Commentary:
PLEASE VOTE—BUT NOT FOR ROMNEY

Commentary:
NRA PROPS UP VIOLENT CRIMES

Disability Rights Activist
Denise McQuade
Did Her Part to ‘Change the World’

Election Day is
November 6, 2012
Don’t forget to exercise your right to vote!
“Vote as if your life depends on it; it does,” the late Justin Dart, the well-known disability advocate, once told a group of people with disabilities prior to a presidential election.

This November, another critical election is coming. And, unfortunately, there is much apathy in every segment of the electorate, the result of a weak economy, high unemployment, a deadlock in D.C., and, in all honesty, disappointment with the current president. But indifference in this particular race is acutely frightening, especially for members of the disabled community. The accuracy of Dart’s words from years past shrieks loudly at us.

Our lives, as we know them, will radically change, and not for the better, if Mitt Romney, or someone with a similar philosophy, occupies the White House in 2013. What voters should fear is the budget proposal put forth by Romney’s recently named running mate, Paul Ryan.

According to Wikipedia, in 2013, Ryan’s proposal would convert the federal share of all Medicaid payments into block grants to be allocated to the states. The total dollar amount of the block grants would increase annually with population growth and with growth in the consumer price index (average inflation). And starting in 2022, Medicaid block grant payments would be reduced to exclude projected spending for acute-care services for elderly Medicaid beneficiaries. States would have greater latitude in designing their programs.

The Ryan proposal, if enacted, would make several changes to the 2010 Patient Protection and Affordable Care Act and the health care provisions of the Health Care and Education Reconciliation Act of 2010. Key provisions of those laws, which deal with insurance coverage, would be repealed, including:

- The requirement that most legal U.S. residents obtain health insurance.
- The establishment of health insurance exchanges and subsidies for some individuals and families who purchase coverage through the exchanges.
- The expansion of Medicaid coverage to include most nonelderly income below 138 percent of the federal poverty level.
- Penalties on certain employers if any of their workers obtain subsidized coverage through the exchanges.
- Tax credits for small employers that offer health insurance.

Ralph Waldo Emerson was right when he said: “To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment.” But how many of us can raise our hand and say, “I am exactly who I hoped to be and where I planned to be at this time in my life?”

I can’t answer yes to the second part of the question, but I can answer yes to the first part.

I think most of us are not where we thought we’d be in life, a truth that is often a translation of: We’re not where we were socialized (culturally brainwashed) into believing we should be. As a result, we begin to experience ourselves as failures, as being less valuable than others, unless we have learned to give ourselves permission to be the unique individuals we are. That’s not easy in a society that tells you to define yourself by extraneous things, things that orbit about you and in truth do not and never will define your worth or, for that matter, your identity as an individual.

People are not defined by iPads or smartphones; they never will be.

We – you, my dear readers – are not failures. Not one of us is less valuable than anyone else. This is a statement of fact.

Because one feels less valuable or feels like a failure does not mean he or she is. Feelings define the emotional condition in a given moment; they do not define the core of who you are, your individuality.

Oscar Wilde was spot on when he said, “Be yourself; everyone else is already taken.”

When, like me, you live with a disability (I have a brain injury), the task of being yourself can be a seriously formidable challenge — especially when you live in a society that frequently tells people with disabilities they are less valuable and — even worse — less human than others.

One glaring example? As far as the man holding this “pen” is concerned, sheltered workshops are nothing more than slave labor, a way for companies and so-called health care providers to make a buck off the backs of people with disabilities. They should not be called sheltered workshops; they should be called what they are: legalized slave labor sites.

To Thine Own Self Be True

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Disability Rights Activist McQuade Did Her Part to ‘Change the World’
By Alan St. James

Take a look at Denise McQuade’s resume, and two truths quickly become apparent – her career is dedicated to serving people with disabilities, and she’s one of the disability movement’s key founders and leaders.

A snapshot shows that she is:

- A grassroots leader, activist and prime mover behind the disability rights movement.
- One of the founders of the independent living center (ILC) movement.
- A leader in the fight for public transportation, public housing, education and employment access.
- A co-founder of Disabled In Action (DIA).
- A former deputy director of the New York City Mayor’s Office for People with Disabilities.
- A board member of the National Council on Independent Living (NCIL).
- The first executive director of the Brooklyn Center for Independence of the Disabled, one of the first two ILCs in New York state.
- An administrator at the Metropolitan Transportation Authority.
- One of the original planners, proponents, driving forces and activists behind the passage of the Americans with Disabilities Act (ADA).

And it all happened, in part, so Denise could prove her mother wrong.

"I contracted polio in 1951 when I was three and a half and, at first, no one realized what I had," McQuade said. "I was susceptible to sore throats and running fevers, so everyone thought it was just a bad sore throat.

"After we knew it was polio, my mom was very practical about what she thought I could expect from others as a person with a disability. She used to tell me that all wasn't fair in the world if you had a disability, and the world wasn’t going to change for me; I’d have to change."

McQuade, however, never totally bought into her mother’s advice. Looking back, she said, "Mom was wrong – we did change the world!"

For McQuade, that change began in the late 1960s and early 1970s, when she was introduced to – and then worked alongside – fellow disability movement activists such as Pat and Denise Figueroa, Larry Allison, Fred Francis, Judy Heumann and Bobbi Linn.

"It was all very grassroots," McQuade said. "We did things by the seat of our pants. Some of us were students, some worked – all of us were very idealistic."

McQuade went to her first disability rights meeting in 1969 at Long Island University because she was curious, intrigued and hoped to meet other like-minded people with disabilities.

"I went to that conference and I didn't say anything, just listened. People were talking about discrimination, sharing their experiences about some of the inequities in education, employment, transportation and housing and complaining about all the different things that were barriers to people with disabilities."

The following year, she attended another conference at which Heumann was speaking. "People were talking, and I'm realizing everyone said the same thing the year before, so this time, I spoke up." She told the group: "There are a lot of us. We need to get more militant. We need to take action rather than just talking about it. Afterward, Judy came over to me and said she was interested in what I said, invited me back to her apartment, and we started talking."
Commentary

Voter Fraud? More Like GOP Fraud

By Kathi Wolfe

Emmanuel Aziz, a former disk jockey who has multiple sclerosis, uses a wheelchair, is unable to drive and lives in a skilled nursing facility in Missouri.

"On a good day, for half an hour, (Aziz) will be highly energetic — able to go online or to chat with a visitor," said Denise Lieberman, a senior attorney with the Advancement Project, a civil rights and voting rights group. "But then Emmanuel can’t hold his head up. He has to rest. He can’t manipulate his index finger to activate his motorized wheelchair."

Yet, despite the challenges in his life, Lieberman said, Aziz cares deeply about voting. He wants his vote to count. In the next election, he wants to cast his ballot in person at his polling place.

What could be a more reasonable desire? But many of us in the disability community have long known that voting has been far from simple or, in some cases, even possible. Until recently, accessibility has prevented many people who use wheelchairs, folks with intellectual disabilities, those with vision impairments and others from having equal access to the polls.

Thankfully, some progress has been made toward making voting accessible.

Along with increased accessibility, the National Voter Registration Act of 1993 (known as the Motor Voter Act) has made voting easier for many, including people with disabilities (PWDs). For folks with limited resources or who can’t drive, Motor Voter makes it possible to register to vote at independent living centers and other social service and advocacy organizations.

Despite entrenched inaccessibility — and apathy — PWDs have recently turned out in increasing numbers to vote, said James C. Dickson, head of the American Association of People with Disabilities’ Disability Voting Project. In 2008, 14.7 million PWDs voted, said Dickson, who is blind. "Our turnout was only seven and a half percent below voters without disabilities. That was more than the Latino vote and almost as much as the African-American vote."

Recently, however, state legislatures across the country have introduced voter ID laws and other restrictive measures that could keep people of color, students, seniors and PWDs from voting.

It has been common practice for states to require voters to bring some form of identification when they come to cast their ballots. For an individual, it could take the form of a voter registration card, a utility bill or some other correspondence.

Voter Registration card, a utility bill or some other correspon-

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Computer Sports Putting Autistic Teen ‘In the Game’

By John M. Williams

Seventeen-year-old Tim Mather sits in front of a computer in his northern Virginia home. He waits patiently for the alarm clock near his desk to ring. His daily routine is to wait until the alarm rings at 9 a.m., put on his headphones, turn on the computer and wait for it to boot up. When it does, he clicks on the My Football icon and stares at the screen until he hears: "EA Sports. It’s in the game."

A smile appears on his face as the picture of a football player appears. He can choose to play either a child’s version or an adult’s version of My Football Game. "I love action," Tim says.

"Tim will sit for hours every day and play My Football, My Golf Game and other computer games with movement," says his father, Michael.

Tim’s father is overwhelmed with joy that Tim has found an activity that occupies many hours of his time during the day. Tim is autistic. Autism is a neurological disorder characterized by impaired social interaction as well as repetitive behavior.

Tim is looking at a picture of a football player. "Big and strong," he says. He clicks on the adult version button. He is looking at buttons numbered levels 1, 2, 3 and the words "Championship ring." Each level brings him to a different activity.

“Tim has never clicked on Championship ring,” said Lucifer, Tim’s 20-year-old brother.

Tim loves clicking because it brings him new pictures. He clicks on Level 1. Lucifer then clicks on a button, and now Tim is staring at eight football icons. The icons are drills for rookies and cover kicking, trench fight, ground attack, QB pocket reserve, passing, tackling, punting and squat ball. Tim clicks on the kicking icon. He says, "I kick far."

There’s an expression of joy on his face as he practices kicking. He loves seeing the kicker kick and the ball soaring through the air. "Watch the ball," Tim says as the ball soars through the goalpost uprights.

Except for moments like these, Tim seldom shows any emotion, his father says.

Tim’s IQ is about 75. When speaking to people, he seldom looks at them. He rarely starts a conversation. He prefers being alone. His sentences seldom are more than five words, and if you sit him in front of a computer chess board, he stares at it and never makes a move. But if someone moves a piece, he becomes engaged and starts moving his pieces. Sometimes he wins.
Commentary
NRA Props Up Violent Crimes Like a Holster Supports a Gun

By Peter S. Kahrmann

When it comes to promoting a safe society, the horrifying display of gun violence at the Aurora movie theater in Colorado once again underscores the accuracy of the phrase “actions speak louder than words.” Given that, it seems clear to me that the National Rifle Association is a leading supporter of violent crime.

This must change.

Journalist Bill Moyers was right when he said the NRA is the killer instinct’s best friend and, I would add, a great supporter of violent crime.

The facts establish beyond a reasonable doubt that lax gun laws directly contribute to the massive amount of criminal killing and disabling in my country. The NRA instinct to oppose anything that would do so much as slow down people’s ability to buy firearms of any kind no matter their background has proved to be a recipe for death, and I firmly believe the NRA knows this and doesn’t care.

The NRA’s mantra that responsible gun-control measures will only take guns away from good and decent law-abiding citizens falls on its face when confronted with, well, reality. Let’s remember that it was the lack of responsible gun-control measures that made it easy for alleged Colorado shooter James Holmes to buy an assault weapon, shotgun, handgun and 6,000 rounds of ammunition legally.

Another NRA mantra, that criminals will always get guns if they want them, is more of a reason, not less of one, to develop more effective and responsible gun-control measures.

It is the very lack of responsible gun-control measures that makes it easy for criminals to get guns. The NRA knows this, likes this and perpetuates this. The people of this country would be well advised to call out the NRA over its oft-stated claim that it supports the enforcement of current gun-control laws and the goal of keeping guns out of the hands of criminals for what it really is: utterly delusional or an outright lie. I believe it’s the latter.

Our elected officials should call them out too, but that would require courage and a willingness to risk one’s job to do so. Why would they want to risk their jobs? So what if, as the Children’s Defense Fund reports, more than one million people have been killed with guns in the United States since 1968, the year Dr. Martin Luther King Jr. and Bobby Kennedy were assassinated? So what if 40 percent of gun purchases happen in secondary markets (gun shows) where there are no background checks?

Can any of us imagine living in a country that requires a license as proof that you know how to drive but doesn’t require one – or insurance -- if you buy a used car from a private individual or secondhand dealer?

The NRA opposition to any responsible gun-control measure – including safety checks to make sure guns are well manufactured! – reveals a support for death and injury by gun, whether intentional or by accident.

The NRA doesn’t care, and some of our elected officials don’t care, while others don’t care enough.

They don’t care enough that 39 percent of TBIs (traumatic brain injuries), like mine – meaning brain injuries caused by external force -- are caused by guns. Nor do they seem to care that the Harvard Injury Control Research Center reports that guns in the home result in higher rates of homicides, suicides and unintentional shootings.

The NRA has a well-documented history of opposing bans on armor-piercing (cop-killing) bullets.

Just as scary, the Brady Campaign to Prevent Gun Violence recently reported that Florida attorney general and NRA darling Pamela Jo Bondi “filed a notice of appeal to the U.S. Court of Appeals for the 11th Circuit, seeking reversal of the June 29, 2012, ruling by U.S. District Judge Marcia G. Cooke permanently blocking Governor (Rick) Scott’s doctor gag rule that restricted doctors from in-

formed patients about the proven risks of guns in the home."

Why would anyone want to stop doctors from simply talking to patients about the proven risks of having guns in the home? Can you imagine being a pediatrician and being told you are not allowed to mention to parents the importance of gun safety?

Talking to families about gun safety does not infringe on anyone’s Second Amendment rights. And let me just say this: If the founding fathers were to come back to life and tell us that the Second Amendment meant that anyone and everyone can get any kind of firearm they want whenever they want, then we might want to revise or get rid of the Second Amendment altogether.

I don’t for a second think that’s what the founding fathers would say. I think the NRA chants the Second Amendment mantra simply to cover its primary purpose, which is to make as much money from promoting the sale of firearms as it possibly can, death and carnage be damned.

I believe too that the NRA knows its fanatical opposition to responsible gun control and gun safety fuels violent crime, which in turn fuels the NRA’s fear-based sales pitch: You’d better buy a gun to protect yourself.

The NRA is only part of this
When you think of Parkinson’s disease, you don’t often think of humor. People with this disability can experience such symptoms as shaking, difficulty controlling muscle movement, altered speech and memory problems, along with encountering stigma and employment discrimination. If they hide their condition from their families, friends, colleagues and others in their lives, they often feel even more stressed.

Despite these serious issues, Dr. Karen Jaffe, a Cleveland obstetrician and gynecologist who has Parkinson’s, and her husband founded Shaking with Laughter, a foundation that uses humor to raise money for Parkinson’s disease research. Karen and Marc Jaffe recently chatted by phone separately with a reporter.

Karen Jaffe spoke from the back seat of a car on her way to Iowa, where she was about to participate in the Des Moines Register’s annual Great Bicycle Ride Across Iowa. (She rode with a contingent of people with Parkinson’s, she said, for the exercise and to raise awareness of the disease.) During the chat, Jaffe discussed what it’s like to live with Parkinson’s, the stress of keeping her disability under wraps and Shaking with Laughter. From Cleveland, Marc Jaffe -- a playwright, writer and comedian -- spoke of his shock when his wife’s illness was first diagnosed and what it’s like to be a spouse of someone with that disability.

When she was first diagnosed with Parkinson’s at age 48, “I didn’t believe that guy (the neurologist),” Karen Jaffe said. “I thought he was crazy. When the diagnosis was confirmed a year later, I finally believed it. I’d just completed my training as a mohel (someone who circumcises Jewish babies). What a day to find out.”

Fearful that she would be stigmatized if people knew about her disability, she at first told only her husband. “It was very difficult,” she said. “The kids found out by accident. Then they had to keep it a secret. It nearly killed our youngest daughter -- it was so stressful.”

It took time to get over the shock when he learned that his wife had Parkinson’s, said Marc Jaffe, who was a writer with the “Seinfeld” TV show. “It was very difficult,” he said. “The kids found out by accident. Then they had to keep it a secret. It nearly killed our youngest daughter -- it was so stressful.”

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Looking back, it was difficult for him as well as for his spouse, Marc Jaffe said. “I was in the same situation of having to keep it (Karen’s Parkinson’s) a secret. Karen has to take the meds and had to hide her physical symptoms and emotions. But I didn’t have people I could talk to. I was getting support from family or friends.”

Being closeted about her illness became so stressful that Karen Jaffe decided to stop hiding her Parkinson’s. “My neurologist’s office was next door to mine,” she said. “I kept sneaking in the back door to see him, hoping my patients wouldn’t see me. I felt like Mata Hari.”

Though revealing that she has Parkinson’s was difficult, “coming out as a patient is, I hope, the bravest thing I have to do in my life.”

Despite the difficulties, being open about her condition has helped to break down the stigma surrounding Parkinson’s, Jaffe said. “I’m asking my patients to trust that I can still work, that I’ll know when it’s time for me to hang up my stethoscope, which may not be for a long time.”

Her patients have been supportive, Jaffe said. “I’ve hugged more women in pink gowns,” she said. “They’ve known me for a long time. One patient, Jill, said jokingly to me, ‘I don’t care if your arm starts shaking, I’m still going to let you put your finger up my butt.’”

Once she stopped being secretive about her disability, “I figured I couldn’t just complain about having Parkinson’s. I decided I’d have to use my voice as a doctor -- to do something about it.”

Out of this desire, Karen and Marc Jaffe established Shaking with Laughter, a Cleveland-based foundation that presents events, using humor, to raise money for Parkinson’s disease research. Proceeds are given to the

A promotional photo for “Side Effects May Include...”
School’s Behavioral Approach Gets High Marks from Parents

By Amy Halloran

The Albany Free School doesn’t classify ADHD as a learning disability. The small private school in upstate New York takes kids at face value, rather than identifying them by labels.

The word free in the name refers to the democratic education at the root of the school’s mission. About 50 to 60 children attend in any given year. The school, which started in 1969, serves preschoolers through eighth graders.

Chris Mercogliano taught at the school for 35 years and retired from directing it five years ago. He’s written four books on education: “Making it Up As We Go Along: The Story of The Albany Free School,” “Teaching the Restless: One School’s Remarkable No-Ritalin Approach to Helping Children Learn and Succeed,” “How to Grow a School: Starting and Sustaining Schools That Work” and “In Defense of Childhood: Protecting Kids’ Inner Wildness.”

“Assume they have a problem, and the chance of solving it goes down,” Mercogliano said when asked to discuss ADHD and schools. “When kids have problems, they’re often fairly complicated. Creating labels and lumping kids is dangerous because kids are so different from each other, and problems are very specific and extremely contextual.”

The Albany Free School’s approach is to consider each child individually, without comparing anyone to anyone else. The school trusts children’s wisdom to find what they need. Very often, Mercogliano said, the children have the answer, and any solutions sought involve the child.

This is not to say that if categorization is stripped away that the answers are easy to find. Mercogliano has worked with a range of kids with a variety of struggles. He’s observed high levels of impulsiveness that get in a child’s way.

“Some kids are so high energy, I don’t think it feels good to be that way,” he said. “Their inability to relax deprives them of success.”

But saying ADHD is genetic and incurable and is only solved by a pill lets people off the hook, said Mercogliano, who referenced a 1994 article in The New York Times by Natalie Angier titled “The Debilitating Malady Called Boyhood.” The article discussed the medicalization of behaviors that used to be accepted as boylike.

“I don’t think it’s that simple, but that’s part of the picture,” he said. “I don’t think nature is ever that simple. There is no cause-and-effect chain. Living organisms don’t work that way. Everything is connected to everything else by thousands of feedback loops. You can’t separate an organism from its environment.”

In other words, there is a social element to the problem, and some people believe it can be tackled through behavior. One couple, “Sean” and “Sara” (whose names have been changed to protect their privacy), found great relief from this approach when they brought their son “Matt” to the Albany Free School for seventh and eighth grade.

“There were behavioral issues when he was younger, as well as ADHD, and a lot of his issues were attributed to ADHD,” Sean said of his son. “He was typically hyperactive, not being able to sit still, and was being distracting to other students. We worked with teachers to try to figure out systems, but schools wouldn’t allow Matt to attend unless he was on medication.”

Of course, schools could not legally insist on medications, but the implication was clear during weekly meetings with guidance counselors, teachers and principals. Eventually, Sean and Sara grew so frustrated with trying to work with their son that they went to see a parent coach. The coach never met Matt but worked with his parents on how they engaged with him. The couple learned how to focus their attention on the positives and totally ignore anything that was negative.

The method was transformative. Within two weeks, Matt was a different child. He went from being incredibly violent and totally belligerent to being able to go to school without medication.

“That right there speaks volumes about ADHD issues and how society and schools are not set up to handle...
Soon, other like-minded individuals joined them, and New York state's fledgling disability movement began. Back then, McQuade said, people attended meetings based on their work schedules or other commitments.

"Judy had a job where she finished work early in the day, so she went to the day meetings. She also had a place where the core group could get together for meetings and planning sessions. It was all very informal but deliberate. We were organizing a community."

Because there was no accessible transportation, McQuade said, anyone who had a vehicle would pick up anyone else who needed a lift. "We were meeting, basically, in Brooklyn at anybody's house that was accessible. From there, we later branched out to the other boroughs throughout the city to meet."

Initially, the group worked on advocacy and legislation, along with broadening physical access as well as access to city government. Group members also "took notice of what the leaders of the black civil rights movement were doing, and we patterned some of what we did after that (movement)," McQuade said. "We chained ourselves to buildings, invaded decision-makers' offices, and let ourselves be led away in handcuffs to bring attention to the inequities and injustices we faced every day."

As their "community" jelled, group members decided they needed a unifying name. Initially, they called themselves Handicapped in Action.

"We later changed that name after Judy said, 'Someone mentioned that we shouldn't call ourselves handicapped. Anyone could have a handicap, but if you're disabled, it's a stronger word, and not everybody can be disabled.' I said that's fine with me so, with that, we became Disabled In Action."

Pat Figueroa, who was to become another core leader of the disability movement and who recently

Michael J. Fox Foundation for Parkinson’s Research.

Using Marc Jaffe’s connections with the entertainment industry, the couple has persuaded comedians, musicians and other entertainers to perform at Shaking with Laughter fundraisers. Comedian Jake Johannsen, who appears regularly on “The David Letterman Show,” and Grammy-winning blues singer Keb’ Mo’ will perform Sept. 22nd at Shaking with Laughter’s annual gala at the Ohio Theater.

In 2010, Marc Jaffe began writing, with playwright Eric Coble, “Side Effects May Include,” an autobiographic comedy about a comedian whose wife has Parkinson’s. “It’s about how their life is changed (after her Parkinson’s is diagnosed),” Marc Jaffe said. “It deals with the impact that issues of drugs, side effects and secrecy have on their relationship."

Contrary to what some might expect, “Side Effects,” though it deals with serious matters, is often comic. “In the show, one of the side effects of one of his wife’s drugs (for her Parkinson’s) is that her libido is increased,” Marc Jaffe said. “He has a hard time keeping up with her!”

“Side Effects May Include” was first performed at the Cleveland Public Theatre. The one-man comedy, starring Andrew J. Pond, is now on tour. Ten percent of the proceeds from the show is donated to Shaking with Laughter.

“Their’s so much fear involved with Parkinson’s, from ‘Will I find employment’ to ‘No one’s going to want to have a relationship with me because I have this illness,’” said Wendy Kaplan of MadKap Productions, the producers of the play. “But the show is very funny. You tell people that, and they say ‘How can it be funny?’ But Marc and Karen Jaffe look at the world with humor. That’s how they deal with everything."

The emotional feelings evoked by “Side Effects” are universal, Kaplan said. “Name your disease,” she said. “My mom died from early onset Alzheimer’s disease. We all have some degenerative disease or know someone who does. ‘Side Effects’ is poignant and comic and touching."

For more information, go to: www.shakingwithlaugher.com org www.madkapproductions.com

Kathi Wolfe writes frequently on disability issues. She is a contributor to the anthology “Beauty Is a Verb: The New Poetry of Disability.”
change. The mechanics of our disability process comprised history, culture and inclusion in a way that the rest of our community would be proud of."

Eleanor Smith, executive director of Concrete Change, said she would rather have two square feet of a permanent disability rights exhibit than 400 square feet of an annual or “now and then” exhibit. Dan Wilkins, communications director of the Ability Center of Toledo, Ohio, recalled his experience at the ADA’s 10th anniversary celebration at the Smithsonian National Museum of American History. He had viewed the disability history exhibit positioned next to the famous Woolworth’s lunch counter from the civil rights movement and, when he returned, noticed that the disability exhibit was gone. Then he remembered that the Smithsonian had labeled it a temporary display.

“It was a joy to see us working in concert,” Smith said. “In the end, the CEO suggested a permanent exhibit with changing content, and we all assented to that.” At the suggestion of Laurie Block, executive director of the Disability History Museum, a committee of Georgia-based advocates was formed to provide content to the NCCHR.

Smith sees the battle for disability rights being told in three strands, or braids, for which templates could be developed and sent to centers for independent living. The first braid would be about pre-ADA discrimination that would include, for example, stories about education, transit and institutionalization before those involved had any rights at all. A story about a person who missed the wedding of his sister or the christening of her niece because of a paratransit ride that never came would fall into this category.

A second braid would be people who benefited from the enactment of the ADA and recognized moments when things were different.
In 2011, Samuel R. Bagenstos — now a professor of law at the University of Michigan, then the principal deputy assistant attorney general in the Civil Rights Division of the U.S. Department of Justice — said: “[W]hen individuals with disabilities spend years — indeed, decades — in congregate programs doing so-called jobs like these, yet do not learn any real vocational skills, we should not lightly conclude that it is the disability that is the problem. Rather, the programs’ failure to teach any significant, job-market-relevant skills leaves their clients stuck … [T]he ineffectiveness of sheltered workshops for helping individuals progress to competitive employment is well established.” And, I would say, purposeful. I have no doubt the absence of teaching job-market-relevant skills is by design.

Nevertheless, all of us, with or without disabilities — I wonder if anyone, upon honest reflection, can claim membership in the latter group — live in a culture that says our identity is found in our job titles, years of education, where we live, what we drive, and, underpinning it all, the size of our income. Making money for others gives you value but, in that case, it’s value as a commodity, a machine, a thing.

This society says the wealthier you are, the greater your value as a human being.

Nothing could be less true.

Yet, it is terribly difficult to break free of this message. It is a savage message that has imprisoned the majority of us in cells of cultural mores designed to destroy individuality, condemn us to a life of subservience to the economically powerful, those who, more than simply controlling the purse strings, own them.

So, what to do?

Give yourself permission to be yourself to the best of your ability. While I cannot and should not attempt to dictate how you should do this, I can tell you some of the strategies I use in the hope that some of them may work for you or prompt thoughts of others that will work for you.

One of my strategies consists of making an effort to stay aware of and connected to the parts of life that give me joy and fulfillment and are not highly reliant on my pocketbook or the permission of others. Those who know me well will say my first love is reading. They are right. When I am reading a book I love, there is no person or element of society capable of intruding on the relationship between me and the unfolding tale.

The same can be said of my love of music, or the joy I feel when immersed in the embrace of nature. Conversations with friends are untouched by extraneous things. When I write, like now, I am fully me, and the cost of the clothing I’m wearing or the brand of the computer I’m using have no bearing on the words I set down. If they have meaning for you, it is because of their content, not the wealth or lack of wealth linked to the man who wrote them.

I have learned this too: As long as I’m here I will not only be OK, but my value will never be diminished. And I can say to each of you with absolute certainty: As long as you know you’re there, being you, you are right where you’re supposed to be.

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

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NRA

country’s truly sick relationship with and understanding of guns. One of the most disturbing things I heard in the wake of the brutal shootings in Colorado was a young man saying it was a good thing Holmes could get guns and ammunition legally because it saved lives. This person’s troubling and bizarre reasoning? Had Holmes not been able to buy an assault weapon, shotgun, handgun and 6,000 rounds of ammunition, he would have blown up the theater and killed even more people.

This is only one of the sickening and deeply disturbing things I’ve heard from some of those who call themselves gun advocates. Others said that if theatergoers had concealed weapons, they could have shot back. Former Pennsylvania Governor Ed Rendell right-sized this craziness beautifully: “We would...
The Community Living Assistance Services and Supports Act (CLASS Act) program for long-term-care insurance, as well as a number of mandatory grant programs including funds for so-called high-risk pools, reinsurance for early retirees, and prevention and public health activities.

The provisions that created the Independent Payment Advisory Board, which has the explicit task of reducing the rate of growth in Medicare without affecting coverage or quality.

The expanded subsidies aimed at closing the “coverage gap” in Medicare Part D, the so-called “doughnut hole.” The gap is a range of spending in which many Medicare beneficiaries are financially responsible for the entire cost of prescription drugs until the expense reaches the catastrophic coverage threshold.

On Election Day, Nov. 6th, the disabled community must come out in droves, bringing friends, relatives, even the butcher and the corner locksmith, to vote for President Obama. We must ensure that the programs we need for our continued existence in the community remain functioning.

Barbara “Bobbi” Linn has been a disability rights activist for the past 35 years. She is the founding executive director of Bronx Independent Living Services and served as chairwoman of the New York State Independent Living Council.

ADA Legacy

such as their first ride on a lift-equipped bus or the first time they used a curb cut. The second braid would speak to how some rights have not yet been achieved, and how some people are still locked away in institutions against their will; cannot find accessible, affordable, integrated housing; and remain unemployed.

“Go for the gut,” Smith urged. “Do not be afraid to tell how happy you were on the second braid, and how you felt intense pain and exclusion in strand one. Show that gut-level pain, anger and fear. People in institutions still cannot speak their minds without fear of serious reprisal.”

Johnson urged people to be patient with the process. “You can be doing great work by yourselves, but by coming together, the 25th anniversary and the ADA Legacy Project results will be far greater.”

To join the ADA Legacy Project, go to http://www.facebook.com/ADALegacy.

Janine Bertram Kemp is a writer, advocate and president of the Disability Rights Center. A former communications director for AAPD, she left Washington, D.C., to take refuge in the forests of Zig Zag, Oregon. She also is a member of ADAPT.

NRA

of no one who thinks of Martin Luther King Jr., Gandhi, Nelson Mandela or, for that matter, Jesus, as being weak.

Gun carnage will not stop until the people en masse and our elected officials stand up to the NRA and put the safety of the people -- our children! -- first.

In short, safety before financial profit.

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

For Blind People Everywhere, U.K. Technology is TV ‘Guide’

By Deborah Kendrick

To illustrate how fond people in the United Kingdom are of television, Richard Orme said that “there are more televisions than there are people in the U.K.” Orme, who is head of accessibility and chief of digital inclusion at the Royal National Institute of Blind People, was referring to all citizens of the United Kingdom, but he quickly followed that up by saying that blind people in his country love television just as much as everyone else -- and that is a lot.

Surprising though it may be to most Americans, when it comes to blind people and television accessibility, the United Kingdom is miles ahead of the United States. First, there is the content itself. With the recent implementation of the Twenty-First Century Communications and Video Accessibility Act, the U.S. now offers four hours per week of programming with video description on nine different networks. Video description, which the British call “audio description,” is the additional audio track that contains descriptions of such visual elements as gestures, actions, facial expressions, and so on, thus rendering the visual elements of a television program accessible to those unable to see it.

By comparison, the United Kingdom boasts 69 channels that offer programs with descriptions, many of which provide descriptions for as much as a third of all broadcasts. But what many find amazing about the U.K.’s major technological leap forward is the commercially available equipment used for watching television.

Those who are blind are frustrated by the absence of description when part of a show is silent or just playing music suggestive of a car chase or other bit of suspense. How do they find out which channel is playing or what’s on tonight at 9? People know, of course, because they see and read the onscreen menus -- unless they can’t see them.

Blind TV
“And a lot of that has to do with priorities.”

Those priorities focused on helping each individual develop as a person. There really wasn’t a lot of room for Matt to frustrate people, his father said. Matt learned the system and grew exponentially. One element that helped boost his confidence was the fact that he wasn’t constantly reprimanded. Although he saw his son succeed through the school’s behavioral methods, Sean still sees a place for medication. In fact, now that Matt is physically large enough to handle medication and articulate enough to help modulate it, the family sees medicine as a useful tool to help Matt work within the academic system. (He attended a boarding school in the fall and will attend a private high school this year.)

“I bet you the majority of the cases could be handled by behavioral therapy – first, the parents,” Sean said. “If teachers were trained correctly, I think we’d have a lot less kids on medication. I’ve seen Matt go through a couple of years of his life as a zombie. It doesn’t help people become a real person, doesn’t help confidence levels, doesn’t help kids figure out ways to deal with their problems or figure out solutions that do feel good.”

Of course, the financial realities of both public school systems and pharmaceutical companies oppose this kind of solution, but Sean believes such change would dramatically alter the educational landscape.

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Of course, the financial realities of both public school systems and pharmaceutical companies oppose this kind of solution, but Sean believes such change would dramatically alter the educational landscape.
The National Federation of the Blind (NFB) is urging everyone who thinks it’s important for people with disabilities to find meaningful employment to take action by boycotting Goodwill Industries.

“Goodwill Industries is one of the most well-known and lucrative charitable organizations in the United States, yet it chooses to pay its workers with disabilities less than the federal minimum wage,” Dr. Marc Maurer, president of the NFB, said in a June 7th statement. “We are calling upon all Americans to refuse to do business with Goodwill Industries, to refuse to make donations to the subminimum-wage exploiter, and to refuse to shop in its retail stores until it exercises true leadership and sound moral judgment by fairly compensating its workers with disabilities.”

Section 14(c) of the Fair Labor Standards Act permits employers to petition the U.S. Department of Labor (DOL) for certificates exempting them from paying minimum wage to certain workers with disabilities. An estimated 420,000 disabled workers are paid less than minimum wage under this provision.

A statement issued by Goodwill in response to the NFB acknowledged that 64 of its organizations report paying approximately 7,300 of its 30,000 employees with disabilities less than minimum wage. But, according to the statement, the average hourly wage of those workers is $7.47.

NFB, however, said that documents obtained from the DOL under the Freedom of Information Act revealed that some Goodwill workers were being paid as little as $1.44 per hour. Maurer called that “blatant hypocrisy” when contrasted with the salary of Goodwill CEO James Gibbons, who is blind. Gibbons’ annual salary is $443,000, and his total compensation is $612,000.

Chris Danielsen, director of public relations for NFB, acknowledged that Goodwill is a symbolic target. He said that other well-known organizations such as Easter Seals, UCP and the ARC use wage-exemption certificates. NFB’s research revealed an Easter Seals facility paying as little as 52 cents per hour. The boycott, Danielsen said, is intended to draw attention to the campaign to permanently repeal the 14(c) exemption.

“One of the major hurdles to repealing Section 14(c) is that most people are unaware that it is legal to pay workers with disabilities subminimum wages,” Danielsen said. “Goodwill is a household name and the self-proclaimed leader in providing employment services for people with disabilities. The boycott is an awareness campaign that will capitalize on the public’s recognition of Goodwill to inform the public of this unfair, discriminatory and immoral practice and motivate members of the public to take action to assist us in repealing Section 14(c). Goodwill has the most common household name, with locations across the country. They are the most prone to public scrutiny and the simplest entity that the most people can boycott.”

On Oct. 4th, 2011, Congressman Cliff Stearns, R-Fla., and Congressman Tim Bishop, D-N.Y., introduced the Fair Wages for Workers with Disabilities Act of 2011 (H.R. 3086). The bill would phase out Section 14(c) over a three-year period.

“Simple fairness and decency require that workers with disabilities receive equal pay for equal work,” Stearns said.

NFB is one of more than 40 disability organizations supporting passage of the bill. But Goodwill is firmly opposed.

Brad Turner-Little, director of mission strategies for Goodwill, said that his employer “has a long history of supporting a variety of strategies and initiatives that create employment opportunities for people with disabilities. We are supportive of using all the tools available to create employment opportunities. The special minimum-wage certificate, we believe, is an important resource for creating employment opportunities for individuals with significant disabilities and should remain being available. It is a tool in the toolbox.”

Turner-Little emphasized the word “significant” when characterizing the disabilities of those paid less than minimum wage because to receive a certificate of exemption, an employer must make the case to the DOL that an individual worker is less productive performing a job than a worker without a disability.

“The certificate creates a context where it removes the economic disincentive around productivity,” he said, adding that those making the lowest wages also receive other forms of public support, such as Social Security. “Financial independence is not necessarily the goal. The goal is to create a work opportunity that can work within the benefits structure that a number of people with disabilities have to navigate.”

Said Gibbons: “We don’t think the legislation is going anywhere, but we don’t support it as written. There are ways of utilizing (Section) 14(c) that are really meaningful. When done right, it’s a very, very useful tool.”

Gibbons speculated that Goodwill workers earning far less than minimum wage are people with multiple, complex disabilities who might not be productive enough to have a job at all if not for 14(c). “This is an opportunity for them to come to work, have a safe environment where they can contribute at the level they can contribute.”

In a letter to all members of Congress urging their support for the Fair Wages Act, Maurer wrote: “Those of you who are cosponsoring...”
McQuade
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passed away, remembered McQuade and those times.

"That's where I first met Denise – at a DIA meeting in Judy's apartment at 175 Willoughby Street," Figueroa said. "She was shy and soft-spoken, but she became a very strong voice for disability rights. Judy asked her to take a letter and started dictating it to the commissioner of the New York City Housing Authority about a housing issue I had. It was then and there that I realized she was one of Judy's confidantes – her go-to person.

"Judy and Denise became two of my favorite advocates and friends," he continued. "Sometimes, Denise would give me lifts to meetings and other actions. When I was director of the Center for Independence of the Disabled, New York (CIDNY), I was happy to see Denise become director of the Brooklyn Center. She developed a strong personality and confidence."

McQuade was among the first to see the need for independent living centers, but she gives full credit to other disability leaders such as Fred Francis, Greg O'Connor, Pat and Denise Figueroa, and many others for their creation.

"The growth of independent living in our state really came out of the efforts of people like Fred, Pat and Greg. They went to grassroots organizations around the state to encourage people to apply to become a center. They really are responsible for a lot of the access, if not all of, the access that came about. The first two centers were CIDNY and us in Brooklyn. We divided up the city – we took care of Brooklyn and Queens, and they did Manhattan and the Bronx.

"We started the ILCs to have a different philosophy from MDA's 'Help Jerry's Kids' way to get people to act. They used pity and guilt. Our philosophy was to first show you how to do something. Then, if you couldn't do it, we'd help you do it or -- only if necessary -- do it for you. That was a new thing to people."

From there, McQuade volunteered with, worked for, or was asked to join many other key disability organizations and committees. Two of the most prominent were the New York City Mayor's Office for People with Disabilities and the National Council on Independent Living.

"During the time I was at the ILC, we worked on so many critical disability issues including legislation like polling access, statewide accessible mass transit, or uniform building codes. We worked on changing New York City.

"At NCIL, we also worked on the Air Carrier Access Act and the Fair Housing Act, among others. But one of the major functions of the committee I was on at NCIL was to pass the ADA. That day when I was in the Rose Garden (at the White House) and the ADA was signed into law was a tremendous and exciting time and one of the proudest moments in my life."

She is, however, most proud of DIA's success.

"We are all citizens of this country and we deserved the same civil rights as anyone else. We had rights that were being denied – I believe righting that wrong is DIA's greatest achievement, and I am most proud of playing a role in that accomplishment. DIA always supported independence and people making their own decisions, which was a huge, important step for people with disabilities."

Currently, McQuade works for the Metropolitan Transportation Authority, a turn-around that even surprises her. "If somebody told me I'd end up working for New York City Transit, I would have told them they were insane," she said with a laugh. "We spent so many years opposing them over the whole issue of accessibility. However, a Transportation Disabled Advisory Committee was formed and an agreement worked out to improve city bus and subway access, as well as purchase new accessible vehicles. I was appointed to that oversight committee and, now, here I am!"

"Looking back, it's one thing to bring things up, it's something else to set goals and get things done. We got things done -- that's one difference between the Occupy Movement and our movement. We didn't view ourselves as heroes. We were all committed to doing whatever it took to reach our goals. I was just happy I was involved and helped bring about change."

* * * * * * * * *

Alan St. James is a professional editor and writer and a longtime disability advocate. He enjoys traveling, cruising with his classic muscle car and musical theater. He lives in Albany, N.Y.

Voter
Continued from page 4

dence showing the voter's address.

But in 2011, 34 states introduced strict voter ID laws that would require potential voters to show photo identification before they cast their ballots. The legislation was passed in 13 states but vetoed by governors in six of them. The laws in some states are being reviewed by the U.S. Department of Justice (DOJ) to determine if they comply with Section 5 of the Voting Rights Act of 1965, designed to keep southern states from implementing poll taxes or other Jim Crow-like measures.

These restrictive voter ID laws would require voters to bring unexpired driver's licenses, unexpired state ID (non-driver) cards obtained from state divisions of motor vehicles, or unexpired student ID cards as identification when they come to the polls. Why is this legislation so onerous? Because you can’t just go to the Department of Motor Vehicles and get a driver’s license or state ID.

Said Lieberman, "What many people don’t realize is that you have to provide sources of identity — a birth certificate — if you’ve gotten married or divorce documents to document your name change — proof of residency — or citizenship before you can get a driver’s license or state ID."

Voter
Continued on page 15
“We’ve never had a case in Missouri of a person falsely identifying him (or her) self at a polling place,” said David Newburger, co-director of the Starkloff Disability Institute in St. Louis. “Their (voter ID) laws are designed to solve a problem that doesn’t exist.”

You’d have to go through a lot of trouble to steal someone’s identity in order to vote, Lieberman said. “It virtually never happens.” John Ashcroft, attorney general under President George W. Bush, was charged with cracking down on voter fraud. He did a five-year study that found only 86 instances of voter fraud.

Most of those acts involved people who were improperly registered, said Lieberman, who added that “most get caught in the process.”

The ACLU, the Advancement Project and other advocacy groups are submitting letters of comment to the DOJ asserting that voter ID laws shouldn’t be implemented because they would be an unduly burdensome requirement for minority voters. “It’s a voter-suppression tactic,” said Nancy G. Abudu, senior staff counsel for the American Civil Liberties Union. “It discourages voter turnout and registration. It’s the opposite of what we should be doing.”

Challenging voter ID laws and other voter-suppression measures will be hard. But people with disabilities, people of color, young voters, seniors and others who are (or would be) adversely affected by such legislation shouldn’t give up. I’m not saying that we should vote for any particular party. But voting is a right, not a privilege.

What can we do to protect this precious right? Lieberman offers these tips:

1. Tell your story. Most people don’t realize that some voters don’t have an ID or would have difficulty getting one.

2. Call or write your state legislators and let them know you oppose voter photo ID laws and share your story.

3. Testify at the state capitol against repressive voting measures when the legislature holds hearings on the issue.

4. Write a letter to the editor telling your story and why you oppose repressive voting measures.

5. Agree to be a plaintiff in a legal challenge to voter ID laws.

6. Volunteer with your local voter protection coalition or disability vote project to help educate fellow voters.

For more information, send an email to: vrp@aclu.org

Kathi Wolfe is a writer and poet.

“Rather than participating in a constructive dialogue about what life will be like for workers with disabilities once the subminimum wage exemption is phased out in three years as required by H.R. 3086, the workshops choose to cultivate correspondence meant to pull on your heartstrings, to evoke your pity, and to promote low expectations.”

Maurer also wrote: “There was a time in our nation’s history when African Americans were believed to have limited capacity and were fit only for slave labor on plantations. There was a time when women were thought capable only of maintaining the family home, and thus were not even permitted to vote. Fortunately, we realized as a nation that it was bigotry and low expectations that were defining the roles of African Americans and women rather than their true capabilities. We realized, albeit belatedly, that America would be a better nation if the true capacities of these citizens were unleashed. Americans with disabilities are now calling upon our fellow citizens to realize that the soft bigotry of low expectations is condemning workers with disabilities to near-slave labor, and that the system that arises from these low expectations must be abolished.”

Danielsen said HR 3086 faces formidable opposition from “members of the
sheltered work system" who see Section 14(c) as a “cash cow.” The campaign against Goodwill may not be able to build the momentum to get the bill passed, he said, but maybe enough pressure can be generated to get Goodwill to change the way it does business.

“If we can get Goodwill to adopt a new policy to pay at least the federal minimum wage to all of its workers with disabilities, then there will be no excuse for Easter Seals, UCP and the ARC and the other entities not to follow.”

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

When it comes to playing computer games with movement, Tim is proactive. He is a fanatic for repetition.

Fifteen minutes after he starts My Football Game, an alarm goes off. Tim knows it is time to go to another activity. Lucifer picks passing. Tim’s face lights up as he practices having the quarterback pass to different receivers. He does this by pressing the keys S, R and F. He points to the football in the air and says, “I throw the ball.” There is a triumphant look on his face.

“Tim can associate causal relationships. I believe he thinks that since the ball can only be thrown when he pushes a key that he’s the one throwing,” says Lucifer, who is certain that the different activities the game offers improves Tim’s hand-eye coordination and concentration. Tim plays two different drills daily. He is good at pushing the keys to produce action.

Fifteen minutes after starting this exercise, an alarm again goes off, and Lucifer shows Tim how to exit the activity. Skipping level 2, they proceed to Level 3, a 20-minute game between opposing teams comprised of four five-minute quarters. Today, the teams are the Chicago Sailors and the Indianapolis Romans. Tim’s favorite is the Eagles, followed by the Tigers. He owns a parakeet and has a picture of a white tiger on his bedroom wall. As Tim and Lucifer prepare to start the game, Tim’s demeanor changes. He removes his headphones and listens to the crowd noise. He is often disturbed by loud, continuous noises, but the simulated crowd noises don’t bother him.

“Listen,” he says as he diligently watches the coin flip. “Yes,” he exclaims while pumping his arm in the air. His team has won the coin toss and will receive the football.

Tim watches closely as Lucifer sets up his defense against a runback. The football is kicked off. Tim’s team receives it and returns it 20 yards. On the first offensive play, the Sailors run the ball wide left, and the runner scores a touchdown. Realizing what has happened, Tim turns to Lucifer and says, “Touchdown for me.” After seeing an instant replay, Tim says, “My runner.”

As Tim’s team prepares to kick off, by pressing the S key, he selects one of the three defenses that appear on the screen, “I don’t know how he does it, but Tim appears to understand these different defenses,” says his father.

Lucifer says, “Computer games such as My Football Game help improve Tim’s hand-eye coordination and thinking skills.”

For 20 minutes, Tim is alert. He watches, thinks and responds to plays. When the game is over, he has won. Proud of his victory, he points to his chest and says, “I won.” Sometimes he says, “The winner.”

Tim plays a second football game, this time against his father. Tim wins 24–17. The second win increases his confidence to the point that he seems as though he is bragging. “Bring it on,” Tim says with defiance.

“Tim prefers My Football Game,” his father says. “He spends three hours daily playing the game.” But last year, he started playing computer golf, including a Tiger Woods game.

Three years ago, Tim played his first game of computer putt-putt (miniature) golf. Since then, he has become a fanatic and plays the game weekly with his father, Lucifer and his 14-year-old brother Thomas. He affectionately calls Thomas “little brother.” He sometimes calls him Tom, but never Thomas.

When playing putt-putt golf, Tim takes a lot of time studying each hole. He is limited to 60 seconds a shot. He takes the full 60 seconds always. He seldom goes over par on each hole. Recently, Tim and Thomas set up My Golf Game. One of the activities of My Golf Game is practicing putting. Tim loves putting and puts for 30 minutes at a time. He goes to that activity first when playing.

Tim enjoys the chip shot exercise. There are five opportunities to put the ball in the hole. While he fails most of the time, that doesn’t deter him. When he puts the ball in the hole, he congratulates himself by clapping.

Tim is enthralled by My Golf Game’s create-your-own-golf-character feature. He created a youthful golfer in his image. Tim uses his image all the time. Pointing to his avatar, he says: “Tim. That’s me.”

“My brother thinks he is on a putt-putt golf course when playing My Golf Game,” Thomas says. He putsts with Tim.

The games were created by veterans with disabilities. “I am so happy to learn about Tim’s success with the games,” says Chuck Bergen, president of VTree LLC and creator of both games.


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