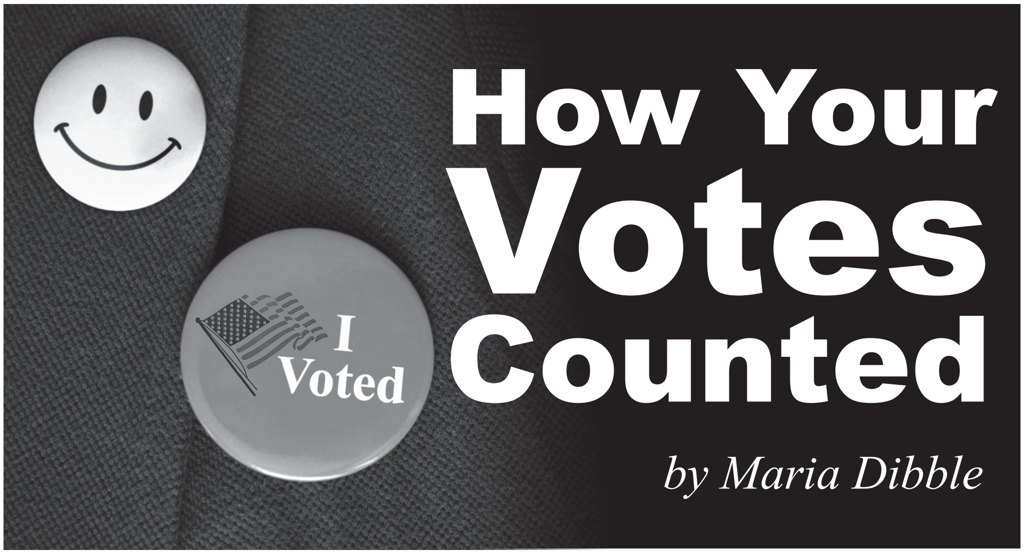
The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

AccessAbility

Winter 2018-2019
Number 133

INSIDE



How Your Votes Counted

by Maria Dibble

By now, you are probably as tired of hearing about the mid-term elections as I am, but they could have major impact on the lives of people with disabilities.

First, state government. The Senate now has a super-majority of Democrats, and will set the agenda for the year. The Assembly remains strongly in Democratic hands, though they did lose a few seats. And, of course, Governor Cuomo easily won re-election as well.

So, in 2019, all branches of NY state government will firmly be held by Democrats. What does this mean?

Hopefully, we will see passage of some important bills that will benefit people with disabilities. This could include: "source of income" legislation, a bill to end the practice of paying sub-minimum wages to people with disabilities (usually in sheltered workshops), and a bill to waive the State's sovereign immunity to claims under the ADA and Section 504. Additionally, we will once again be fighting for the creation of an Office for Community Living (OCL) as well as an increase of $5 million for the 40 Centers for Independent Living (CILs) across the state.

What makes all of these issues so critical?

The first issue, "source of income" legislation, would make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law. Affordable, accessible housing is at a premium in NY and people on a fixed income often cannot afford to pay the rents. The only way they can remain in the community is with appropriate housing that meets their needs, but they simply cannot achieve this without the use of subsidies of some type. Unfortunately, instead of considering such a subsidy a guarantee of payment, landlords fear late payments or no payments at all. And racist landlords use source of income as a "placeholder" for people of color who have low incomes, whom they just don't want to serve at all. This legislation would prevent landlords from discriminating in this manner. Source of income protections already exist for New York City, but not upstate. We hope to see this change.

For decades, sheltered workshops have paid workers less than minimum wage, a reprehensible practice helping to keep people with disabilities in poverty. The proposed bill, which has a good chance of passing both the Senate and Assembly next year, will stop the practice for good in NY.

Since the US Supreme Court's *Garrett* decision, state workers have been unable to sue the state for discriminatory practices, a right all other workers have. If the state explicitly waives its "sovereign immunity," their right to do so would be reinstated, as the Americans with Disabilities Act intended.

Creating an Office for Community Living would greatly benefit people with physical disabilities, finally giving us a voice in state government. The initial purpose of the office would be to reinstate an "advocate" for people with disabilities, representing our concerns, preferences and issues to the Executive Branch. We hope that eventually it will expand to include more.

CILs like STIC haven't seen a budget increase in 13 years, yet health insurance costs have grown by double digit percentages for most of that time. Utility costs have risen, as have rents and equipment leasing costs, and new requirements to comply with cyber security regulations have been imposed, leaving CILs to scramble to cover costs. We had to eliminate a position due to lack of funding, as have other centers. Perhaps a unified legislature can remedy this situation.

AccessAbility

December 2018

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

AccessAbility is published seasonally (Spring, Summer, Fall, Winter) by Southern Tier Independence Center. Letters, information, articles and ads are always welcome. Deadlines are February 15, May 15, August 15 and November 15.

Our address is:

AccessAbility
Southern Tier Independence Center
135 E. Frederick Street
Binghamton, NY 13904

Subscriptions

Subscriptions are $10 per year (4 issues). Subscriptions are voluntary, but very much needed to help cover newsletter production costs. Use the form on the back to subscribe.

Advertisements

AccessAbility prints unclassified ads free for disabled consumers, unless they promote a for-profit business. For-profit businesses can advertise in *AccessAbility*, in Un-classifieds or a display ad, at our regular rates. Ask the editor for information.

Reprints

Any *non-copyrighted* information *originating* in this newsletter may be reprinted without permission. If you want to reprint an article or opinion piece, please credit *AccessAbility* and the author.

Authorship

All articles appearing in this newsletter are written by Ken Dibble unless otherwise noted. Generally, I get tired of seeing my name on every page, and I'd rather use the space for something more interesting. I do put my name on controversial stuff, though, so you'll know who to blame.

www.stic-cil.org

Of course, one thing can bring our hopes to a screeching halt: Governor Cuomo's veto pen.

On the national level, there will be a much different Congress convening in 2019, with the House of Representatives under Democratic control. The Senate is still in Republican hands, almost guaranteeing gridlock for the next two years. Yet gridlock on the federal level can be beneficial if it prevents draconian Medicaid and Medicare cuts, and more raids on other benefit programs such as SNAP.

On the positive side, hot off the presses, Senators Orrin Hatch (R-UT) and Tim Kaine (D-VA) have introduced the "Fair Housing Improvement Act of 2018" (S.3612). The bill expands the Fair Housing Act's protections to prohibit housing discrimination based on source of income or veteran status. Under the bill, source of income includes a Section 8 housing voucher or other form of federal, state, or local housing assistance; Social Security or Supplemental Security Income; income received by court order, including spousal support and child support; and payment from a trust, guardian, or conservator. The bill has been referred to the Senate Committee on Banking, Housing, and Urban Affairs. If it passes and is signed into law, we probably wouldn't need the NY bill.

However, the only way to accomplish anything in Congress is through cooperation with each other and the President, a rather unlikely scenario. It is a sad commentary on our nation's government when we breathe a sigh of relief because there will be gridlock in Washington. I certainly would like to see the branches work together, but I fear that each side is so entrenched in its own rhetoric and beliefs that few people will reach across the aisle to their colleagues on the other side. I hope I'm proven wrong.

Pass the Child Victims Act

by Pat Green Gumson

While I am not a stranger to the disability community, an introduction may be helpful. I began my work as a Head Injury Advocate at the Southern Tier Independence Center (STIC) in Binghamton in 1986. I worked with people with brain injuries and their families. I greatly admired and respected the mothers of young people with traumatic brain injury (TBI) who, like the mothers in Mothers Against Drunk Driving (MADD), used their anger to help others as advocates for prevention and services.

At that time, I did not know that one of my five children was being viciously and sexually abused by a pedophile priest, starting at age eight, and that he, as is typical, would not come forward for another 35 years. So, now I am one of those angry advocate mothers.

In 1993, based on my work at STIC, the New York State Department of Health (NYSDOH) hired me to come to Albany to start and manage the TBI Home and Community Based Services (HCBS) Medicaid waiver for persons with TBI. In 2001, I married Robert Gumson, who recently retired as the manager of the Independent Living Services Unit at ACCES-VR, within the New York State Education Department.

My son, in a crisis, came forward in 2015 at age 44. Advocates had been advocating for the Child Victims Act (CVA) for over a decade. It has passed in the NYS Assembly every year, but the Republican-controlled Senate would not bring it to the floor for discussion and vote due to the lobbying efforts of the Roman Catholic Church, the Boy Scouts of America, a few private schools, and insurance companies. The Senate now has a

BAD WEATHER?

If the weather is bad, **call 724-2111 (voice/TTY)** to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

Democratic majority. The legislation would identify hidden predators and eliminate New York's statute of limitations—the third most predator-friendly in the nation.

This is a prevention issue, this is a justice issue, THIS IS A DISABILITY ISSUE!

The Center for Disease Control (CDC)-Kaiser Permanente Adverse Childhood Experiences (ACE) Study, one of the largest investigations of childhood abuse, found that childhood sexual assault victims have a higher incidence of risky health behaviors, chronic health conditions, low life potential and early death. The CDC found increased risks for alcoholism, drug abuse, sexually transmitted diseases, obesity, self-mutilation, depression and suicide attempts. (How many suicides are individuals who were never identified as abused?) Further, they are more likely to smoke, have poor general health, and experience homelessness. ACE is related to adult diseases such as ischemic heart disease, cancer, chronic lung disease, skeletal fractures, liver disease and drug addiction.

Recent surveys completed by the Bureau of Justice Statistics found that both male and female incarcerated offenders (about a third of whom have mental health disabilities) were twice as likely to have experienced childhood sexual abuse than individuals in the general population.

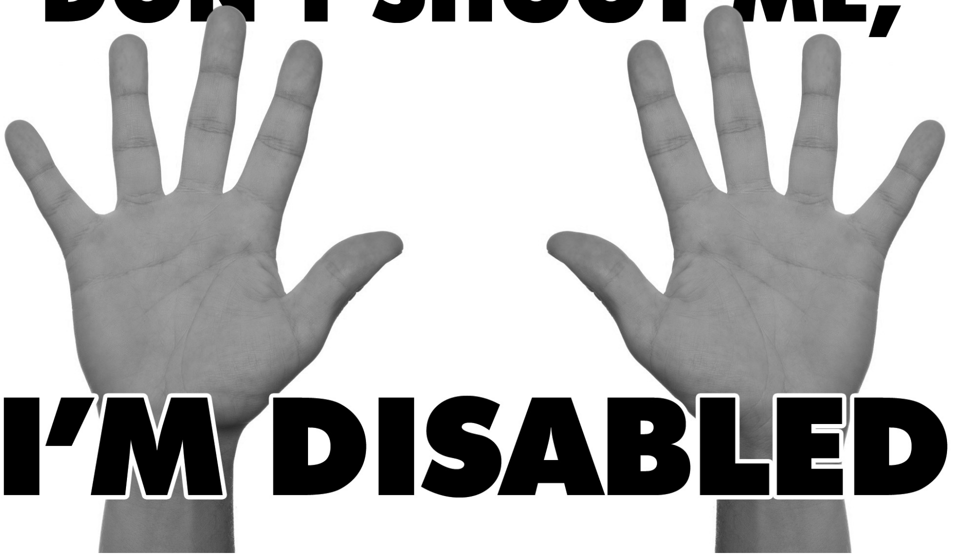
Children do not even have the vocabulary to process or communicate what is being done to them by persons in power over them. The Shaw Mind Foundation states that "these feelings of being trapped and stressed, leading to an overwhelming coping response, is the definition of trauma. This fear, helplessness and powerlessness are all features that mean PTSD [post-traumatic stress disorder] is more likely to occur." The PTSD from childhood feelings of not being safe can last a lifetime, resulting in nightmares, insomnia, anxiety and psychiatric disabilities.

Earlier in 2018, NPR reported that people with intellectual disabilities were seven times more likely to be sexually abused or assaulted than nondisabled people.

The CVA must pass this year. This is a No Excuses Year for the Senate. A lot of lobby dollars will try to weaken the legislation for the benefit of institutions that covered up these crimes all these many years. Ask your Senator for full support. And if you have any information about abuse by Catholic clergy, call the New York State Attorney General Hotline at (800) 771-7755, or use the web form at https://ag.ny.gov/clergyabuse-form.

Thank you.

DON'T SHOOT ME, I'M DISABLED



"I have been asked questions like 'You mean they are not all the same?' or 'So they are not out to hurt us?'"

That's Patti Saylor, who trains police officers in how to deal with people with disabilities.

You may remember the name Saylor. Ethan Saylor was a young man with Down syndrome who was killed by police because he wanted to stay in his seat in a movie theater and watch a film a second time. Patti is his mother. We told his story in *AccessAbility* back in the summer of 2016. Unfortunately, little has changed since then.

As of October 1, according to the Washington *Post*, 857 people were shot and killed by police in 2018 in the United States. 159 of them, or 18.5%, had "mental illness." We previously reported that between 25% and 50% of people killed by police have some sort of disability, so this may seem like an improvement. However, media people typically don't have a good grasp on the definition of "mental illness," so we don't really know what that category refers to in the *Post*'s report. We do know that the police have killed people whose disabilities clearly were physical as well, such as Sandra Bland and Eric Garner, so it's likely that the total percentage of disabled people killed by police remains about the same.

On the other hand, police shootings of unarmed people are dramatically down this year compared to previous years—though we also don't know what "unarmed" means. Consider Magdiel Sanchez, a deaf man with intellectual disabilities who was killed in September 2017 in Oklahoma City. The police had come to talk to his father about a hit-and-run accident, and they saw Magdiel walking outside the house with a pipe in his hand, which the cops apparently at first mistook for a gun. They shouted at him repeatedly to drop it. Of course, he couldn't hear them, which they knew because nearby neighbors shouted back at them, also repeatedly, that Magdiel was deaf. He ran toward the police at one point, but backpedaled. It turns out that Magdiel was playfully imitating one of his neighbors, who had a habit of riding his bike while carrying a piece of wood to ward off stray dogs. We don't know whether Magdiel would be counted as unarmed or not. We do know that the Oklahoma City police chief thought that officers who shot a man who they knew was deaf because he didn't follow spoken orders, a man who was not actually behaving in a threatening manner, were fully justified in what they did.

This incident, Patti Saylor's quote, and much more appeared in a story on the British Broadcasting Company (BBC)'s website in October 2018. The story accompanied a BBC documentary film called "Don't Shoot, I'm Disabled," about the propensity of American police to kill people with disabilities.

Also on the website was a piece of police body-cam video of cops torturing Adam Trammell, a young African-American man with schizophrenia, with tasers in Milwaukee in May 2017. The police were called because of a report that Adam was standing naked in the hall of his apartment building and "talking about the devil." When the police arrived he was not in the hall, but in the shower in his apartment. His father said that he would sometimes take a shower to calm himself down when he was feeling agitated. Three police officers broke into the apartment and charged into the bathroom, calling him "Brandon" instead of his name for some reason, and telling him that they were there to "help" him and that he needed to "calm down." In the video Adam does not respond directly to them, but seems pretty calm. He does eventually splash some water at the cops; his father speculated that, because they were using a different name, he thought the police were a hallucination, and he may have splashed them to try to verify that they were real. They were real, all right. When he did not follow the officers' orders to get out of the tub, they tased him 15 times in ten minutes. The video shows Adam screaming and writhing in pain in the bottom of the bathtub. The police had gloved hands on his body and, at least during the brief portion shown on the website, they could easily have pulled him out of the tub, handcuffed him, and taken him to a hospital for evaluation. Instead, Adam stopped breathing. He did go to the hospital then, where he was pronounced dead.

The medical examiner found the cause of Adam's death to be "excited delirium" (reported by CNN as "characterized by agitation, aggression, acute distress, unexpected physical strength and sudden death"), and the manner of death was "unknown." The Milwaukee district attorney said, "There was no basis to conclusively link Mr. Trammell's death to the actions taken by the police officers," and he declined to prosecute them.

"Excited delirium" sounds like a pathetic 19th-century medical "diagnosis." The man was not visibly resisting in the video on the BBC website, he was not breathing or moving when he got to the hospital, and it's likely that the medical examiner relied on self-serving reports from the officers who killed him. Probably he had a heart attack from being repeatedly electrocuted.

Whether or not the tasers killed him, those cops should have been prosecuted because they violently attacked a man who was not fighting them, and who was obviously mentally ill, merely because he didn't immediately do what they ordered him to do.

As so often happens, it's right there in the video, but people who defend police behavior appear not to see it. In Trammell's case, the DA told the BBC reporter that the police "had to get him under control, so they could get him some medical attention." The man wasn't ***out*** of control, at least not before they started tasing him, and if they had shown some basic patience and intelligence, they could have got him that medical attention without anybody getting hurt.

As we pointed out in 2016, the problem is what the BBC calls "command and control policing"; the idea that the safest way to approach these incidents is to be aggressive and intimidating, and plan to win a power struggle by any means necessary. But that's only safer for the police.

What needs to change is the notion that the safety of police officers is more important than that of innocent civilians in crisis. The police are trained, and paid, to take risks to protect the public. Yet most police departments seem to operate on the principle that they will accept no risks to their employees and have no responsibility to protect innocent people from them. Given a choice between injuring a cop and killing a disabled person who is not committing a crime, most reasonable people would go with injuring the cop. But the police and the elected officials who support them are in a privileged position, immune to reason or basic fairness. It's not just their apparent belief that all disabled people are "out to hurt" them that has to change; it's their expectation that they won't be held to account for their own criminal conduct in these situations.

courts watch

***Tri-City, Endor, et. al. v NYC Taxi and Limousine Commission:* All Your Base are Belong to Us!**

We've reported on the progress of various lawsuits against Uber and similar companies filed by people with disabilities over the issue of accessible rides (see *Access-Ability* Winter 2016-'17, Fall 2017, Summer 2017). This case is a counter-suit. International companies like Uber and Lyft use local "bases" that handle ride requests and dispatch vehicles. The bases are separate corporations that are "children" of "parent" companies like Uber. There are also completely local bases in the city, including so-called "black car" and other types of on-call ride services. Some of those local bases are quite small. Tri-City, Endor, and the other plaintiffs are Uber, Lyft and independent base operators.

A few years ago, New York State granted permission to companies like Uber to operate in New York City. Almost immediately traditional taxi services in the city, which are clearly subject to accessibility requirements, began losing riders to the cheaper ride-sharing companies. Disability advocates who had been campaigning for accessible taxis for several years saw what little ground they had gained slipping away, and they organized to get the city to do something about requiring ride-sharing companies to provide reliable accessible services.

Our previous coverage tried to indicate how difficult this is for the standard Uber/Lyft model, where a driver owns his/her own vehicle and is typically working part-time. The situation in New York City is more complicated than that, because many of the independent ride services actually own the vehicles, which drivers are compelled to "lease" on a daily basis. It might be easier to require these services to purchase some number or percentage of accessible vehicles, but such vehicles are much more expensive than the ordinary (often "pre-owned") vehicles that these services operate, so this might only be cost-effective for the larger companies.

In response to pressure from advocates, and following a public hearing, the city's Taxi and Limousine Commission issued two competing, and perhaps conflicting, requirements: A pilot program, proposed by the ride-sharing companies, to centralize accessible ride dispatching for those base companies that agreed to participate; and an escalating requirement for a minimum number of rides dispatched in accessible vehicles, to reach 25% after four years. All of the "base" companies in the "for hire vehicles" category—in other words, any on-call ride service, but not including individual street-hail taxis—are subject to these requirements.

It's the "25% rule" that is the subject of the lawsuit. The suit was filed in the NYS Supreme Court for New York County (Manhattan), the lowest rung of the state court system. Though our situation in the Greater Binghamton Region is quite different from what New York City faces, there are still some points of interest for upstaters.

Nobody thinks that 25% of the people who live in New York City have disabilities, and they certainly do not believe that 25% of city dwellers use wheelchairs. The Commission seems to believe that requiring 25% of on-call rides to take place in accessible vehicles is a way to get enough accessible vehicles on the streets to ensure that a person who requests one can reliably get one without waiting longer than a nondisabled person would for an ordinary pickup. The plaintiffs allege that the Commission didn't collect reliable data or perform any valid analysis to support this belief. They also claim that the Commissioners themselves have acknowledged that there isn't much objective data supporting their plan, and that its percentage goals might be impossible to achieve. Since all we have is the plaintiffs' complaint, and no response from the Commission, we can't evaluate that allegation.

However, the plaintiffs did quote a member of a well-regarded advocacy group, Disabled in Action lawyer John Gresham:

"It seems to me that the metric is rides, not cars, and I suppose the reason for that is you can't readily tell when accessible cars are actually being used, or hanging out at the garage, or at the curb or whatever. And I appreciate that that's what you're trying to do, but here's the problem:

Even when we get to 25% of the proposal for four years, that's not going to necessarily produce anything close to 25% of the accessible vehicles. It will be far less because you can meet the 25% by transporting anybody for any distance.

So if I was transported for two blocks—I don't need a wheelchair yet—that would count, and it's fairly easy to gain this metric by using ... one accessible vehicle for example, as your workhorse for all your short trips that are in a concentrated area, and there's your 25%. It accomplishes rather little."

Then there's the pilot program—and again, we only have the Uber side of this story. The pilot is voluntary; base companies don't have to participate. The idea is to establish up to three centralized dispatch points in the city, and the bases would be encouraged to link up with most or all of them. This would allow the companies to pool the available accessible vehicles to make most efficient use of them. Theoretically, this would make it more likely that all of the accessible vehicles would be in near-continuous use, serving only people who requested accessible rides and ensuring full-time employment for drivers/owners of those vehicles. The pilot also requires maximum wait times: In year one, each dispatcher would have to respond to 60% of accessible ride requests within 15 minutes; in year two, the requirement would rise to 80%. During both years at least 90% of ride requests would have to be filled within 30 minutes. While this is not really comparable to actual NYC wait times for Uber or Lyft rides for nondisabled people, it is certainly much better than the typical paratransit wait time, and somewhat better than New York City's average wait time for an accessible taxi today.

The plaintiffs say the pilot program encompasses some good ideas that actually originated with them. But they don't like it because the 25% rule would immediately be applied to any dispatcher that didn't meet the wait-time requirements, and because the pilot will end after two years. The plaintiffs submitted a "Central Dispatch" proposal similar to the pilot, but it called for an ***average*** wait time of 15 minutes, not a minimum percentage of rides to be dispatched within that period. The proposal also called for fines for failure to comply: $500,000 if the average wait was above 15 minutes on January 1, 2019, and $1.5 million if that were the case a year later. We can't evaluate whether those amounts would be large enough to motivate performance.

As we've pointed out previously, most wheelchair-accessible vehicles are very utilitarian and designed for disabled drivers, not riders. Nondisabled people are not likely to regard them as comfortable and pleasant forms of transportation. There are very nice accessible taxi vehicles that offer good ride quality to nondisabled as well as disabled riders. But they are very expensive compared to the typical vehicles that on-call ride services use. We don't think the general public would be very happy with a system that requires everybody who asks for a ride to make one-fourth of their trips on a hard, slippery bench seat up against the back doors of a typical accessible van. Nor would many Uber riders be happy with a degradation in their usual short wait times caused by the requirement to ensure that their ride is accessible 25% of the time.

Neither a "25% rule" nor the pilot program really addresses the problem in smaller communities, where it will be extremely difficult to convince enough people to volunteer to operate enough accessible vehicles to ensure anywhere near adequate service. Although the ride-sharing companies and the regulators are experimenting in big cities, nobody seems to be making much effort to address small towns. Sadly, Uber, Lyft, and their ilk are just as likely to drive traditional taxi services out of business up here as they are down there. Not that there are a lot of accessible taxis upstate now, you understand, but, contrary to claims made by some disability advocates, these companies will never become a useful part of the solution to the upstate accessible transportation shortage.

Meanwhile, there have been some developments on the arbitration issue. Uber and similar companies claim that customers, by signing up for the service, have agreed to arbitrate any disputes, and therefore cannot sue them. The "agreement" to arbitration allegedly occurs when the customer presses the final button on the last registration screen of the app. The actual language requiring arbitration appears in a typically long "Terms & Conditions" document that is not actually visible when the user clicks the button.

Back in 2016, a Brooklyn resident, Elizabeth Ramos, sued Uber for failing to deliver accessible rides. In State Supreme Court for Kings County, Uber pointed to its Terms & Conditions and said, "She can't do that." The judge did not agree; he found, in May 2018, that Ramos did not knowingly agree to arbitration when she registered for Uber.

Unfortunately, that's not as exciting as it might seem. The argument came down to the layout of the app screens. An Uber programmer supplied screenshots and a written explanation. The explanation says that prior to pressing the final "Done" button, Ramos would have seen the words "By creating an Uber account, you agree to the Terms & Conditions and Privacy

Policy," and "Terms & Conditions and Privacy Policy" was inside a "rectangle," which Uber believes should clearly have been perceived as a button that could be clicked to display the legal boilerplate. So Ramos was theoretically on notice that legal requirements would apply, and she could find out what they were.

However, before getting to this screen, Ramos saw previous screens that explained how her email address and other personal data would be used by the app. She alleged that she thought "the Terms & Conditions and Privacy Policy" referred to the previous screens, and she did not realize the "rectangle" was a clickable button.

Now, a 2017 federal Circuit Court decision known as *Meyer* found that a similar final screen, which displayed "Terms & Conditions and Privacy Policy" as a typical blue underlined hyperlink, clearly conveyed the message that the customer was agreeing to terms that s/he could read if she wished. Everybody, the Court opined, knows what a blue underlined hyperlink is.

The Brooklyn judge did not indicate he was aware of that decision. But in recent years web and app designers have aped Microsoft's so-called "Metro" or "Modern" style, which replaces raised and shadowed images that clearly look like buttons with flat rectangles that look more like signs. Probably younger people are not confused by this, but Ramos was 56 years old. On the other hand, the "Done" button may have been in the same style as the "Terms & Conditions" button; we don't know because we haven't seen the screenshots. It's also unclear why that screen didn't have a blue underlined link like the one in *Meyer*, for which we do have screenshots.

So the judge in Brooklyn determined that there was no agreement because Ramos didn't know what she was agreeing to. It appears that an appeal is underway; the case has been moved to a federal district court. We'll try to follow the case and report back here.

Haynes v Dunkin Donuts: Slam Dunkin!

Since our last report on web accessibility lawsuits (*AccessAbility* Winter 2017-'18), there have been several cases, many of which were decided in favor of the notion that the ADA requires websites to be accessible to people with disabilities. Most of those decisions do require that the website have a "nexus" to a physical place of public accommodation, such as a store. (There are a few federal district court decisions that don't require a physical location, but there are no federal appeals court rulings supporting them.) *Haynes*, decided in the 11th. Circuit, is interesting because it clarifies exactly what this "nexus" thing means.

The Americans with Disabilities Act (ADA) prohibits discrimination by public accommodations that denies people with disabilities the "full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations" of a business that is open to the general public. Haynes is a blind person who uses the popular JAWS screen-reader software. Even with that software, he was unable to use the "store locator" feature on the Dunkin Donuts website, or to purchase gift cards there.

In just six pages, the Court explained why the Dunkin Donuts site violates the ADA. The law says that illegal discrimination occurs if a public accommodation "fail[s] to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services." (One might argue that JAWS was an auxiliary aid that was not absent, but the law actually requires that such an aid be effective in providing access. As another case, *Gomez v GNC*, determined, JAWS, like other screen-readers, doesn't work very well if the website isn't properly designed; in that case, elements on the web pages were improperly labeled so JAWS couldn't figure out what they were.)

In a previous case, the Court had found that the ADA "covers both tangible barriers ... and intangible barriers ... that restrict a disabled person's ability to enjoy the defendant entity's goods, services and privileges." An "intangible" barrier is one that is not physical, and it does not have to be at a physical place of public accommodation. In that case, known as *Rendon*, a disabled person sued the "Who Wants to be a Millionaire" TV game show because its telephone selection process screened out people with disabilities as potential contestants.

In *Haynes*, the Court summed up by saying, "It appears that the website is a service that facilitates the use of Dunkin Donuts' shops, which are places of public accommodation. And the ADA is clear that whatever goods and services Dunkin Donuts offers as a part of its place of public accommodation, it cannot discriminate against people on the basis of a disability, even if those goods and services are intangible. … [T]he alleged inaccessibility of Dunkin Donuts' website denies Haynes access to the services of the shops that are available on Dunkin Donuts' website. …The failure to make those services accessible to the blind can be said to exclude, deny, or otherwise treat blind people 'differently than other individuals because of the absence of auxiliary aids and services.'"

That seems simple enough, but we should point out that the Court agreed with other decisions that found that a website that only provides information about a physical public accommodation, and not goods, services, or advantages of that accommodation, does not have to be accessible.

EEOC v UPS: Obvious Discrimination

Thomas Diebold was a UPS driver. He had a minor stroke that left him unable to drive, so he requested a reasonable accommodation of being allowed to take a non-driving ("inside") job.

UPS had a policy of allowing drivers who lost the ability to drive to take non-driving jobs for which they were qualified. Oddly, if the driver could no longer drive because his or her license was suspended or revoked, which usually occurs only as a result of illegal activity while driving, s/he would be paid 100% of the usual wage for the alternate job. But drivers who became disabled through no fault of their own and could no longer drive would only get 90% of the usual wage. This policy was part of a collective bargaining agreement with the employees' union.

The federal Equal Employment Opportunity Commission (EEOC) sued UPS in a federal district court in Kansas, alleging violation of the Americans with Disabilities Act (ADA) Title I provisions against discrimination in employment. In July 2018, the judge ruled against UPS.

The issue is pretty obvious: If you're going to let workers take alternate jobs because they can no longer drive for some reason, then you can't pay a different wage in an alternate job merely because the reason is disability.

The usual argument that the law can't override an existing collective bargaining agreement is moot because the agreement expired at the end of July. The judge simply ordered that the next agreement not discriminate.

UPS tried to argue that it's impossible to know whether a particular employee would come out better or worse with the alternate job wage without knowing all of the facts of his or her case. The judge said that such arguments are "red herrings" and "attempts to create confusion where none exists." You just can't pay a lower wage for the same job because the person doing that job has a disability, period.

Ciaramella v Zucker: A Decision You Can Sink Your Teeth Into

This class action suit was filed in federal district court for the southern district of NY in August of this year. The issue is, once again, New York State's ongoing refusal to obey the federal Medicaid law's "medical necessity" requirements.

Frank Ciaramella has multiple disabilities, including kidney failure, heart disease, and diabetes, as well as malnutrition related to his kidney problems. He had a full set of dentures paid for by Medicaid, but the lower piece didn't fit well and kept moving around in his mouth. Once, it slid back into his throat, causing a choking incident. Although the complaint says Ciaramella's uppers "fit well," for some reason they fell out of his mouth one day and were run over by a car.

The other named plaintiff, Richard Palazzolo, has bipolar disorder and diabetes among other disabilities. He lives in a supported housing setting with three other people. Medicaid provided partial lower dentures to him, but they were stolen from his room, along with other items.

The New York State Department of Health (DOH), under Commissioner Howard Zucker, refused to replace Palazzolo's partial and Ciaramella's uppers. It also refused to provide dental implants to better anchor a set of lowers for Ciaramella.

Drivers who became disabled through no fault of their own and could no longer drive would only get 90% of the usual wage.

At the time of the lawsuit, DOH's policy stated that Medicaid will not pay for dental implants except in cases of jaw reconstruction, and it won't replace dentures more than once every eight years unless they become "unserviceable" as a result of some physiological change in the wearer.

There are a variety of sound medical reasons why well-fitting, well-functioning dentures may be necessary for a person's health. Foremost among them, of course, is eating. People have to eat. In order to eat a fully nutritious diet, people have to be able to chew. Dietary fiber is an essential nutrient for most people, and the only way to get its full benefit is to chew up fibrous foods. Beyond these obvious facts, Ciaramella's kidney problems necessitated good protein and fiber intake, and made high-liquid protein "shakes" inappropriate. Absence of, or bad, dentures contributes to gum disease, and gum disease can be much worse in people whose diabetes interferes with healing of open sores.

This particular complaint is interesting because it actually cites the state's past history of illegal conduct. It mentions that the state previously lost court cases over its refusal to pay for compression stockings or for medical care related to transgender issues. All of these cases are part of NY's longstanding "So sue me!" approach to reducing Medicaid spending. Refusal to provide legally required services saves money. If somebody manages to sue, and the state loses, there's no requirement to "pay back" any of those saved dollars, nor can state officials be held personally liable for damages to people's health or welfare. And conducting a deliberate, willful cost-cutting strategy of violating Medicaid law and waiting for people to sue over it is not a crime—though it should be.

Less obvious is how DOH is violating the Americans with Disabilities Act (ADA) as the plaintiffs claim. Although they, and their class members, have disabilities, both the ADA itself and its legal history make it pretty clear that it's not intended to require changes to medical insurance coverage, or to differential treatment of people with disabilities on a medical basis.

In any case, DOH may have seen the writing on the wall early this time. About a month after the suit was filed, the agency announced changes to its procedure manual for Medicaid dental services. Now, dentures may be replaced when determined medically necessary: "Prior approval requests for replacement dentures prior to eight years must include a letter from the patient's physician and dentist. A letter from the patient's dentist must explain the specific circumstances that necessitates [sic] replacement of the denture. The letter from the physician must explain how dentures would alleviate the patient's serious health condition or improve employability. If replacement dentures are requested within the eight-year period after they have already been replaced once, then supporting documentation must include an explanation of preventative measures instituted to alleviate the need for further replacements." Also, implants will be covered if medically necessary and letters from the dentist and physician are provided, along with supporting documentation and x-rays.

These changes took effect on November 1, 2018.

The plaintiffs' lawyers appreciate the changes, but they have concerns about the limitations still in the revised procedure, and they point out that without a court order, there will be no way to enforce the new rules. So they are proceeding with the suit. We'll keep you informed.

FHJC v Cuomo, et. al.: No Chair-y Picking

In April 2018, The Fair Housing Justice Center (FHJC) sued the New York State Department of Health (DOH) and four operators of "adult care facilities" in New York City, alleging housing discrimination on the basis of disability, on behalf of an elderly disabled woman identified as "Mary Doe." The specific charges were that the residential facilities refused admission to people who used wheelchairs, and that DOH regulations specifically permitted this. The complaint was filed in federal district court in New York City. In September, the court issued a preliminary injunction in favor of the plaintiff. We've read both the complaint and the judge's decision.

Mary Doe lived in an "assisted living program" (ALP) called VillageCare, in New York City, for many years. She needed verbal cues to dress and prepare food and physical assistance to bathe, had urinary incontinence issues, and although she could walk short distances on level floors with a "rollator" (a type of wheeled walker), she needed somebody nearby to make sure she didn't fall, and she could not climb stairs without hands-on help. She did not use a wheelchair, initially.

Over time her health declined and she had frequent falls. The process accelerated after her mother died and she became depressed. In March 2017 she was hospitalized for several days for a urinary tract infection. Spending all that time in bed caused severe deterioration in her ability to walk or care for herself, so she was transferred to a nursing facility for temporary rehab. There she began using a wheelchair, though not all the time. In June she was examined by VillageCare staff, who determined that she could not return to the ALP due to her use of the wheelchair, and her admission there was terminated. Assuming that more physical and occupational therapy would improve her condition, she continued to get rehab in the nursing facility and reapplied for admission to VillageCare in October. She was denied, again due to the wheelchair. She appealed and was again denied. VillageCare claimed that it had no choice in the matter; that DOH regulations forbade ALPs from admitting people who used wheelchairs.

This case illustrates how subjective both needs assessments, and interpretation of regulations, which are supposed to be objective and uniform, can be.

Let's be clear about what VillageCare is. Physically, it's a six-story apartment building, with common living areas and offices on the lower floors, in Manhattan. The building contains small studio and one-bedroom apartments that operate on three different sets of regulations. It's been called an "adult care facility," an imprecise generic term that is defined differently depending on who you ask. For some people, it means any residential facility for people with non-specific disabilities (as opposed to an OPWDD group home, for example) and which provides some level of personal assistance services, but which is not a nursing facility. In terms of NY regulations, it only means "enriched housing" and "adult homes." Within the VillageCare building, ten "beds" are "enriched housing," available to people over the age of 65 who need minimal personal care while living in individual ordinary-seeming apartments. Most VillageCare "beds" are part of an "assisted living program," another imprecise term that has different definitions, although under NY regulations it is not an "adult care facility," and it is not a nursing facility. Unlike enriched housing, there's no requirement for separate apartments for residents, but VillageCare's ALP has apartments. Then there are ten "beds" at VillageCare, also in separate apartments, that are not classified as either enriched housing or ALP; we don't know what they are, actually.

Mary Doe was living in an ALP apartment in VillageCare before her hospitalization.

In order to live in an ALP, you must be formally assessed to need a nursing facility "level of care" (NFLOC). DOH uses a standardized assessment, the Uniform Assessment System (UAS), to determine level of care. It produces numeric scores, and under current regulations, a 5 or above gets you the NFLOC. However, the amount of care you are actually supposed to get in an ALP isn't strictly regulated. ALP operators appear to have considerable latitude in deciding how much is too much. At the time of Mary Doe's hospitalization, the DOH regs essentially only required that a resident be able to safely evacuate in an emergency, and not be chronically "chairfast" or "bedfast," archaic terms meaning that the person is completely dependent on a wheelchair for ambulation, or that she is unable to get out of bed for any significant period of time. Within those limitations, ALPs were apparently able to staff their programs as they saw fit, and also to refuse admission to people who needed more assistance than their level of staffing could provide. VillageCare used an NFLOC score of 15 as its cutoff.

The situation was further confused because some people in the VillageCare ALP do use wheelchairs, either solely while in their apartments, or once out on the street. The facility's written policy was that not only people who needed wheelchairs to negotiate the building's common areas, but who needed continuous "contact guard" assistance to walk (meaning someone constantly touching or partially supporting them), could not be admitted. In fact, there were also people who didn't use wheelchairs but always had to have someone support them while walking living in the ALP.

As Mary's health declined, her NFLOC numbers went up, at one point reaching 29.

The termination of Mary Doe's admission seems to have resulted from the fact that when a VillageCare evaluator visited her in the nursing facility, she happened to be sitting in a wheelchair, even though she didn't use it all the time and was therefore not "chairfast." It was also later claimed that she couldn't safely evacuate without continuous assistance, but in actuality, with only a literal handful of aides on duty at any time, VillageCare's emergency evacuation plan doesn't rely on anyone's ability to use stairs. If the fire department turns off the elevator for safety reasons, then the facility deploys stair "slides."

As Mary's health declined, her NFLOC numbers went up, at one point reaching 29 in March 2018, after she had been in the nursing facility, where she was not allowed out of bed unless someone was with her, for almost a year. That particular UAS assessment was done by an independent third party who had no relationship to VillageCare. We don't know who it was, but the examiner's impression was that Mary was experiencing dementia and had almost no ability to do anything on her own. However, her physician said that she was alert and responsive, had some self-care ability, could walk short distances safely with her rollator, and that with ongoing therapy would probably regain more of her abilities. The doctor didn't perform a UAS assessment. Getting a high UAS score can be a good thing if you are trying to qualify for the NHTD Medicaid waiver in order to get a lot of services in your own home; perhaps the independent assessor had that orientation. Or it may be that Mary just didn't like her and was deliberately not cooperating. So much for the objective accuracy of these kinds of assessments.

After the complaint was filed DOH issued emergency regulations that got rid of the "chronically chairfast" language and added the following: "An operator shall not exclude an individual on the sole basis that such individual is a person who primarily uses a wheelchair for mobility, and shall make reasonable accommodations to the extent necessary to admit such individuals, consistent with the Americans with Disabilities Act."

During the hearings on the case it emerged that some people in the VillageCare enriched housing program were actually being served under Medicaid managed long-term care plans (MLTC), which paid for all of their homecare services. In fact, DOH plans to move all Medicaid ALP services to MLTC as well, but the distinction in this case is not so much about the funding as about the services, with "MLTC" being used as shorthand for Medicaid homecare services (including personal care, home health care, and "visiting nurse" services) provided independent of the place of residence. VillageCare was not averse to letting Mary back into the building if she got MLTC services; the primary selling point seems to have been that the facility didn't believe it would be liable for anything bad that might happen to her if she didn't get enough care.

So that's what the judge ordered. He refused to order that she be readmitted to the ALP specifically; he partially credited VillageCare's claims that her needs were too great to be safely served by that program, which is allegedly staffed to provide only about two hours of personal care daily. (The judge also said, in a footnote, that if VillageCare's ALP is operating at its 80-resident capacity, with only 10 attendants working there across three shifts as reported by the company, it could not possibly provide anywhere near that much care anyway.) It's not clear if she was allowed to return to her previous apartment; this is the point at which the ten "beds" that are apparently not part of the ALP or the enriched housing program came in; she might have moved into one of those, or it might be that her existing apartment was reclassified.

The judge dismissed the charges against the state because DOH had already changed the regulations.

FHJC had also conducted "testing" against the three other facility operators named in the suit and found that they, like VillageCare, had been telling people who used wheelchairs that they couldn't be admitted. There's no mention of those operators in the judge's decision, so perhaps the case will continue against them.

WE'RE RIDING ON THE MARRAKESH EXPRESS

(It's Crosby, Stills & Nash. Look it up. Seriously good song.)

October 12, 2018 was a milestone day for people who have visual or other disabilities that affect the ability to read. On that day President Trump signed the Marrakesh Treaty.

The treaty's full name is "Marrakesh Treaty to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired, or Otherwise Print Disabled," and it's commonly referred to as the MVT. It was adopted by the World Intellectual Property Organization (WIPO) in 2013, and took effect for those countries that ratified it in 2016. Nearly every country in the world belongs to the WIPO, including the United States, so what Trump actually signed this fall was "implementation" legislation so the rules of the treaty could operate in the US.

What are those rules?

Essentially, they provide that signatories must create exceptions to their copyright laws to allow the (relatively) free distribution of versions of published works that are "intended to be accessible" to people who are blind or have visual or "print impairments." These lucky folks are referred to as "VIPs".

The works that can be distributed include anything "in the form of text, notation and/or related illustrations, whether published or otherwise made publicly available in any media," including audio books. The distribution is in the hands of various government and not-for-profit entities.

Each country can write its own rules as long as they make accessible versions of published works available for free to people who can't read ordinary books. Notably, countries can choose to limit the list of audio books covered by the program to only those deemed too expensive for typical VIPs. They must take measures to ensure that only eligible people receive the free materials. And there's a requirement that the program "shall not conflict with the normal exploitation of the work; and shall not unreasonably prejudice the legitimate interests of the rightholder."

The treaty also provides for importing and exporting accessible versions of copyrighted works.

Now, the US Library of Congress already has a National Library Service for the Blind and Visually Handicapped (NLS) that distributes both braille and audio versions of books for free to people with disabilities. The audio versions are always read by good voice actors, and in recent years the Service has arranged with commercial audio book companies to distribute some of their stuff. (Check them out at https://www.loc.gov/nls/) So you may ask why we in the United States need this treaty.

Well, for one thing, it requires the federal government to enact changes in national copyright laws to remove any remaining serious impediments to free access to printed material for people with disabilities. Last time (*AccessAbility* Fall 2018), we reported on a legal case involving the Amazon Kindle, in which Amazon turned off the device's accessibility features allegedly to protect the interests of certain audio book publishers. As we pointed out, the experience of having a computer voice read a book suffers vastly in comparison to having that book read by a voice actor, so much so that almost no one who likes audio books would be motivated to use the computer voice to save a few bucks on commercial audio books. In other words, leaving the Kindle's screenreader intact would "not unreasonably prejudice the legitimate interests of the rightholder." So there should now be legal clarity on issues like this so companies like Amazon won't feel they have to impose ridiculous limits on their products. This is especially important for textbooks and scholarly periodicals, which the NLS typically does not offer.

VIPs in the US may also benefit from the import of accessible books from other countries, books that up to now weren't available here due to the difficulty of arranging specific permissions for each book across international borders.

Get Out the Vote!

by Maria Dibble

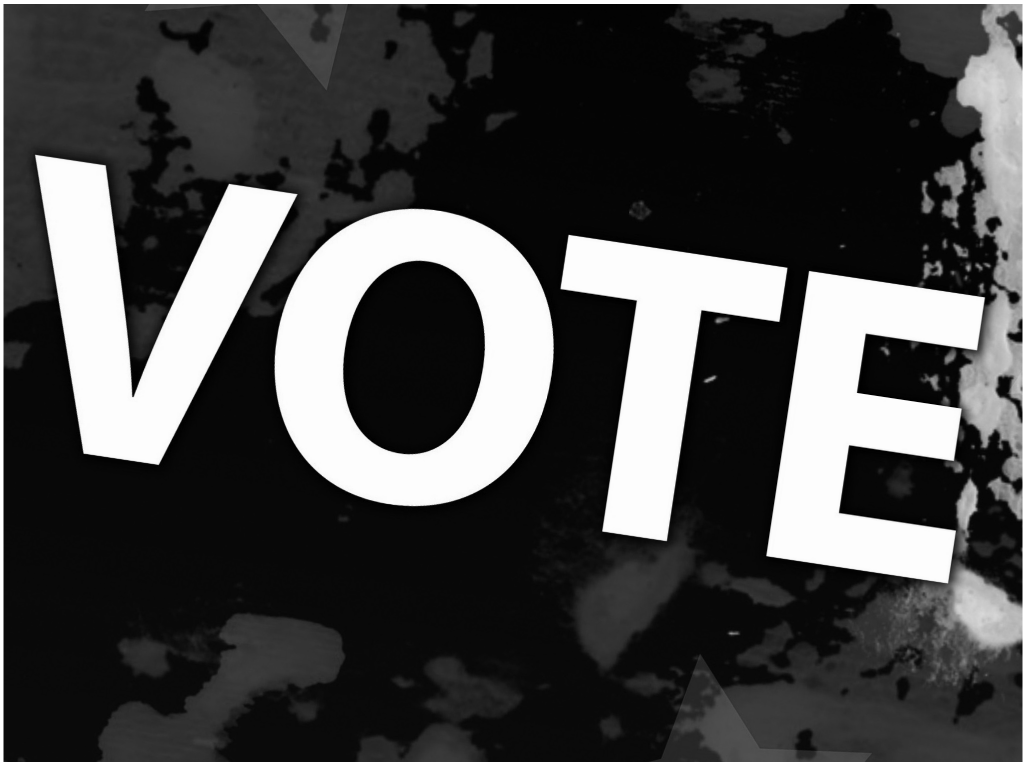
Southern Tier Independence Center (STIC) submitted testimony to the NYS Assembly Standing Committee on Election Law, Subcommittee on Election Day Operations and Voter Disenfranchisement, for their hearing on "Improving Opportunities to Vote in NYS" in November. If reforms occur, it could affect tens of thousands of people with disabilities, as well as millions of New Yorkers overall.

The right to vote is guaranteed to all American citizens by the constitution, yet tens of thousands of people are often denied this right due to inaccessible polling sites and overall inaccessible voter registration and absentee ballot processes in NY.

While STIC strongly believes that all polling places must be accessible as required by law, we also think that if potential voters would find it easier, more accessible, or more convenient to vote by absentee ballot, they should be allowed to, without needing to provide a reason (known as "no excuse absentee ballot"). This would virtually guarantee that every eligible voter could cast their vote without any impediment. Americans increasingly are working more than one job, have child care issues, and overall are extremely busy. This option would create more opportunities for individuals to vote, and will hopefully be implemented for the 2020 election.

STIC also strongly supports early voting for many of the same reasons. It will allow more people to cast a ballot, and will provide a voice to many who may otherwise find it difficult to get to the polls on just the one designated election day. Additionally, transportation is a major issue for people with disabilities who may find it difficult to get a ride on election day, would prefer to vote in-person, and would potentially be able to secure transportation on a different day that polls might be open. We also support early voting by mail, which should be available to everyone.

I am a totally blind person who has experienced issues when trying to request an absentee ballot. I usually vote in-person, but two years ago I required surgery and needed to be able to vote by absentee ballot. When I tried to do so online, the form was a PDF, which I could read, but couldn't fill out because it wasn't a "writeable form." Instructions said to download the form, print it, fill it out and mail it to the designated entity. While I could download, read and print the form, I couldn't fill it out and mail it without assistance. I provide this example because it is essential that ALL forms and procedures used in the voting process be fully accessible to everyone, including those who are totally blind or have partial vision. (*Editor's note: The state Board of Elections settled a lawsuit about this issue a couple of years ago (see* AccessAbility, *Fall 2016); the Board agreed to redesign its website and forms to make them accessible. We asked the law firm that filed the suit, Disability Rights Advocates, for an update on whether the Board is complying with the settlement, but had received no response at press time.*)



To save millions of dollars and level the playing field even more, STIC would support using only mail-in ballots by everyone, saving the need for upkeep and/or purchase of voting machines, the need to make polling sites accessible to voters with disabilities, and other related costs to hold on-site elections. For a couple of years now, Governor Cuomo has proposed a package of reforms similar to the ones mentioned here, but the legislature has failed to pass it. With full Democratic control of the legislature, this may finally be enacted. While I'm not sure that mail-only voting is up for consideration, I offer it as a simple, secure way to allow all eligible voters to cast their ballots. A few other states already have this.

The right to vote is sacred in this country. Anything that can be done to expand opportunities for voting and encourage people to cast a ballot is a worthy endeavor. Early voting and no-excuse absentee ballots will help to level the playing field for all voters, and eliminating the need for voting machines, polling sites, etc. would save millions of taxpayer dollars and would be the overall fairest alternative. It would be the best method to get out the vote.

STIC NEWS

Temple Grandin at the Summit

by Maria Dibble

Temple Grandin, Photo Courtesy of WikiCommons

STIC's 2018 Autism Summit at Tioga Downs on November 14, sponsored by our Southern Tier Parent Technical Assistance Center and Mid-South Early Childhood Direction Center, featured a presentation by Temple Grandin, known for her work with animals, the livestock industry, and for her design of livestock handling facilities around the world. She has a Ph.D. in Animal Science and is an extremely accomplished scholar, authoring over 400 articles and many books. She also just happens to be "on the spectrum"; that is, autistic. She has appeared on CNN, 20/20, and 48 Hours, among others, and an HBO movie was made about her life. In 2010 she was named by *Time* magazine as one of the one hundred most influential people in the world. Oh, and she also teaches at Colorado State University.

Her presentation addressed autism, what you need to know and understand, and how we should be meeting the needs of those on the spectrum. She addressed many concerns about how autistic children are seldom expected to "over-stretch" themselves and strive to surpass their goals. Her concerns centered especially around the fact that children are often over-protected by well-meaning and loving parents, who want to save them from taunting and teasing.

She also addressed, in detail, why children should be allowed to do volunteer work, followed by several jobs, so they can truly figure out what they may want to do for a career.

She explained how autistic children may think differently, but that they do think. They may have to process information using alternative methods, such as through visualizing pictures, as she does, or by envisioning patterns in their minds. If we can discern what method children use to think and problem-solve, then we can more easily assist them in finding jobs and careers that will be rewarding and fit who they are.

I agreed with all that she said without reservation. I know it must be a painful thing for a parent to hear, that they are over-protecting their child and may actually be causing them harm, but it is a critical message for parents to process. And the message applies to all parents of children with disabilities, not just those with autism.

I'm very fortunate. When my parents had twins that were totally blind, myself being one half of the dynamic duo, they decided that they were going to raise us and treat us no differently than my older nondisabled sibling. Yet, so often I've seen blind children—and the resulting adults— who have been so protected that they can't walk through their own homes without help. They also don't work, or if they do it's in a sheltered workshop, and they never learned basic living skills that all people must learn to survive as adults. So instead of being self-sufficient, productive and self-supporting individuals, they become a burden on their families and other loved ones, though most families won't admit that.

But the most important message we heard from Dr. Grandin is that we need to listen to the people with disabilities, hear what they're saying and what they want, and this includes children. Professionals shouldn't be the ones deciding the destinies of people with disabilities, the people themselves should, to the maximum extent of their abilities, be involved in the development of their IEPs, Life Plans, or whatever other fancy names we want to come up with for "the things we need to know to live happy and successful lives."

Dr. Grandin was a powerful and engaging speaker, passionate about her topic and eager to reach her audience. If you have a chance to hear her speak, I highly recommend it.

Rent-a-Tent (Apologies to Kurt Vonnegut)

by Maria Dibble

STIC is working on its fourth Xscapes room, “Wizards and Dragons.” It promises to be challenging and lots of fun. We’re hoping it will debut during the second quarter of 2019. We’re also thinking about making both an adult and a children’s version, but we’ll finish the first before we make those plans definite.

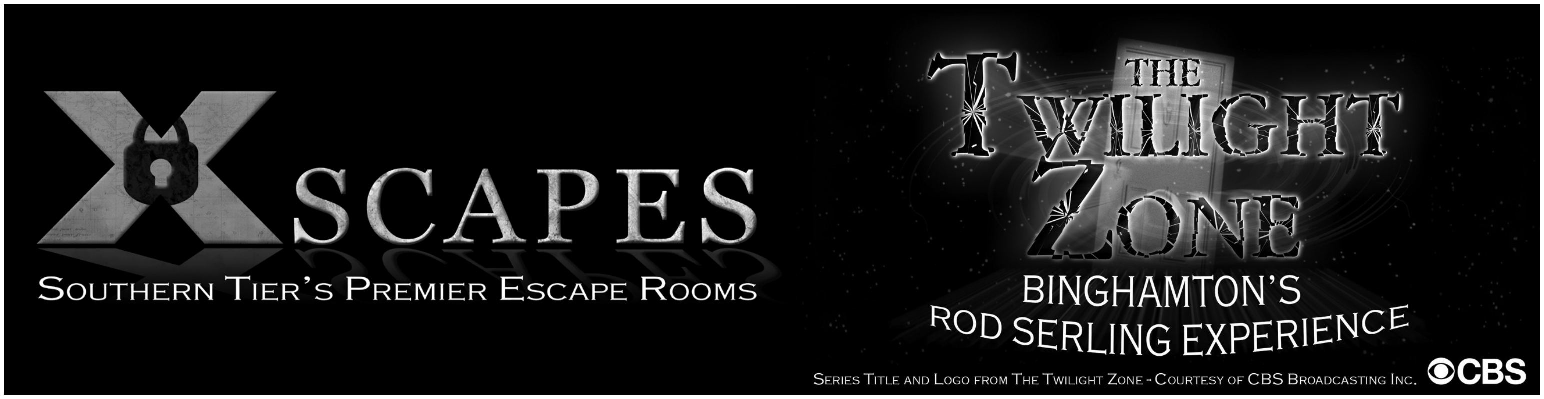
The Twilight Zone Xscapes room (which is a 90-minute game rather than the typical hour) is extremely popular and going like gangbusters. CBS recently gave us permission to continue using things from *The Twilight Zone* TV shows until May of next year. We submitted footage for their review as to how we’re using identifying information about *The Twilight Zone*, with the hope that they will give us longer or permanent authorization to use the copyrighted materials.

We are now offering portable rooms (“tents”) for rent. Two games are available: “Immunity Quest” and our most recent, “Infection.” The latter is a bit more difficult, but we’ve received good reports on both. So if you’re having an event of any size, these tents are ideal and can be set up indoors.

Lastly, it’s not too late to get gift certificates for our Holiday special: all three games for $50.00. If bought separately, the games would cost a total of $65.00, so it’s a bargain. Remember though, the certificates must be used for these three games by March 31, 2019.

For more details on prices, information, pictures and the like, visit our website at xscapes-stic.com and find our Facebook page from there.

If you love puzzles, investigating clues, connecting the dots, so to speak, and working with a team to solve your quest, then give one of our rooms a try. You won’t regret it.



Go DSPs!

by Lucretia Hesco

STIC celebrated DSP Appreciation week, along with the rest of NY state, from September 9 through September 15, 2018. There were small activities and raffles that went on all week and the celebration ended with a picnic at Cole Park. Thank you to our DSPs (Direct Service Professionals) for all you do each and every day! STIC DSPs are truly the best around!! Our Executive Director, Maria Dibble, shared the following letter of gratitude:

“I’d like to take this time to thank each and every Direct Support Professional (DSP) that works for STIC and our consumers. You are a critical component in the lives of the people we serve, enabling those with intellectual and developmental disabilities to learn new skills and become more independent.

Community Habilitation can be a life-changing program for consumers and their families, and you are at the center of their achievements, mentoring and teaching them, and forming friendships that are meaningful and uplifting.

You represent what is the core of the Independent Living Philosophy on which STIC was founded, fostering the independence that people are capable of, allowing them to live in the community, rather than in institutions or other segregated settings.

I hope you will take this opportunity to reflect on all you give to the people you serve, and what your efforts mean to them, as well as the long-term impact you have on their growth, development, and goals. What you do today to teach a skill, may become crucial to the person’s ability to find their place in our society and become fully participating members of their communities in the future. You plant a seed, which may flourish and grow, long after you’ve moved on, the resulting bloom sustained by all you’ve done. Your work provides consumers with an invaluable gift, that of your experience, generosity, and humanity.

Therefore, it is right that this week is celebrated in your honor. It is well deserved. Thank you once again for all you do.”

Become a Direct Support Professional at STIC!

As a Direct Support Professional, your role would be to assist individuals in learning the skills they want to learn to become more independent in their community and at home.

- Full-time or Part-time positions available.
- Salary: $12.00 /hour
- On the job trainings (CPR, 1st Aid, etc)
- Hours are based on the needs of the individual.

Requirements

- Valid driver's license and reliable transportation.
- High school diploma/GED
- Travel in multi-county area
- Communication skills, documentation skills and a willingness to help others.

Benefits

- Medical/Dental/Vision/Life insurance
- 403(b) retirement plan
- Community based position
- Generous Paid Time Off benefits @ 17.5 hours/week
- Paid holidays off @ 17.5 hours/week
- Supportive work environment
- Qualifying Employer for Public Student Loan Forgiveness Program
- Verizon Employer Discount
- Chamber of Commerce member discount

If you seek a rewarding career providing one-on-one supports to people with disabilities, this is the job for you!

Email your resume/application to: apply@stic-cil.org

OR

Applications can be found on our website @ www.stic-cil.org or from our office at 135 E. Frederick St. Binghamton, NY 13904

SELF HELP

ADAPT Returns Home

by Nicole Hakes

"Free our people," we chanted as we walked. Where we were going, only a select few knew. This is how ADAPT works. In mid-November, the 40th anniversary of ADAPT took place in Denver, Colorado. It all started with a gang of 19 people in the 1970s. The original acronym stood for Americans Disabled for Accessible Public Transit. They were protesting the lack of accessible public transportation for people with disabilities in their city. Those 19 spent the weekend stopping traffic and blocking buses to get their voices heard after nothing else worked. Over the years, many different chapters of ADAPT started to emerge. Local chapters try to make changes in their communities, and then come together at national actions to work on bigger causes.

The causes changed throughout the years and their name did too. Now, ADAPT stands for Americans Disabled for Attendant Programs Today to showcase another cause which they are fighting for, attendant wages.

Along with celebrating the history of this group, there was work to do in Denver. We rallied at Civic Center Park. We protested at the Health and Human Services Building and Division of Housing. We chanted in front of a Senator's office to get his attention. All of this for different issues, but all to benefit people with disabilities. I have been fortunate enough to be involved with our local chapter, Southern Tier ADAPT, for a little over a year now. This was my third national action, and I've learned a lot. Not just about government, disability rights, and civil disobedience; but about myself. Where you walk, you don't know. Where you're going, you don't know. How long you'll be there, you don't know. You put a lot of trust in the leadership of the organization. I've learned strength. Not just physical and emotional strength, but the strength of people as a whole. The people you meet will forever change you. I have never known such a feeling of pride as when we all were outside the Senator's office chanting in unison, "FREE OUR PEOPLE!" and the ADAPT logo was projected onto the Federal building. We were all there to make a change for the better, to better all people with disabilities. It was a feeling like no other.

Social Security Disability Appeals Changes

by Frederick M. Maurin, NY Regional Commissioner, Social Security Administration

Effective January 1, 2019, the Social Security Administration (SSA) will implement a change to the Social Security disability appeals process in New York.

Under the Social Security Act, a claimant who applies for Social Security Disability Insurance Benefits (DIB) and/or Supplemental Security Income (SSI), and who is dissatisfied with SSA's initial determination, may request further appeal of that determination under appropriate procedures established by the Commissioner of Social Security. Since 1959, the reconsideration step has been the first level of SSA's disability process.

In the mid-1990s, SSA explored ways to improve the disability appeal process and piloted the elimination of the reconsideration step in 10 states, including NY. As a result, claimants in NY followed a different appeals process. If a NY claimant applied for DIB and/or SSI and was dissatisfied with his/her initial determination, s/he bypassed the reconsideration step and proceeded directly to the second level of appeal, which is to request a hearing before an SSA Administrative Law Judge (ALJ). Currently in NY, claimants who receive an initial denial of their disability claim follow this process.

In January 2019, SSA will begin to reinstate the reconsideration step back into the disability process in NY.

This means that NY residents who apply for DIB and/or SSI and receive an initial determination on or after January 1, 2019, now will have to request reconsideration if they wish to seek appeal of their initial determination, instead of proceeding directly to the second level of appeal. Only if residents are denied at the reconsideration step may they then seek further appeal of their claim by requesting a hearing before an ALJ.

By reinstating the reconsideration step into the disability process in the 10 states:

- SSA will have a national, unified disability process that affords all claimants the same due process rights no matter where they live;
- Some disability claimants will receive a favorable determination more quickly; and
- SSA will be able to reduce the average wait times for a hearing, thereby achieving greater balance to the overall disability appeals process.

By Jimmo!

(from the Center for Medicare Advocacy)

(Editor's note: The Jimmo settlement was covered in AccessAbility *Winter 2012-13)*

With support from The John A. Hartford Foundation, the Center for Medicare Advocacy has produced two new checklists to help Medicare beneficiaries and their families respond to unfair Medicare denials based on an erroneous "Improvement Standard."

Per the *Jimmo* settlement, CMS revised the Medicare Benefit Policy Manual to clearly disavow any notion that residents of a skilled nursing facility [or any Medicare recipient] must improve in order for their care to be covered by Medicare.

Medicare Home Health Coverage Requirements Checklist

The following checklist provides Medicare beneficiaries and their families with an overview of the home health coverage criteria, providing an emphasis on the *Jimmo* Settlement. As the checklist illustrates, beneficiaries who meet the coverage criteria cannot be denied care solely because of an erroneous “Improvement Standard.”

Download the Home Health Coverage Checklist at:

http://www.medicareadvocacy.org/wp-content/uploads/2018/09/Home-Health-Jimmo-Checklist.pdf

Skilled Nursing Facility Expedited Appeals Checklist

The following checklist provides readers with an overview of the expedited appeals process in traditional Medicare, focusing on the termination of skilled care solely based on an erroneous “Improvement Standard.” The Center hopes this checklist will help beneficiaries and their families as they appeal improper terminations and denials.

Download the Expedited Appeal Checklist at:

http://www.medicareadvocacy.org/wp-content/uploads/2018/09/Expedited-Appeals-Fact-Sheet.pdf

SNF Coverage Checklist

The two checklists above are in addition to our previously published checklist outlining the coverage criteria for care at a skilled nursing facility and emphasizing language from the *Jimmo* settlement agreement.

Download the SNF Coverage Checklist at:

http://www.medicareadvocacy.org/wp-content/uploads/2018/08/Checklist.pdf

Social Security Announces 2.8 Percent Benefit Increase for 2019

From the Social Security Administration

Social Security and Supplemental Security Income (SSI) benefits for more than 67 million Americans will increase 2.8% in 2019.

The 2.8% cost-of-living adjustment (COLA) will begin with benefits payable to more than 62 million Social Security beneficiaries in January 2019. Increased payments to more than 8 million SSI beneficiaries will begin on December 31, 2018. (Note: some people receive both Social Security and SSI benefits). The Social Security Act ties the annual COLA to the increase in the Consumer Price Index as determined by the Department of Labor’s Bureau of Labor Statistics.

Some other adjustments that take effect in January of each year are based on the increase in average wages. Based on that increase, the maximum amount of earnings subject to the Social Security tax (taxable maximum) will increase to $132,900 from $128,400.

Social Security and SSI beneficiaries are normally notified by mail in early December about their new benefit amount. This year, for the first time, most people who receive Social Security payments will be able to view their COLA notice online through their *my* Social Security account. People may create or access their *my* Social Security account online at www.socialsecurity.gov/myaccount.

Information about Medicare changes for 2019, when announced, will be available at www.medicare.gov. For Social Security beneficiaries receiving Medicare, Social Security will not be able to compute their new benefit amount until after the Medicare premium amounts for 2019 are announced. Final 2019 benefit amounts will be communicated to beneficiaries in December through the mailed COLA notice and *my* Social Security’s Message Center.

The Social Security Act provides for how the COLA is calculated. To read more, please visit www.socialsecurity.gov/cola.

If We Only Had a Brain

STIC won 2nd place in the Broome County Parks Scarecrow Contest! We would like to thank everyone who visited Otsiningo Park and voted for us! This is such a fun community event and we look forward to participating next year!

Nursing Home Abuse Podcast

by Richard J. Mollot, Executive Director,
The Long-Term Care Community Coalition

I am writing to share a new Nursing Home Abuse podcast in which I participated. It focuses on how to find and assess information on nursing home quality and safety posted for the public on the federal website, “Nursing Home Compare.” I hope that it is useful to you and those with whom you work.

Here is the link: https://youtu.be/telLQvUrc-w.

The Nursing Home Abuse Podcast is hosted by Georgia trial lawyers Rob Schenk and Will Smith. Rob and Will also invited me to participate in a second, related program that discusses federal guidelines for and oversight of nursing homes. That podcast is available here: https://youtu.be/YJ2JFa9Xco0.

I also highly recommend Rob and Will’s other podcasts, which I think are engaging and informative.

THE NURSING HOME ABUSE PODCAST

STIC
Southern Tier
Independence
Center
Access your world.

This newsletter is also available in large print, on cassette, and online, at:
www.stic-cil.org

NON-PROFIT ORGANIZATION
U.S. POSTAGE
PAID
BINGHAMTON, NEW YORK
PERMIT NO. 126

135 E. Frederick St.
Binghamton, NY 13904
(607) 724-2111 (voice/TTY)
Toll Free (877) 722-9150
email: stic@stic-cil.org
RETURN SERVICE REQUESTED

Free Access Is Not Free

STIC is a 501(c)(3) corporation, and governing documents, conflict-of-interest policy, and financial statements are available to the public upon request.

If you would like to support STIC, please use this form. Minimum membership dues are $5.00 per person, per year. If you want to be a member, you must check one of the **first five** boxes **and** the "Make Me a Member" box. **NEWSLETTER SUBSCRIPTIONS DO NOT COUNT AS MEMBERSHIP DUES.**

☐ Individual $5
☐ Supporting $25
☐ Patron $50
☐ Contributing $100
☐ Complimentary $_______
☐ Newsletter Subscription $10/year
☐ **Make Me A Member**

MAIL TO: **Southern Tier Independence Center, Inc.**
135 E. Frederick St.
Binghamton, NY 13904

Name ____
Address ____
City ___________________________ **State** ___ **Zip**_______
Phone ____

All donations are tax-deductible. Contributions ensure that STIC can continue to promote and support the needs, abilities, and concerns of people with disabilities. Your gift will be appropriately acknowledged. Please make checks payable to Southern Tier Independence Center, Inc.

THANK YOU!

Southern Tier Independence Center

EXECUTIVE DIRECTOR	**ASSISTANT DIRECTOR**
Maria Dibble	Jennifer Watson

ACCESSIBILITY SERVICES: Frank Pennisi
ADA SERVICES: Frank Pennisi
BEHAVIORAL CONSULTING: Gerard Griffin
Rachel Schwartz Maria Walensky Medina
BENEFITS & HOUSING SERVICES:
Joanne Carlyle
CARE COORDINATION: Marci Germond
Rebecca Smith Cynthia Lord Kathy Sas
Erin Gabriel Jessica Arnold Stacey Engel
Cynthia Meredith Kristin Phillips Krista Acker
Emily Neville Angela VanDeWeert
Tammy Virgil Rhonda White Craig Lucas
Laura DiRenzo Marisa Hadden
Sann Dee Walter Leslie Hadden
Kim Bailey Poreda Steve Van Austin
DEAF SERVICES: Heather Shaffer
DEVELOPMENT: Bill Bartlow
ECDC: Laurie Wightman Kelly Mikels
Karen Lawrence
EDUCATION SERVICES: Stephanie Quick
HABILITATION SERVICES: Cathy Sostre
Theresa Thornton Matthew McLain
Hannah Hickox Kim Kappler Brittany Hall
Lucretia Hesco Terry Valdes Julia Massaro
Kathleen Scanlon Katie Trainor-Leounis
HEALTH EXCHANGE NAVIGATORS:
Christy Sodan Winta Michael Joy Stalker
Pamela Rockermann Loretta Sayles
Chad Eldred Theresa Kircher Patricia Lanzo
Brittany Pritchard Brittaney Carey

INTERPRETER SERVICES: Stacy Seachrist

MONEY FOLLOWS THE PERSON:
Peg Schadt Krystal Pierre Millien

NHTD RESOURCE CENTER: Ellen Rury
Daena Scharfenstein Belynda Raminger
Laura O'Hara Pamela Lounsberry

NY CONNECTS: Marcy Donahue Amy Friot
PEER COUNSELING: Jane Long
Danny Cullen Robert Deemie
Richard Farruggio Susan Link

PERSONAL ASSISTANCE SERVICES:
Susan Hoyt Tess Savage
Katina Ruffo Carole Roche Alicia Riehle

PSYCHOTHERAPY:
Charlie Kramer Jane Long

PTAC: Sue Lozinak Beth Kurkoski
Shannon Smith

SUPPORTED EMPLOYMENT:
Kandi Stevens Michelle Dunda
Rachel Barton Crystal Musshafen

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER: Belinda Turck
Ellen Rury Cortney Medovich Lori Wilmot
Valerie Soderstrom Melissa Rafael

TECHNOLOGY SERVICES:
Jessica Kendricks Decker Ayers