from easy. After he’s wounded, Timberg must deal with the reactions of others to his disfigured face. Children stare at him. He stares at his face in the mirror and flinches. Even after all the surgeries, his face will never look like it did before the land mine detonated. Yet, he must find something to do after he’s transferred to the Marine Corps’ “medically retired” rolls. Timberg becomes depressed, thinks of suicide and struggles, he writes, with “the living hell that had come to define my existence.”

This isn’t acceptable to Jane, who insists that Timberg must begin to re-create his life. “At some point...you’re going to have to figure out where you go from here,” she tells him.

This scares the stuffing out of Timberg. “Anything having to do with the future seemed to mean getting a job,” he writes, “which meant leaving the safety of the hospital or our apartment, and I was in no way anxious to take that on.”

On a whim, Timberg decides to become a journalist and to study journalism at a graduate school at Stanford. “I threw a dart and that’s where it landed,” he writes.

Though Timberg has had a rewarding personal and professional life, he still has trouble, at times, accepting how the land mine disfigured his face.

“...stared at the face looking back at me from the mirror and I lost it,” Timberg writes. “‘Enough already!’ I shouted. ‘I’ve been this way since 1967...and it’s time for this...to end!”

Looking at his face in the mirror, Timberg wanted “time to return to normal.” “I have been wounded at twenty-six; I wanted to look like I would if I have just aged naturally,” he writes.

There are far too many sappy, “inspirational” memoirs of saintly people “overcoming” injuries, war wounds and disabilities. Timberg’s memoir isn’t one of them. It’s a riveting, authentic, moving story of a life. Timberg neither flagellates nor sanctifies himself. He reveals not only his successes but his failures from his journalistic scoops to his extramarital affairs. At a time when increasing numbers of disabled veterans are coming home after serving our country, “Blue-Eyed Boy” is a must-read.

Kathi Wolfe, a regular contributor to Independence Today, writes frequently on disability and other social and cultural issues.

My stuttering was the reason I could not get the job I wanted. It was the reason I could not maintain a relationship with women. It was the cause of anything I failed at. I was not a nice person sometimes. Carrying a cross did not do anything for my career. I recognize that now.

Since I was diagnosed with Parkinson’s disease, I have talked to many, many people with Parkinson’s disease. Too often, they have known people with extreme cases of Parkinson’s. The person has lost his or her memory and the ability to care for him or herself. The person has become a total invalid.

My daily fear is that I may eventually be unable to care for myself and therefore will become a burden on my family. In that case, I do not want to live.

As I aged and began making a name for myself as a writer, my stuttering became less of a burden to me. Editors only wanted a story; how I got it was my business. As a result, I developed a positive attitude about myself and my abilities. I no longer carried that cross on my back. I was free and happy. I was determined.

I have a positive attitude regarding my Parkinson’s. I am determined to do everything I can to prevent it from taking control of my body. My stuttering has shown me what is possible. Without having experienced the challenges associated with stuttering, I believe I would have a negative attitude toward my Parkinson’s and be worse off.

John M. Williams coined the term "assistive technology." His website address is www.atechnews.com.
Quantum theory and black holes aren’t remotely on my radar screen. Yet, like everyone who doesn’t live in a cave, I’ve heard about Stephen Hawking, the renowned British theoretical physicist. It seems like I’ve seen him everywhere -- maybe more than I see my closest friends and relatives.

I’ve watched video of Hawking, 72, who has motor neuron disease, giving lectures from his wheelchair, and I’ve smiled when I’ve heard his iconic, American-accented “voice” on the “The Simpsons.” Hawking’s so embedded in our pop culture DNA that it’s not surprising that he’s appeared on beloved TV shows from “Star Trek” to “The Big Bang Theory.” Hawking’s scientific brilliance and pop cult celebrity have made him, perhaps, the most famous person with a disability in our time.

Last fall, Hollywood played off his fame. In November 2014, “The Theory of Everything,” the Hawking biopic, was released. Most able-bodied people whom I talked with looked forward to seeing the movie, while many in the disability community gritted their teeth. We know all too well how much Tinsel Town loves “inspirational” stories about “overcoming” disability. With exceedingly rare exceptions, films of these narratives don’t feature actors with disabilities as background extras or in supporting roles (such as the lead actor’s best buddy) – let alone in leading roles.

From “The Miracle Worker” to “Forrest Gump,” such films have won Academy Awards. In January, “The Theory of Everything” was rewarded with big-time Oscar love. The film received Oscar nominations for best picture, actor in a leading role (Eddie Redmayne as Hawking), actress in a leading role (Felicity Jones as Hawking’s first wife, Jane), original score (by Johann Johannsson) and adapted screenplay. And on Feb. 22, Redmayne was awarded the best actor Oscar for his role in the film.

“The Theory of Everything,” though not a documentary, is based on a memoir titled “Traveling to Infinity: My Life with Stephen” by Hawking’s ex-wife Jane Hawking. The film tells the story of how Hawking was told that he’d have only two years to live when he was diagnosed with motor neuron disease in his mid-20s. It depicts how he and Jane (a graduate student in European literature) fell in love, married and had three children.

In the movie, Hawking emerges as an internationally renowned scientist and celeb wheelchair-user and gradually accepts his need for help with the intimate tasks of
daily living (eating, dressing, etc.). Jane takes on the role of caregiver. Without giving too much away, it’s safe to reveal that the couple’s marital conflicts unfold in the movie. Though they remained friendly for the sake of their children, as the marriage unravels, Jane becomes close with Jonathan, a music teacher and choir director, and Stephen takes up with his nurse.

Critically, the film has been generally well-received. Most reviewers drank the “inspirational” Kool-Aid, and few, if any, questioned why Redmayne, a highly talented but non-disabled actor, was cast as Hawking. Variety said of the film, “The intricate workings of a rare and wonderful mind are rendered in simple, accessible terms in ‘The Theory of Everything,’ a sensitively directed inspirational biopic...”

"Here is an unexpectedly charming, moving and powerfully acted film..." The Guardian said of “The Theory of Everything.” “Screenwriter Anthony McCarten and director James Marsh have swerved a lot, if not quite all, of the clichés. They have created a startlingly grown-up portrait of a difficult, troubled relationship.”

The movie, “is poignant and honest in showing how Jane and Stephen’s marriage leaves both of them exhausted and unfulfilled,” The New York Times said.

Munching my popcorn, watching “The Theory of Everything,” I couldn’t help but be drawn in. The pace of the movie is engaging, and it was fun to watch Stephen and Jane meet and fall in love. I know the film’s account of their meeting isn’t completely accurate, but I enjoyed the May ball scene, with Stephen as a gangly, awkward grad student dancing and dishing with Jane about the stars (in the sky). I’m a physics dummy, and those who know say the science in the movie isn’t accurate (what a surprise!). Yet, it was fun to watch Hawking form, discuss and debate his scientific theories.

Hawking, by all reports, is pleased with the movie and by Redmayne’s portrayal of him. “Seeing the film has given me the opportunity to reflect on my life...” Hawking wrote on Facebook.

"...I thought Eddie Redmayne portrayed me very well in ‘The Theory of Everything.’ He spent time with ALS sufferers so he could be accurate. At times, I thought he was me...I think Eddie’s commitment will have a big emotional impact," Hawking said in a video.

According to press reports, Hawking cried during the world premiere of the film and permitted audio from his speech synthesizer to be used in the movie. “It was the last thing we did on the film, creatively...so that felt like an endorsement in the form of a gift,” Marsh told The Frame.
ity to ensure that limited resources benefit those who need the help the most. Unfortunately, this bill is yet another example of an upside-down tax code that provides the greatest benefits to those of greatest means, not to middle class families living paycheck to paycheck.”

Therein lies another deficiency of the ABLE Act. Because it is savings-based, it most benefits people with disabilities who can afford to save because they have high enough incomes or family financial support. But for those with no savings who get by on a monthly SSI check, it offers little, if any, hope.

Some believe incremental progress begets systemic change. So maybe someday the success of the ABLE Act will pave the way for legislation that will finish the job. But Buckland said he fears the opposite reaction. He fears the celebrated passage might create the illusion that the problem is solved and no further action or redress is needed.

Mike Ervin, who writes on disability topics, is a frequent contributor to Independence Today.

Redmayne prepped for months before he portrayed Hawking. Hawking even gave him tips on how he (and his disability) should be portrayed, according to Yahoo Movies and other media outlets.

“Stephen asked me if I was playing him before the voice machine, and when I said yes, he said, ‘My voice was very slurred,’” Redmayne told Yahoo Movies. “When Stephen said that, it reinvigorated me to go back and say, ‘Look, we have to be true to what this disease is.’”

This having been said, I still couldn’t help but wonder: Why was an able-bodied actor chosen to play the most celebrated person in a wheelchair on the planet? If, a biopic were to be made about President Barack Obama, would a white actor, no matter how talented, be cast in the role? I’m far from alone here. Many filmmakers, opinion-makers and actors in the disability community find “The Theory of Everything” to be problematic. Despite Redmayne’s considerable talent, couldn’t his performance (an able-bodied actor playing a disabled character) be viewed as yet another example of “cripface”?

Why are able-bodied actors so often cast as characters with disabilities? Because sometimes having a star such as Daniel Day-Lewis (in “My Left Foot”) or Tom Hanks (in “Forrest Gump”) sells movies. Having a nondisabled performer play a disabled person can enable cultural “fear and loathing around disability” to be “magically transcended,” playwright Christopher Shinn, who had a below-the-knee amputation, told The Independent.

Filmmaker Dominick Evans, who leads the weekly Twitter discussion #FilmDis, raises concerns felt by many of us in the disability community about “The Theory of Ev-
Some people say that an able-bodied actor had to play Hawking because there were scenes of him walking and standing in the movie," Evans, who uses a wheelchair, wrote in an email to Independence Today. "I respond with, 'Disability is more than just the lack of physical movement, at least in the case of those of us with physical disabilities.' There is an entire culture that many of us are part of that often goes ignored in media portrayals of disability.

"How can [actors] authentically portray disability without experiencing this, the oppression, and the culture of disability? How can they do it if they have to change the entire way they look and perceive life and living?"

Filmmaker Dominick Evans

Evans said he wonders how you explain to an actor who sees "their normal" as being able-bodied what it's like to have "your normal" be something different. "How can they authentically portray disability without experiencing this, the oppression, and the culture of disability? How can they do it if they have to change the entire way they look and perceive life and living?"

I'll continue to be a movie aficionado, and I wish Eddie Redmayne well. Yet, I'll continue to hope that one day "cripface" will be historical relic.

Kathi Wolfe writes frequently about disability and the arts. Her poetry collection is forthcoming from BrickHouse Books.

I am working on putting together a book called "Wisdom on Wheels." I am inviting people who use wheelchairs, walkers, scooters or any mobility device on wheels to submit their stories. Topics of interest include self-care, people pleasing, setting boundaries, getting out of your comfort zone, self-acceptance, trusting your abilities, listening to your gut, overcoming obstacles, and letting go.

Submissions of stories should be between 500 and 3,000 words. Deadline for submission is May 1, 2015.

Proceeds from the book will go the Ms. Wheelchair NY Program. Please can contact me at mwny2006@yahoo.com with any questions.

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Peter S. Kahrmann is a writer and an advocate for people with disabilities.
Achievement Center of Texas in Garland. The center provides day care and life-skills training for children and adults with special needs.

The center reported that children with autism who were exposed to the curriculum and interacted with Milo had observable increases in eye contact, body language and friendliness.

Janet House, a special education teacher and parent of a 7-year-old boy with autism, recently saw Milo at the annual Assistive Technology Industry Association in Orlando.

“Martin, my autistic son, was mesmerized by Milo,” she said.

Bill Thompson, the father of a 10-year-old autistic boy, said, “I have seen Milo demonstrated twice; I know he can help William junior.”

Frances Connors, a special education consultant at the University of Miami, said Milo “creates an elevated level of engagement that makes learning fun and necessary.”

John M. Williams can be reached at jwilliams@atechnews.com. He is a frequent contributor to Independence Today.