DISCOVERING ONE’S OWN

FIGHT YOUR DEMONS – AND BE YOU

MICROSOFT RAMPS UP ACCESSIBILITY

SOCIAL MEDIA NEW WAY TO CONNECT WITH ROLE MODELS

AUTHOR HAS NEW TAKE ON FDR, POLIO

TECHNOLOGY LEAPS EMPOWER AMPUTEES

FUMING OVER SEIU-BACKED TRAINING MANDATE

HARRIS V. QUINN CASE DIVIDING DISABILITY COMMUNITY, UNIONS
A ballot measure called the In-Home Supportive Services, Wages and Mandatory Training Initiative is moving forward in California. The initiative has many people with disabilities who receive in-home assistance through California’s In-Home Supportive Services (IHSS) program feeling furious and betrayed. They feel as if they’ve been stabbed in the back by the Service Employees International Union.

SEIU is the driving force behind the initiative, which, if approved by voters, would require “workers providing home care services to the elderly, blind, and disabled pursuant to the state In-Home Supportive Services program to receive 75 hours of training in subjects such as personal care, disease management, diet, nutrition, physical activities, workplace safety, and consumer and provider roles and rights.”

Nancy Becker Kennedy is a quad wheelchair user who lives in Los Angeles. She gets 269 service hours each month through IHSS, which she uses to employ a crew of people to assist her with a wide variety of tasks.

“We have known the freedom of the social model of in-home supportive services where we pick the people we want to care for us in the way we want our bodies to be treated, and we make the choices of how we will live,” she said. But the training will add an unnecessary layer of needless medicalization that will make it much harder for people like her to hire the person of their choosing, she said.

“Seventy-five hours is a prohibitively long general training for very minimal benefit that will virtually exclude any worker who doesn’t want to work for an agency or nursing home,” Kennedy said. Working for her, she said, is not a medical job that requires certified nursing assistant training, and she doesn’t think it’s fair to limit her hiring options. That contradicts the spirit of independent living, she added.

The final days of my non-sober life saw me smoking pot every possible moment, inhaling two to three nebulizer treatments daily to keep my lungs open so I could keep smoking the stuff, and then, as if all that weren’t enough, ending each day with up to 15 gin and tonics (tall glasses, no ice).

To further underscore how off the deep end I was, I would call my doctor, the one desperately trying to help me manage my disability (a brain injury as the result of a gunshot wound) on a regular basis because I couldn’t figure out why the medication he had me on wasn’t helping.

The fact that, at the time, it never occurred to me that combining pot, alcohol and prescription medication was a threat to my life makes me shake my head in amazement to this day. It’s good to remember, though. And it’s helpful to remember how far down you were to remind yourself how far you’ve come.

I’ve been sober more than 11 years now.

For some, addiction has caused the disability. For others, it’s been a tempting way of living with a disability. The less felt the better, as it were. For still others, it’s been both: cause and lure. After all, losing (or never having) the ability to walk or talk, breathe on your own, remember, see, hear and so on, is no easy row to hoe. Is it any wonder many of us seek refuge in alcohol and drugs? I think not. As if that weren’t bad enough, we live in a society that all too often sees us and treats us as if we are less human and therefore of less value than others.

Who in his or her right mind wouldn’t want to turn to some illegal substance or medication for relief? The answer? Someone who realizes that he, not the disability or the addiction, has the right to be the manager of his own life.

Speaking for myself, the last thing on earth I want to do is give my brain injury -- and, for me, its appendage: post-traumatic stress disorder -- any more control than I have to. As for my sobriety, no human or circumstance can take it away from me unless I allow it. Life happens to us whether we like it or not. That’s a fact. And while we don’t have complete control over what happens, we do have control over how we respond.
Harris v. Quinn Case Dividing Disability Community, Unions

By Janine Bertram Kemp

Disability rights leaders are divided over Harris v. Quinn, a case recently heard by the Supreme Court that challenges collective bargaining concerning wages and benefits for personal care attendants.

The case involves a challenge by Illinois resident Pamela Harris, a parent and personal care attendant. The suit, heard by the nation’s highest court on Jan. 21, attests that states should not be allowed to compel PCAs (also called home care workers) to submit to exclusive representation by a labor union and then pay for the privilege. The court’s decision is expected by June.

Illinois has designated SEIU Healthcare Illinois & Indiana, an affiliate of the Service Employees International Union, as the exclusive representative for caregivers in bargaining with the state over reimbursement rates.

Some Illinois organizations and Washington, D.C.-based national groups signed on to an amicus brief supporting SEIU and collective bargaining for PCAs. These groups maintain that a decision against the unions as the collective bargaining agent for PCAs will threaten independence for people with disabilities who use personal care assistants in consumer-directed programs.

The argument, in very basic terms, is that people with disabilities must have PCAs to live independently. Low wages and no or poor benefits mean that it is harder to find reliable, competent PCAs, and the only way to ensure a living wage and decent benefits is through collective bargaining and unions.

Both sides of the controversy support good wages and benefits for PCAs and say that they are essential for finding and maintaining good employees.

The California In-Home Supportive Services Consumers Alliance (IHSS), several ADAPT chapters and centers for independent living, plus parent groups in the developmental disabilities community, believe that unionizing threatens consumer control and independence. They feel that advocacy is the best means of garnering higher wages for PCAs and say that reliance on SEIU and collective bargaining will wrest more independence away from consumers.

SEIU’s job-training requirement is seen as an example of loss of consumer control. In Washington state, SEIU insists that all PCAs go through 75 hours of state-funded job training, a mandate that takes time away from consumers and wages from PCAs. Some say that the $150 cost is simply

Activist Flora Johnson demonstrates outside Supreme Court/Google Images

SEIU members/Google Images
The Bionic Man (and Woman) Returns: Technology Leaps Empower Amputees  

By John M. Williams

In the mid-1970s, one of my favorite TV shows was “The Six Million Dollar Man,” starring Lee Majors as astronaut Steve Austin.

When Austin is severely injured in the crash of an experimental aircraft, he is “rebuilt” in an operation that costs six million dollars. His right arm, both legs and left eye are replaced with “bionic” implants that enhance his strength, speed and vision far above human norms. After Austin is rebuilt, he has the equivalent power of a locomotive, is able to run up to 60 mph, and has a 20:1 zoom lens and infrared capabilities in his enhanced eye. Those abilities served him well as a secret agent for the Office of Scientific Intelligence.

In the fields of bionics and prosthetics, the six-million-dollar man is here – minus the superpowers.

Bionics is the technique of replacing a limb or body part with an artificial limb or part that is electronically or mechanically powered. A prosthetic is an artificial device used to replace a missing body part, such as a limb, tooth, eye or heart valve.

“The major difference between bionic and prosthetic is how they are powered,” said bionic engineer Jesse Watt.

Today’s bionics will not allow users to run 60 miles an hour or rip off steel doors from their frames. What’s important to the beneficiaries of either bionics or prosthetics is how those ever-changing fields allow them to incorporate it feels good to be included. We all knew that in the seventh grade. Microsoft Corp. has done a decent enough job over the years of acknowledging that people with disabilities were out there, using their products. In the last year, however, they’ve stepped up their efforts in a number of directions, and those efforts warrant conversation.

Let’s take the most recent public nod to disability first. The Microsoft-sponsored commercial during the Super Bowl was the kind of representation of disability many would like to see more often. Former Seahawks player Steve Gleason has ALS (Lou Gehrig’s disease), uses a wheelchair and controls much of his environment through eye movement on a Microsoft tablet.

The commercial’s primary focus is a sweet dad-daughter image; only in the close-up at the end do we totally get that he’s in a wheelchair. Some viewers maybe don’t get at all that the words the dad speaks are actually coming from a technological device with text-to-speech capabilities -- and, really, that’s the way it should be. They are, after all, coming from his heart.

This, too, is a tremendous step forward. Microsoft provided training to their top technicians, which meant not only that tech support people knew how to use the products from the standpoint of users with various disabilities, but that they were now schooled in the use of appropriate language. According to many people with disabilities, the results have generally been positive. Not only are the technicians not saying things such as “Click on the red square” to callers who self-identify as being blind, but they actually seem to understand (and thus can solve) technical issues. The Microsoft Answer Desk can be reached by calling (800) 936-5900.

On Jan. 14, a press conference was held in Fort Wayne, Ind., that rocked the world of developers, trainers and users of assistive technology for blind and low-vision people. On that day, a partnership between Fort Wayne-
When I was in high school, I’d already known for some time that I wanted to be a writer when I grew up. Teachers praised my creativity and clarity, and friends wanted my help writing papers.

When I applied for funding for college from the state vocational rehabilitation agency, however, the counselor assigned to my case scoffed at my aspirations. A blind girl couldn’t be a writer, he told me, and dismissed my goal as unrealistic. My view of the world, and my own place in it, was too childlike, he said.

Years later, with my feet firmly planted in my roles as columnist and editor, I began meeting other writers with disabilities, some of them blind. One such writer was Beverly Butler.

Butler was the author of several young adult novels, one of which was “Light a Single Candle.” That book, the story of a teenager losing her sight, drew a fair share of critical acclaim, including the Clara Ingram Judson Memorial Award given annually to the most creative children’s writing in the Midwest.

That book, published in 1962, already had been around a number of years when my vocational counselor dismissed my dream of becoming a writer. Why, I wondered as a 30-something writer, hadn’t that counselor -- or my high school librarian or English teacher or somebody -- pointed out this book to me? Why hadn’t someone mentioned this author to me as an example of who and what I might become?

The simple, sad truth is that, more than likely, none of them knew about Beverly Butler or her book. They were limited by their own attitudes toward what a blind girl could do, and thus it never occurred to them to search for any appropriate role models.

Fast forward 40 years and a zillion or so communications tools. Today, the possibility for role models and connections to like-minded kids and adults for young people with disabilities is just about limitless.

I work with a group of blind and low-vision students,
Be You

Continued from page 2

It is very clear to me that walking into the always-waiting arms of addiction gives more power to your disability, more power to those who seek to control your life (often-times unethical health care providers who see us as little more than revenue streams) and enhances society’s view that we are less than human.

I am not revealing a heretofore untold truth when I say that much of addiction is about burying emotions: sadness, fear, anger, confusion, pain --- Yes, in my book, there is an emotion called pain -- and so on. Many of us grew up or are growing up in a society that says admitting to anything but positive uplifting emotion is an act of weakness. Rubbish. First of all, if it’s an act of weakness to tell someone when we’re sad or angry or frightened, then why is it so hard for so many to do? Second, why on earth would we be given emotions if we weren’t supposed to feel them?

Empowering our disabilities, walking into the arms of addiction (which includes alcoholism for those straining not to accept this), means we will never fully live our lives being the people we actually are.

Now, whatever your belief system is, it will, if it is a healthy one, support the following tenet: You were put on this earth to be you, not some altered version of you. You may, as you read this, believe yourself to be worthless or bad or dirty or possessed of a character so hideously flawed that those around you will reject you outright if you give yourself permission to go ahead and be you. The fact of the matter is you are not some horrible person. Don’t you think you have a right to discover this? I do. Yes, it is true, not everyone will like you. God knows there are plenty of people who don’t like me. But I’ll be damned if I’ll let anyone or anything (disability, addiction or society’s bigotry) rob me of my right to be myself.

So don’t let anything or anyone or any of life’s challenges rob you of your right to be you. You were born you, after all. And that’s a good thing.

Be well, stay safe, and remember to live.

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Peter S. Kahrmann writes a blog on disability issues. He resides in Massachusetts.

WRITERS WANTED!

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Discovering One’s Own Sanctuary

By Peter S. Kahrmann

I would like to think all of us have found places to go over the years that give us a sense of comfort and safety -- sanctuaries, if you will. It could be a favorite clearing deep in the woods, perhaps, or a park bench, a comfy chair in a library, a particular booth in a diner or restaurant, a house of worship, home. Ideally, a sanctuary should, on the one hand, provide a few moments’ refuge from life’s worries, tribulations and fears and on the other allow you to relax, breathe freely and bask in all that is wonderful about life itself.

Some of us -- and I am no exception -- have looked for sanctuary in another person. Such an effort doesn’t work. I believe Buddha was right when he said, “Do not look for a sanctuary in anyone except yourself.” The challenge for so many of us is discovering that the who of who we are is indeed a sanctuary worth reveling in. More often than not these days, I am able to find sanctuary in myself. There are days, however, when it is not a slam dunk. That too is OK. One day at a time.

Over the years, I have enjoyed many places of sanctuary.

The 7A Café in New York City’s East Village was such a place for me in the 1980s, which is why it broke my heart when I learned that it had closed at the end of January this year.

7A Café’s owner, Moshe Hayat, and a delightfully eclectic and more often than not nurturing staff played a pivotal role in helping me rejoin daily life after I was held up and shot in the head in August 1984 and then held up again at gunpoint less than a year later. Needless to say, those experiences made going out in public feel like I was walking into a firefight with no protection whatsoever.

I had a Siberian Husky named Bubba at the time. For a midmorning breakfast, the two of us would walk the seven blocks to 7A, which, not surprisingly, was located on the corner of Avenue A and East 7th Street. (Moshe was clearly a realist when it came to names.) Bubba and I would sit at one of the outdoor tables. I’d drink coffee, eat my breakfast and write in my journal. I got to know the waiters and waitresses, and real friendships were formed. Slowly but surely, taking part in daily life became easier.

7A was not my first sanctuary in life by any means. Sanctuaries, as you likely know already, can take many forms. When I was a boy, the tree house my father and
Author Has New Take on FDR, Polio

By Kathi Wolfe

Few people with disabilities will ever be more famous than Franklin Delano Roosevelt, who was president of the United States from 1932 to his death in 1945. Since the publication of the late writer Hugh Gregory Gallagher’s book “FDR’s Splendid Deception,” it’s been widely believed that Roosevelt hid his disability from the public.

In his engaging, provocative new book “The Man He Became: How FDR Defied Polio to Win the Presidency” (Simon & Schuster), historian and journalist James Tobin argues that, on the contrary, Americans of his time were aware that Roosevelt had polio.

Tobin’s books include “To Conquer the Air: The Wright Brothers and the Great Race for Flight,” which received the J. Anthony Lucas Work-in-Progress Prize, and “Ernie Pyle’s War: America’s Eyewitness to World War II,” which received the National Book Critics Circle award in biography. After earning a B.A. and a Ph.D. in history from the University of Michigan, Tobin became a reporter at The Detroit News, where his work was nominated twice for the Pulitzer Prize. Currently, he teaches narrative nonfiction in the Department of Media, Journalism and Film at Miami University in Oxford, Ohio.

In “The Man He Became,” Tobin writes about how FDR dealt with his disability from the time he contracted polio in 1921 until he was inaugurated as the 32nd president of the United States on March 4, 1933. Recently, Tobin spoke at length by telephone with Independence Today on a wide range of topics from history to disability to stigma. Excerpts are as follows:

Q: What got you into the subject of FDR and polio?

For Speech-Impaired Patients, New Tool Aids Communication

By John M. Williams

A new icon communication aid has the potential to improve health-care services between speech-challenged patients and nurses.

VerbalCare, developed by Boston-based Verbal Applications, is a cloud-based computer system (platform) that connects patients in hospitals with nurses through software installed either on a mobile device that is worn by nurses or on a computer.

The system, founded in 2013, was designed to allow patients to verbalize their needs and know they are being heard. With VerbalCare, patients who use an iPad or other tablet can select large picture-based buttons with which to communicate such needs as “I’m hungry,” “I have to pee” or “I need my medicine.” At the other end, nurses are aware of a patient’s needs before walking into a room, thus speeding up care and increasing patients’ satisfaction.

VerbalCare can replace primitive communication technology such as letter boards, whiteboards (large boards with a smooth white surface that can be written on with special markers) and lip reading. The program also can be produced in a variety of languages.

In addition, there are ways for patients to communicate their needs through voice systems. Clinical staff can see requests through a tablet dashboard, an iPhone or an iPod touch and then can reply to patients.

Karen Kelly works with patients who have aphasia, a language disorder that negatively affects a person’s ability to talk, read, write and understand the spoken word. Aphasia results from brain damage, such as Alzheimer’s disease or stroke. More than 30% of stroke victims suffer aphasia to some degree. Kelly’s mother has aphasia.

For four months, Kelly tested VerbalCare with aphasia patients. “VerbalCare performed the way it was designed,” she said, adding that patients and nurses were
a back-door way of filling SEIU coffers. Some longtime PCAs, who have already been instructed as to how a consumer wants his or her care provided, call the training a burden and a threat to consumer direction of PCA services.

Those who support the collective bargaining side of Harris v. Quinn outline a two-pronged model for managing consumer-directed care. Most consumer-directed models of attendant care are funded by Medicaid dollars, which are administered at the state (and sometimes county) level. Because the state pays wages and determines benefits, it is suggested that collective bargaining can occur with the state around these issues only. That leaves hiring, firing and the specifics of work tasks to be directed by the consumer.

Access Living, a large Chicago CIL, signed on to the Harris v. Quinn amicus brief that supports collective bargaining. “Together, we have strengthened programs in Illinois to ensure that people with disabilities maintain control over services that support their independence, while at the same time increasing wages and benefits for workers, creating a stable relationship that prevents costly institutionalization,” said Marca Bristo, Access Living president and CEO.

“People should have self-direction and a co-employer relation with the state or county,” said Galen Smith, co-founder of Minnesota ADAPT, which, as of press time, has not taken a position on Harris v. Quinn. Smith noted that it is either the state or county that administers payment. “They set wages, requirements, training opportunities, and the workers should be able to bargain over these. The rest must be controlled by consumer: hire, fire, and all the tasks that make up the job.”

Smith believes that Harris v. Quinn is part of a broad-based attempt to attack unions. “The bottom line is, there are people and corporations and big-money interests whose mission it is to make sure people can’t join together and have better conditions for workers,” he said. “In this case, they have also attacked the disability movement and people who care about self-direction.”

Michael Bailey, past president of NDRN and a longtime advocacy leader, agreed. He feels the gains in his home state of Oregon show the effectiveness of collective bargaining.

“Since adoption of the Home Care Commission, Oregon’s wage for home support workers is now $14.25 to start and includes health-care and worker compensation,” he said. “Without collective bargaining, we would still be paying $8 an hour with no benefits.”

But many disability leaders across the country said they do not believe SEIU negotiates with integrity and, via collective bargaining, would whittle away a consumer’s right to hire, fire and direct their PCAs.

SEIU’s requirement of 75 hours of mandatory training has angered both PCAs and people with disabilities.

“Instead of enhancing and adding labor benefits to that program as they promised, the union is using state-funded in-home supportive services as their own personal piggy bank to build their empires, to collect more dues by requiring more workers, because they must know the state will limit the number of hours caregivers can work,” said Nancy Becker Kennedy, a longtime California-based disability advocate.

“They will use dollars taxpayers intended to pay for the care of seniors and people with disabilities and get that money from the states by taking lucrative contracts to provide 75 hours of mandatory general training,” added Kennedy, who co-founded the IHSS Consumers Alliance and is a board member of the Los Angeles County Personal Assistance Services Council that oversees services for 180,000 seniors and people with disabilities.

SEIU also earned the mistrust of leaders with disabilities when it supported the Department of Labor’s companionship
their new “parts” into their bodies in as normal a fashion as possible.

Recent advances in robotics technology make it possible to create prosthetics that can duplicate the natural movement of human legs. This capability promises to dramatically improve the mobility of lower-limb amputees, allowing them to negotiate stairs and slopes and uneven ground, significantly reducing their risk of falling as well as reducing stress on the rest of their bodies.

Prosthetics have improved so much that Zac Vawter recently walked up 2,000 steps with a bionic leg. He controlled his leg with his mind by sending instructions from his brain to nerves that communicated with his mechanical limb.

In the world of prosthetics, that was a breakthrough moment. Previously, if leg amputees needed to climb stairs, they’d either have to rely heavily on their good leg to propel them upward or use a remote control that required them to stop and start at the base of each stair, which creates movement that’s more robotic than human.

A vast body of research gained from treating American soldiers wounded in Iraq and Afghanistan has led to robotic knees and ankles that adjust to terrain and activity. Leg amputees now run marathons, climb mountains and even skydive. A new bionic arm powered by thoughts allows a user to deal cards, tie shoelaces, use a spoon, open drawers and perform other hand movements. And Ekso Bionics, formerly known as Berkeley Bionics, created eLEGS, a robotic exoskeleton system that allows paraplegics to walk upright.

Newer technologies are making prosthetics more functional than ever. Microprocessors and lighter materials have made the devices easier to use and maneuver. Prosthetics have long helped people regain the functionality of a lost limb. For example, the “Luke” is a robotic arm funded by the Defense Advanced Research Projects Agency, whose goal is to restore functionality to individuals with upper-extremity amputations. According to a spokesman for DARPA, research is still being done.

Prosthetics and bionics are available for just about every body part, from legs and arms to heart valves and breasts. Advancements in design have allowed people to function at a higher level than ever before.
Sanctuary

Continued from page 6

I built was one of my favorites. Spending time in the woods behind our house was another. Crawling into bed next to my father in the early morning was yet another. It seemed back then that many married couples had separate rooms, and my parents were no exception.

I would be remiss too if I did not mention books. Reading has been my favorite pastime and sanctuary for nearly as long as I have memory.

The gift sanctuaries give you is a place to regenerate – a place in which, for the time you are there, you are free of life’s onslaught and, well, life: the good and the bad, so to speak. Sanctuaries give you a time to be with the soul of who you are.

So, if you do not have a sanctuary, I hope you find one. You deserve the peace and healing you will find there. Even more, I hope, like me, you either have discovered or will make the discovery that you, my dear reader, are indeed the finest sanctuary you can find.

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

$25 to $59. Tech support can be purchased at $25 for a single incident or $99 for a whole year.

As Dan Hubbell, Microsoft’s assistive technology evangelist (and senior manager of marketing) put it at the press conference, the two companies have actually been partners for more than 20 years. Microsoft has worked with various assistive technology companies for several years now, and GW Micro has had a notable presence at those seminars.

No one is saying exactly how and when this new offer came to be, just as no one is saying how much money changes hands each time a Microsoft Office customer downloads Window-Eyes. Whatever the case, the bottom line is that Microsoft is offering access to its Windows platform that was once beyond the reach of many customers who need-
invest in it in June.

U.S. hospitals waste more than $12 billion annually as a result of communication inefficiencies among health-care providers, according to a 2010 study published by the National Center for Biotechnology Information. Dougherty said that improving hospital communication through VerbalCare can have a “ripple effect” that will allow hospitals to save money and reduce risks for patients in hospitals.

Patients with communication problems are at the highest risk for preventable, adverse events, according to a 2008 study published by the NCBI.

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

Q: What attracted you to the 1930s and 1940s?

A: My interest in the era comes from hearing my parents talk about the war, especially growing up in the ’30s. I caught the history bug. The more recent decision that I made to write about FDR’s disability came from several factors – if you’d like to talk about that.

Q: That would be great!

A: I had a special curiosity about the way families work. I was looking for a story about a family. As a journalist, I’d covered medicine. I had been interested in writing about medical problems and how people deal with them. I was thinking about David McCullough’s book “Mornings on Horseback” about Theodore Roosevelt.

Q: Doesn’t he talk about Teddy Roosevelt’s asthma – his being sickly?

A: Exactly. I thought: Has anybody done a good narrative study based on primary documents on FDR and polio? I thought there have been some good things written, but I didn’t think anybody had done a closely narrated story of this episode. The major bios of Roosevelt passed over it pretty quickly. My original intention was to take the polio story all the way to 1945. Then I decided that the heart of the story ends with his election as president in 1932. If I were to take the story beyond that, then I realized I was going to be in a holding pattern for the first eight years of his presidency. There’s more to say about polio and his cardiovascular disease in 1944.

Q: It seems as if the country didn’t know the extent of FDR’s cardiovascular disease.

A: That’s certainly true. In the afterword [of “The Man He Became”], I sort of find fault with how FDR handled his final disease. He probably should not have run in 1944. He was unfit – not because of his polio, but because of his cardiovascular disease. His handling of that has been the subject of several books. That was another reason why I was reluctant to take...
Kennedy, who describes herself as "super lefty girl," said her political idol is Eugene Debs, the famed labor union leader. But she feels that SEIU, which represents home care workers across the country, has turned into the greedy force unions are supposed to oppose. She feels that union leadership is trying to tap into state money that funds programs such as IHSS by conducting training that workers don't need and that will not necessarily benefit the people they work for. She fears it will greatly hinder her ability to hire friends, neighbors, family members or local college students who aren't interested in home care as a profession and have neither the time nor desire to invest so much time in training.

"With the mandatory 75 hours of general training, none of these workers who require multiple jobs, or have full-time jobs taking care of their loved ones, will be able to participate in such a lengthy training with such minimal value to the person for whom the care is being provided," Kennedy said.

A similar initiative, pushed by SEIU, was approved by voters in the state of Washington in 2011. Now all home care workers must complete 75 hours of training within six months of their date of hire if they want to keep their jobs.

Kate Sheffield of Sequim, Wash., is a full-time wheelchair user due to multiple disabilities. She says she receives 406 hours per month of in-home assistance through a program called the Community Options Program Entry System (COPES). Sheffield is retired from her most recent job as a member of the Sequim City Council, but she says she is still a "vocal spokesperson" in her state capital of Olympia for people with disabilities.

Does Sheffield think Kennedy's fears about the effect the training will have on her freedom to hire whomever she wants are well-founded? "You better believe it," she said.

The training, Sheffield said, is often "not germane. It's set up by people who have no idea what's needed by me. The training presents us as being unable to make decisions. The system looks upon us as mendicants, beggars. Were just being given another layer of warehousing, only it's in the home."

Sheffield says she's finding that some people she would like to hire are no longer interested in the job when they learn of the training requirement.

The Seattle Times expressed loud opposition to the Washington initiative in an editorial. "It is a grab for public money at a time when there is no money," the editorial said. "Not one voter in a thousand really understood it."

But in states such as Illinois and Massachusetts, disabled activists and SEIU locals have worked together for years to build strong in-home supports and services programs in which workers are unionized and consumers have great latitude in hiring, firing and directing their assistants.

Bill Henning is executive director of the Boston Center for Independent Living. "Presently, the 32,000 attendants in the state are represented by SEIU, and we have been able to maintain a strong, positive working relationship with the union," he said. "Justice is not selective. Workers -- and notably many are single mothers and people of color, including many immigrants -- have a right to collective bargaining. Attendants were not paid well absent organized efforts."

Henning says the relationship has been mutually beneficial. "We were able to negotiate with the union..."
ages 15-20, who have mostly known one another since early childhood. They are all bright, talented and competent and, no, they didn’t go to school together. They were in a number of schools throughout one state, but their parents connected them because of email lists, websites and programs they all found and attended together. Today, they are all connected to one another and many, many others with similar disabilities and interests via Facebook, Twitter, YouTube and other social media.

When one of them is interested in knowing more about mathematics or sculpture or participating in a marching band, she simply assumes that by Googling it, she will find some information on it -- and some role models to boot.

Karrie Brown, a 17-year-old from Collinsville, Ill., is one example. Karrie, who has Down syndrome, loves clothes and posing and has a fashionably healthy sense of self. She wanted to “fit in” and “stand out” all at the same time.

After spying her daughter smiling while posing in front of the mirror, patting her tummy and saying how much she liked seeing herself in her new-school clothes from Wet Seal, Sue Brown was thrilled and snapped some pictures. Those pictures, which she posted on Facebook, attracted attention so quickly that Wet Seal posted a challenge: If Karrie’s pictures drew 10,000 “likes” by week’s end, the company would fly her to Los Angeles for a professional photo shoot.

Karrie got those 10,000 likes, and she got her photo shoot, too. Since then, Karrie and her mom have been hearing from lots of other kids with Down syndrome who are smitten by Karrie’s example.

Most recently, the power of social media and mass communication to connect kids and adults with disabilities to one another was seen in the compelling story of two little girls in New Jersey who contacted a football celebrity.

Twins Riley and Erin Kovalcik, 9, have worn hearing aids since they were babies. When they saw the Duracell commercial featuring NFL fullback Derrick Coleman that aired in January, Riley wrote him a note.

The commercial, powerfully narrated by Coleman himself, is the rapid-fire story of his rise from bullied deaf kid to Super Bowl participant. At the end, his message to others was “trust your power.”

Riley’s note said, in part: “I know how you feel. ... I have faiif [faith] in you.” Her dad was so proud of his little girl that he tweeted that note. Afterward, it wasn’t long before Riley received a personal reply from Coleman.

ABC-TV arranged for the twins and the fullback to meet on the network’s “Good Morning America” program, and the three spent an hour chatting and comparing hearing aids. Coleman invited the whole Kovalcik family to the Super Bowl and provided them with ninth-row tickets to the big game.

You don’t have to be a child psychologist to know that those two little girls have had a huge boost in the dream-come-true and self-esteem departments. And none of it likely would have happened in an era without TV, the Internet, Twitter and Facebook.

Sure, I know other baby boomers with disabilities whose parents were a bit more resourceful and engaged than mine, parents who sought role models, successful people with disabilities, and arranged for them to meet with their children. But today, it is so much easier to connect with other kids.
on key points, including language that moved consumer control -- the right to hire, fire, train and direct attendants -- from just regulation into statute, as well as (include) a no-strike clause."

Calls from Independence Today to SEIU’s national headquarters seeking comment on the issue were not returned.

Henning says any attempt to impose 75 hours of mandatory training would pose a serious threat to the harmonious relationship between SEIU and Massachusetts.

"This would be strongly opposed by many," Henning said. "Some (people who employ attendants) prefer to hire people without experience because it is so important to train attendants around the unique assistance needs of the individual and those with, say, training as a home health aide will do things their way, which is not what may best benefit a consumer."

The community, he added, "needs to organize, organize and organize. We have to recognize that, broadly speaking, home care is about the third-fastest growing place for jobs in the country, so there’s going to be more and more pressure for professionalizing the workforce, whether from unions, agencies or legislators freaked every time something happens to someone."

Kennedy and others who receive support through IHSS are doing just that. They formed the IHSS Consumers Union, which has a lively Facebook page.

"In the end, there’s simply never a substitute for us to be agitating, educating, organizing and getting a seat at the table," Henning said.

Sheffield agreed. "We need to organize ourselves and make our voice loud."

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

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Deborah Kendrick, a frequent contributor to Independence Today, is a writer and editor.

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

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ed it. And that should go a long way toward improved accessibility for people with disabilities.

To learn more or to download a free copy of Window-Eyes, visit www.windoweyesforoffice.com.

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my story all the way to 1945.

Q: In your book, you write about how you see FDR’s handling of his polio as a “masquerade” and not a “deception.” You mention how Roosevelt said to Orson Welles, “Orson, you and I are two of the greatest actors.” Would you talk about the difference between masquerade and deception?

A: I did use the word masquerade. The word I like best is performance. There’s all kinds of evidence that shows [FDR] did not try to persuade anyone that he was not disabled. What he tried to do was to present himself as what he was, which was a healthy man who could not walk without assistance. We have to put ourselves back in that period, when many people were prone to believe that a man who had suffered an illness of that kind was still in some way sick, that he still had a disease -- which he did not.

What he was interested in doing was being the best president of the United States that he could be. To pursue that end, he wanted people to be comfortable with him. FDR did not want to have anyone’s pity – which he was personally uncomfortable with but [which] also would undermine his authority as a leader.

Q: To do that required a kind of performance?

A: This was the performance that he had to pull off. Other politicians have had to pull [off] different kinds of performances. I think of all kinds of parallels with Barack Obama, who is quite clearly dedicated to a performance of the role of a leader who is not what certain people expect of a black man. He is not going to be angry. He is not going to represent only his own ethnicity. It’s a strong parallel. That’s why I get a little miffed with some disability activists who argue that FDR should have done more for disability rights. Sometimes, people tend to miss the complexity of that era in terms of the stigmatization of people with disability.

Again, there’s the parallel with Obama. Here’s this guy – Roosevelt, paralyzed from the waist down – who does what no one thought he could ever have done: He becomes president of the United States. There’s a photo in my book that shows him walking with his braces down the aisle of a large, crowded room. All kinds of people [are] seeing him walking, but [he is] clearly disabled. It didn’t prevent anybody from voting for him.

Q: You write that you use words such as “crippled” and “cripple” to keep the reader in the mindset of FDR’s time. Do you worry that using such terms might perpetuate stigma against people with disabilities?

A: I decided that my job is to tell what happened as carefully and with as much subtlety as I could. It seemed to me that to do that I had to make some use of the language of disability that was used in those days. Anyone who has an interest in this kind of book is sophisticated enough to understand my use of those kind of terms.

Q: Many thanks for talking with me!

A: I enjoyed our conversation.

Kathi Wolfe writes frequently on disability issues. Her most recent poetry collection, The Green Light, was published by Finishing Line Press.
Other advances include myoelectric technology, targeted muscle reinnervation and microprocessor knees.

Myoelectric technology will power future robotic prosthetics. Myoelectric (“myo” denotes “muscle”) prostheses are controlled by placing muscle sensors against the skin at the site of an amputation.

The electric signals generated by the muscle at an amputee’s stump control a processor connected to the prosthesis. Myoelectric technology allows for greater prosthesis control and precision.

With targeted muscle reinnervation, amputees are in the infant stages of controlling prostheses directly with their minds. Through targeted muscle reinnervation, the nerves from an amputated limb are re-energized in a different part of the body, for example, the chest. When an amputee wants to use his or her prosthesis in a particular way, he or she thinks the action, prompting the nerves in the chest to react. That reaction sends a message to a microprocessor in the robotic limb, which performs the action.

Using microprocessor knees, people with above-the-knee amputations have greater control over walking, stopping and moving on inclines. These knees analyze the pressure an amputee puts on the prosthesis. A microprocessor monitors a fluid control unit built into the knee and provides appropriate joint resistance when a user is on an incline. Microprocessor knees have revolutionized safety and stability for people without knees.

As people with disabilities gain more access to bionics, there is no longer any doubt that their independence will increase.

John Williams coined the term “assistive technology.” He can be reached at jwilliams@atechnews.com.