

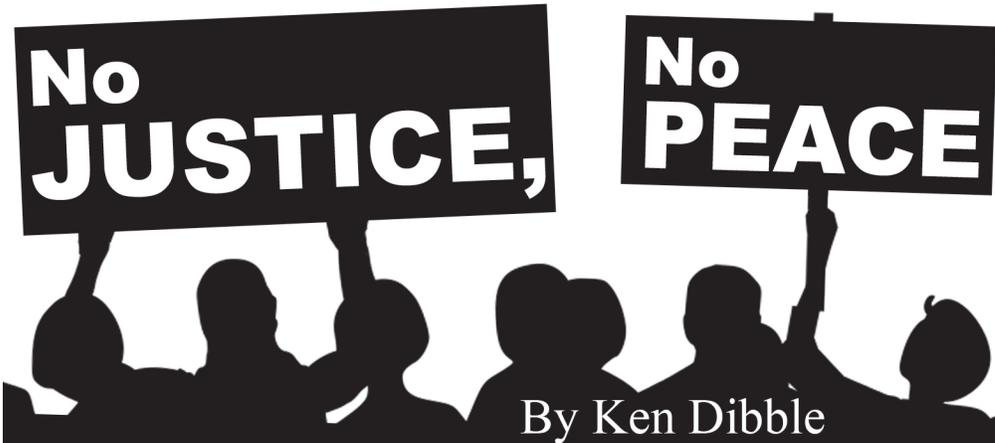
The Voice of Disability Rights in the  
(Bureaucratic) Empire State since 1984

# AccessAbility

Fall 2017  
Number 128

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By Ken Dibble

As we predicted when it opened in 2013, New York State's Justice Center for the Protection of People with Special Needs has revealed itself to be a joke. Unfortunately, it's very a old joke, not very funny, and one that has been shared across the United States.

Most recently in the news was the case of Steven Wenger, a resident of an OPWDD-operated group home in Rome, NY, whose tracheostomy was found to be infected with maggots, twice. A medical expert noted that all it takes to prevent this sort of thing is to wipe the area clean on a regular basis. The Justice Center did an investigation but claimed it couldn't identify any staff members who were specifically responsible, so no one was punished. Instead, they just advised the group home administration to "consider" re-training the staff on tracheostomy procedures.

In our view, anyone who saw a maggot on the guy's ostomy and didn't raise hell about it was "responsible" enough to be punished. And if nobody saw it, then nobody who worked in that group home was doing basic care, and they should *all* be punished, and the administrator in charge of the group home should be fired.

The only reason we found out about this is because the Associated Press (AP) managed to get the Justice Center's report of its investigation, probably from Steven's outraged father. And the only reason the report got out at all

was because the Center did find that Wenger had actually been neglected, even if it declined to identify by whom. The law establishing the Center seals all information about complaints of neglect or abuse that are "unfounded"; it does not permit disclosure to anybody. The state Comptroller can't even get the information to perform an audit of whether the Justice Center is doing its job properly. And Disability Rights New York, the independent Protection and Advocacy agency, one of whose jobs is to oversee the performance of the Justice Center, is still waiting for a decision on its lawsuit demanding files that federal law specifically requires them to have (see *AccessAbility* Summer 2015).

"Unfounded" doesn't necessarily mean that somebody wasn't neglected or abused, it just means the investigators didn't think there was enough evidence in the case. Certainly that includes frivolous complaints made by juvenile delinquents in detention centers, and trivial incidents magnified by over-anxious relatives. But it also includes a substantial number of really bad things that really happened to real people, and that really could have been prevented, where the investigation could not piece together a precise chain of cause and effect.

Harvey Weisenberg is another outraged father. He's a former NYS Assemblyman whose child with a developmental disability suffered abuse and neglect in various residential settings. He is frequently sought out

by journalists when neglect and abuse stories crop up. About the Justice Center in Steven Wenger's case, he told the AP reporter, "What the hell are they hiding? They won't tell the public, or anybody for that matter, what they're doing." But Weisenberg was one of the Assembly sponsors of the law that established the Justice Center, including its extremely restrictive information disclosure rules. Did he even read it? If he didn't, then as Assistant Speaker he had a large staff, and one of them surely should have read it and told him what was in it. We may very well ask, what the hell was *he* thinking?

He was likely thinking about campaign contributions from public employee unions. The original bill to establish the Justice Center would have made it easier to fire state employees who engage in abuse and neglect, and to put their names on a "no hire" registry, than the final law does. These changes were made entirely in response to union lobbyists.

Then there's Assembly member Thomas Abinanti, who has been in the news recently with his campaign to repeal the law that established the Justice Center. But in 2012 he was one of a handful of Assembly Rules Committee members who introduced the bill in that house. Surely he knew what was in it as well.

# AccessAbility

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EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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*AccessAbility*

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## 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.

In fact, Weisenberg, Abinanti, and everybody else in the Assembly and the Senate who supported the Justice Center, as well as Governor Cuomo, knew that there were serious problems with the bill, because we at STIC specifically told them about it, as did many other disability advocates around the state. They blew us off.

And so, over the years, we've seen story after story of some awful, horrendous case of abuse or neglect, in response to which the Justice Center did virtually nothing. In fact, two cases are now making their way through the New York State court system in which a judge said that the Justice Center's rarely-used Office of the Special Prosecutor violates the state constitution, because prosecutors are supposed to be elected by the voters, not appointed by a state agency. So the one potentially effective tool the Center has may ultimately be taken away.

Nor is this just a New York problem. The AP reporter found similar situations in California, Massachusetts, Connecticut and Florida, in which federal inspectors and judges criticized the states for excessive secrecy. If an ordinary nondisabled child is assaulted by a school-teacher, it makes the papers and everybody is up in arms. When cops kill unarmed civilians, people argue about whether it's justifiable, but at least it gets reported and publicly discussed. But when it comes to mistreatment of people with disabilities, nobody wants to talk about it. Overall, people with disabilities are about 2.5 times more likely to be victims of violent crime than nondisabled people, though we rarely hear about that. Nearly 50% of the black people killed by police who made the news over the last few years had significant disabilities that likely caused the behavior that got them into trouble, but this was not usually emphasized by the media.

And the first response by public officials is invariably to try to keep it quiet.

Like many good people, Harvey Weisenberg is capable of compartmentalizing his thought processes when it comes to this stuff. As a father, he was ferocious in his statements about what happened to his son and what should

have been done about it. But as a politician, he was able to put all of that aside and support a bill that was deliberately designed to protect abusers and hide the facts. He's hardly alone in that ability.

Just about anybody will get very upset if they think about their elderly parents, or their disabled children, being mistreated. And a huge proportion of us have elderly parents, disabled children, or both, including those of us who make, or implement, laws or regulations related to disability services. But when one of those people's employees is accused of abuse or neglect, they will still circle their wagons to protect that employee, as well as their own positions and reputations. And when these people are politicians, they will easily come up with excuses for why neglect and abuse has to be tolerated, and information about it hidden, for the "greater good".

This is a very deep thing in human psychology. In our hearts and our guts, our first response to people who do not look or act exactly like us is fear, and the second response is revulsion. This happens before our brains even get to the point of actually thinking about it. By the time they do, the damage has already been done. People with disabilities are "the other". Nondisabled kids who get in trouble with the law and sent to detention centers are "the other". If you're white, people of color are "the other". They aren't really people like us, our guts tell us. They certainly don't rate the same consideration we give members of our families. And so when bad things happen to them in those separate, special, hidden places, well, it's just not that big a deal. Especially if to fix it, we have to take money from, or restrict, or punish, people who we feel *are* just like us.

It's too expensive and restrictive to require nursing facilities to have minimum staffing ratios, as federal regulators decided last year, so elderly people continue to get robbed, slapped around, left unshowered and undiapered, and utterly disrespected, by the tens of thousands. It's too politically difficult to enact laws that say that just "being afraid" is not a good enough reason for a cop to kill somebody, or



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.

[www.stic-cil.org](http://www.stic-cil.org)

that say that public employees can be fired without years of administrative leave and “due process” if they sexually assault or beat up a group home resident.

So this is a hard problem to solve. But we have to solve it. Perhaps the national attention that Steven Wenger’s story has generated may get something started. Don’t get me wrong; we’ll be glad to work with anybody who wants to fix this thing, including Assemblyman Abinanti and former Assemblyman Weisenberg. My point is that the political hypocrisy we’ve seen on this issue is a symptom of the deep, nasty human inclination to discount and disregard “the other”. More po-

litical hypocrisy cannot be a part of any solution to this problem.

We are not on the extreme end of this issue. We don’t agree with people who are calling for wholesale violations of people’s privacy rights by installing cameras in bedrooms and bathrooms of group homes. We don’t think people with developmental disabilities should have electronic chips inserted so they can be tracked like dogs. We don’t think calling the local police is going to help either; the reason why the Justice Center was given a Special Prosecutor in the first place is because local police and prosecutors so often refuse to get involved in these cases.

But if someone is hurt or killed because some facility employee did something wrong, or stupid, or deliberately hateful to them, or didn’t do something that they obviously needed, then “re-training” is never enough. The fact that a terrible thing happened when there were people on hand who could, and should, have prevented it justifies a stern response. When responsibility cannot be pinpointed, then responsibility must be shared, but that is not an excuse for leniency. More or better training may be necessary and should be provided, but those responsible must also be punished in some way, so that their attention will be properly focused on keeping it from happening again.

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# Still Entitled, Still in Danger

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The Senate was unable to pass any kind of bill related to the Affordable Care Act (ACA, or “ObamaCare”) before it went on recess. Nine Republican Senators joined all of the Democrats and independents to block passage of the Senate “repeal and replace” bill, and seven Republicans voted against the so-called “repeal only” bill, but only three opposed the so-called “skinny repeal” bill—the bare minimum to prevent passage. These are misnomers; the “repeal only” bill contained provisions changing the 50-year-old Medicaid entitlement (which has nothing to do with ObamaCare) to a limited appropriation via block grants or per capita caps, and the “skinny repeal” would have defunded Planned Parenthood (also unrelated to ObamaCare) for a year.

Disability activists, and especially ADAPT, played a big role in defeating the Senate bill. They staged “die-ins” in the Capitol and Senate Majority Leader Mitch McConnell’s office that garnered lots of media attention. (Rachel Maddow of MSNBC deserves special mention for her outstanding report on the history of the disability rights movement and ADAPT.) This, in turn, translated into unprecedented widespread and accurate reporting on how essential Medicaid, as the only permanent form of long-term care insurance in the United States, is to the lives of people with disabilities, both in institutional and community settings. And then we began hearing Senators repeating that information. People often talk about how, if Medicaid support services are cut, people will be forced into nursing facilities. The fact is that before there was Medicaid, only relatively wealthy people lived in nursing facilities; the rest were simply bedridden in their

homes, with only as much assistance as their families could manage to provide. Most of the people who live permanently in nursing facilities today are on Medicaid. If the Medicaid entitlement ends and the funding is cut, they won’t be forced *into* nursing facilities, they’ll be dumped *out* of them, with no services or supports whatsoever.

The House passed their “repeal and replace” bill in May, but with the Senate refusing to take it up, the far-right-wingers in that chamber were trying to get a floor vote on an alleged repeal-only bill (probably the same as the Senate’s failed version, which would have ended the Medicaid entitlement) scheduled for September. It may pass there but it’s already dead in the Senate.

The good news is that this seems to mean that the threat to the Medicaid entitlement that we described last time is over for the foreseeable future. The bad news is that the individual insurance market is facing increasing trouble, and the various Medicaid expansions in ObamaCare are still not out of the woods.

The Medicaid expansions are the most important remaining issue for New York. These include the higher income eligibility cut-off for single nondisabled childless adults; the higher federal share of funds for “health homes,” “value based payments,” and use of the Community First Choice Option (CFCO); and expanded funding for the Children’s Health Insurance Program (CHIP, known in NY as “Child Health Plus”). New York is banking on those higher shares to support its move to health homes and CFCO for people with developmental disabilities as part of its roll-out

of managed care (see page 9). If the money doesn’t come through, that could leave people with those disabilities suddenly without some of the services they’ve come to expect.

Although it’s unlikely that the Senate will take up an ObamaCare-specific bill this year, there’s always next year, when there will be even more perceived pressure to get something called “repeal” passed before the far right starts challenging incumbents in the primaries for the 2018 election. An even skinnier “skinny repeal” bill that doesn’t touch Planned Parenthood but phases out the Medicaid expansions over several years could get enough support to pass the Senate. Still, Congress may be able to wipe out the expansions simply by means of a budget bill. Massive Medicaid cuts (around \$800 billion over ten years) have already been proposed by the Trump Administration. While Congress will not pass everything Trump asked for in his budget, they will pass some of it, and some Medicaid cuts are likely to be included.

New York’s individual-coverage health insurance market is still pretty healthy. But we’ll fill you in on what’s happening elsewhere, because the trouble could come here eventually.

The first thing to remember is that premiums for individual health insurance policies were going to go up in 2018 anyway, even if Hillary Clinton had been elected. That’s due in part to ordinary medical inflation, but it’s also because a long-delayed ACA tax on health insurance premium receipts, which the insurance companies will have to pay, will finally take effect. But some insurance companies, looking at the early data, have concluded that

the ObamaCare “individual mandate” isn’t inducing enough healthy people to buy policies to cover the cost of health care for the sicker people (with “pre-existing conditions”). Some analysts say it’s too early to draw that conclusion, and not all companies are doing it, but all of these factors were enough to result in significant projected increases for 2018 before Trump and Congress began arguing about repeal this year.

That debate raised insurance companies’ hackles for two reasons: The chance that the individual mandate would be repealed, and the threat to ObamaCare’s “Cost Sharing Reduction” (CSR) payments. These should not be confused with the tax credits that people below certain income levels can get to offset higher premiums for insurance purchased on the ObamaCare exchanges. CSRs are subsidies paid directly by the federal government to insurance companies to help with the costs of insuring people with pre-existing conditions. Trump has called the CSRs “bailouts for insurance companies,” but that’s misleading. Financial “bailouts” usually refer to payments to prevent a company from going bankrupt. The insurance companies aren’t in danger of that—or in any financial danger at all. The CSRs are paid so that the companies can keep deductibles, co-pays, and premiums affordable. Without them, those companies would either charge customers much more, or drop out of the ObamaCare exchanges; either way they would remain financially stable and healthy.

Back in 2014 some Republicans in Congress sued the Obama Administration to get the CSRs stopped. They won in federal district court, because the language of the ACA, which permanently authorized the tax credits for insurance customers, only provided for one year of CSRs for the insurance companies. Obama had continued the payments every year without Congressional authorization. In court, Obama argued that this was a so-called “drafting error” that should be ignored because it makes no sense for the CSRs not to have been permanently authorized, but the judge just read the actual text of the law. This is the kind of thing that usually gets fixed by a so-called “technical amendment” bill after a big piece of complicated legislation is passed, but because ObamaCare passed with no Republican support, there was no chance of getting any corrections through. The court’s decision is on hold through August while Trump decides whether to appeal it, but he either has to request an extension of the deadline or go forward with an appeal in order to legally be able to continue the payments. He has alternately threatened to drop the appeal, or delay his decision, in order to try to motivate Congress.

In the meantime this uncertainty has been cited by the insurance companies as the reason why they’ve been dropping out of the exchanges or projecting major premium increases (double-digit percentages in 15 states) at a growing rate over the course of the year. It’s important to note that most of the projected percentage increases aren’t larger than last year’s. But

multiple years of double-digit inflation in premium costs is not just scary, it’s likely to cause a lot of people to drop their coverage and just pay the cheaper tax penalty instead—further eroding income for the insurance companies.

There are now bipartisan efforts in both houses of Congress to pass some kind of legislation to “fix” rather than “repeal and replace” ObamaCare. The top of everybody’s list is permanent authorization of the CSRs. Beyond that a few other ideas are being floated. One, to increase the minimum size of organizations required to provide health insurance to employees from 50 to 500, would be a terrible mistake. A lot of companies under that limit provide insurance now, and many of them would just drop it and force their workers into the exchanges. One promising measure would be to cancel the insurance premium tax. The rest of the ideas are unlikely to have much effect one way or another.

Republicans on the right may be able to block passage of a separate “fix” bill. But the Children’s Health Insurance Program (CHIP) must be reauthorized this year, and that has broad bipartisan support. It seems likely that both sides will try to add ObamaCare-related provisions to the reauthorization bill. But the insurance companies are facing a hard deadline in late September to submit their rates for 2018. Getting something passed and signed that can affect those calculations this year is a very long shot indeed. Whatever happens, we’ll be here to tell you about it.

## courts watch

### **The World v Uber: The Value of Actually Suing People**

No, there’s no actual such case. But there are now at least four separate lawsuits filed against Uber in state and federal courts for its failure to provide accessible transportation services.

As we’ve reported, Uber claims it doesn’t provide transportation services. Instead, it says it provides a communication service between drivers and riders, and the riders agree not to sue Uber as part of signing up for the service.

Simultaneously with these lawsuits, Uber has been ramping up its efforts to provide wheelchair-accessible vehicles (er ... so to speak). As we’ve reported, Uber offers

UberWAV (WAV stands for “wheelchair accessible vehicle”) in at least some cities.

People who have tried to use it seem to uniformly report that it doesn’t work very well. According to Washington, DC’s Equal Rights Center (ERC), UberWAV in that city only arranges rides with accessible taxis (*Equal Rights Center v Uber*, filed in DC federal District Court on June 28, 2017). Riders must pay the much higher taxi fees, which on average are double the cost of Uber’s standard rate, while wait times for arrival of the taxi via UberWAV are 840% longer than those for an Uber standard vehicle. And rather astonishingly, the accessible taxi trips are also more than 2 ½ times longer than the same trip in an Uber standard vehicle. And that’s when you can actually get

an accessible vehicle at all. Everyone (including advocates in San Francisco and Portland, OR, among others) reports that there are many times when Uber can’t find any accessible rides. In New York City (*Disability Rights Advocates v Uber*, filed in NYS State Supreme Court for New York County on July 18, 2017), Uber only has 100 accessible vehicles available, less than one tenth of one percent of the city’s total Uber fleet. These do not seem to necessarily be taxis, although in New York City Uber drivers are required to have a commercial Taxi & Limousine Commission license. More to the point, these 100 vehicles are not exclusively reserved for people who need wheelchair access, which means that much of the time they are not available to wheelchair users because they are transporting nondisabled people.

The more recent suits are taking into account Uber's evolving business model, which offers more features tailored to specific types of riders, and which includes, in addition to UberWAV, efforts intended to recruit more drivers of accessible vehicles into its network. The newer complaints provide a lot of detail on those efforts, which vary from city to city: According to ERC, "in Chicago, Uber now arranges for participating drivers to rent accessible vehicles for \$450 per week. It then provides financial incentives to drivers for securing such vehicles, such as waiving the service fees drivers must pay Uber for rides made to wheelchair users, and guaranteeing that, if the drivers are on the road for 35 hours per week, they are paid at least \$20 per hour."

The new complaints also add weight to the charge that Uber's drivers are really employees, not independent contractors. Uber controls many of the details of how drivers are expected to do their jobs, and it throws them out of its network if they don't meet those expectations. For example, drivers are not permitted to smoke while transporting Uber passengers; they must meet or exceed the estimated trip time that the Uber app projects; and they must have high customer-satisfaction ratings. In San Diego, Uber now offers "UberASSIST," in which drivers provide hands-on assistance to people with disabilities who need it, including those who use folding wheelchairs which do not require an accessible vehicle. These drivers get special training.

The New York complaint points out that Uber not only doesn't provide reliable accessible transportation, but that to the extent it does have accessible vehicles, they don't offer the other "perks" that are available to nondisabled Uber customers. For example, Uber has UberCARSEAT, in which you can specifically request a vehicle that comes with a child car seat. The car seat is not an option for UberWAV,

nor can UberWAV riders get a luxury vehicle or use a cheaper car-pooling option that other Uber riders can get. This renders people who use non-folding wheelchairs "second-class citizens" within the Uber universe.

Advocates have long predicted that the much cheaper Uber service would drive cab companies, which are clearly required to comply with federal and local accessibility laws, out of business. The New York complaint provides evidence that this prediction is rapidly coming true, at least in New York City: "TNC [Transportation Network Company] ridership in New York City doubled annually over the last three years, to 133 million passengers in 2016. The fall 2016 ridership averaged 15 million passengers per month, which is more than triple the ridership level of spring of 2015. Since mid-2016, TNCs have added an average of 7 million passengers per month, compared to the same months in 2015 while yellow cab ridership has been declining by 2 million passengers per month, compared to the same months in 2015. It is reported that TNCs transported 87% as many passengers as yellow cabs. From 2013 to 2016, yellow cab ridership fell by 70 million."

The new complaints are much stronger than that filed by Chicago's Access Living, although the parties to that suit have until February 2018 to assemble all of their evidence.

We had earlier predicted that Uber would put itself out of business before it would agree to offer a meaningfully accessible service. But since then, there have been major leadership changes at the company owing largely to other adverse events, including sexual harassment of its employees. The company's new executives do not seem to be as belligerently libertarian as its founders. We still believe that Uber would do virtually anything to avoid a legal decision that its drivers are not independent contractors, or which voids the mandatory arbitration clause in its user agreement. But it now looks like it might at least try to offer accessible vehicles. The New York complaint calls these efforts "nothing more than window-dressing, designed to avoid government regulation and legal requirements." However, Uber's accessible-vehicle recruitment efforts are in their early days. It's possible that they will be more effective over time, and that facing growing legal pressure, the company may add more incentives to sweeten the pot.

On the other hand, in smaller towns and cities, there may be no amount of incentives that will get a sufficient number of vans that have wheelchair ramps or lifts into the Uber fleet. They're expensive, they are typically owned

only by people with disabilities or their families, and only a tiny percentage of those people are likely to want to become Uber drivers in their spare time. Such spare time may also not coincide with the times when people need rides. Voluntary action by Uber is not likely to be an adequate solution in upstate New York, while a wipe-out of the taxi industry by these kinds of companies remains very likely.

Also, anyone who has been in one of those vans is not likely to call them "luxury vehicles"; the notion that there is such a thing as a "luxury wheelchair van" that could even be made available in New York City is probably pure fantasy. Child car seats could be offered in typical wheelchair vans, but in some cases only in the front passenger seat, which is actually an illegal location for car seats. Ordinary accessible vans don't necessarily even have wheelchair tie-downs; they are designed to be *driven* by people who use wheelchairs, not to carry them as passengers. There are purpose-built accessible taxi vans that have wheelchair tie-downs and ordinary rear passenger seats, but Uber will likely have to offer a much more attractive rent- or lease-to-own package to induce many drivers to purchase those very expensive vehicles.

But this story is evolving, so stay tuned.

### ***O'Toole v Cuomo: Enter the Guardian***

This is the long-running adult "home" case; last time we reported that the NY State Department of Health (DOH) and Office of Mental Health (OMH) were apparently conspiring with adult home operators to derail the court settlement that requires thousands of adult "home" residents with mental health disabilities to be given the option of moving to more integrated supported housing. There were several loose ends left dangling in that dramatic story in June. Some of those were tied up around the time our June issue went to press, but were not reported until later.

In May, two men slashed each other with knives, and two dead bodies were discovered—time and cause of death unknown—in Oceanview Manor, an adult "home" in Brooklyn, one of the places whose residents covered by the settlement were supposed to be moving out. These were not unusual incidents there. The facility is located in a decrepit part of Coney Island, across the street from several dumpsters that appear to be used as both a toilet and a food source by some Oceanview residents, according to Pro Publica. It also has a very high rate of visits from police and



firefighters. All of these things, along with the generally dirty and malnourished state of many of the residents, should have triggered serious citations and demands for corrective action from DOH inspectors. Nevertheless, Oceanview Manor is adding a new wing to house elderly people who do not officially have mental health diagnoses, a development that requires, and apparently has received, DOH approval. Although Pro Publica filed a Freedom of Information Act request with DOH to obtain the agency's inspection records for the facility, DOH has so far refused to provide them, citing the ongoing litigation as a reason.

Oceanview Manor is one of the adult "homes" involved in lawsuits to overturn NY state regulations forbidding new admissions of people with mental illness to those facilities. The regulations were issued as part of the state's settlement of the *O'Toole* case. The settlement included a clause, "Section O," that said that if those regulations were rescinded or modified as a result of legal action, the entire settlement would have to be renegotiated, and, if negotiations failed, the case would go to court. Oceanview's lawyer is Jeffrey Sherrin, who tangled with the federal district judge in the case, Nicholas Garaufis, over the suits against the regulations in March. Sherrin is also representing alleged former adult "home" residents who moved to supported living and now wish to return, including the "John Doe" in *Doe v Zucker*. As we reported last time, Sherrin had allegedly told a NYS Department of Health lawyer that his strategy was to recruit former adult home residents to file these suits in order to get the regulations overturned for the benefit of the facility operators.

Back in the first decade of this century, when the original case came before Judge Garaufis, lawyers for the state argued that Garaufis had a conflict of interest because his wife worked for a mental health advocacy organization. Garaufis responded formally and demonstrated that his wife's work would not influence his decisions. All sides in the case accepted that and moved on.

But in mid-May, Sherrin was before Judge Garaufis again, demanding that he recuse himself because of his wife's work. Here's what happened, according to Pro Publica:

"Garaufis said he'd long ago disclosed his wife's work.

'I'm not my wife,' Garaufis said. 'I do what I think is right. I follow the Constitution as I am sworn to do.'

Garaufis then suggested Sherrin may have his own ethical issues. He pointed out that Sherrin had somehow come to represent both adult home operators and adult home residents, parties whose interests may conflict. He asked Sherrin to comment on that in forthcoming papers.

Sherrin would not answer questions as he walked out of the courtroom."

Meanwhile, Garaufis apparently accepted the suggestion of the lawyers representing the original *O'Toole* plaintiffs and the US Justice Department that Section O be removed from the settlement, so that the ongoing litigation wouldn't derail the plan to keep moving people into supported housing.

Although details of "John Doe's" affidavit, demonstrating that he is a real person who actually would rather go back to the adult "home," have been made public, the existence of other such people remains questionable.

At another hearing before Judge Garaufis, in June, it was revealed that some of the plaintiffs included in the class of individuals seeking to return to adult homes were also in the class of those who wanted out of those facilities in the original *O'Toole* case. In both cases, most of these people are anonymous. But at least one such person, who was named in one of Sherrin's suits against the regulations, actually says he didn't sign onto Sherrin's suit, that he is happy in his new supported apartment, and he has no desire to go back to the adult "home."

Despite his decision on Section O, Garaufis still believes that the regulations prohibiting new admissions to the facilities covered by the settlement are essential; without them they "could easily revert to being warehouses for individuals with serious mental illness." So before going further, he said it was essential to determine whether there are any actual people with mental illness who really want those regulations dropped. He appointed a "guardian ad litem" for all of the class members in Sherrin's suits, and ordered her to investigate and verify that they all actually do want to return to adult "homes." And he instructed Sherrin to provide names and contact information for all class members.

Unfortunately, short of investigating possible corruption in DOH, there may not be a way to keep places like Oceanview Manor from becoming warehouses for other people for whom society doesn't seem to have much use. But stay tuned.

### ***Sunderland v Bethesda Hospital:* Try It and See!**

Bethesda Hospital in Florida was already operating under a 2006 settlement with the US Department of Justice concerning its failure to provide sign language interpreters to deaf patients. Initially, to comply with the settlement the hospital used in-person interpreters, but in 2011 it began using a "Video Remote Interpreting device" (VRI).

A VRI is a computerized, internet-driven device with a video screen, microphone, and webcam that allows hearing and deaf people in the same location to connect over the internet to a sign-language interpreter. The interpreter can hear the speech and see the signs of the people using the device, who in turn can see and hear the interpreter as she translates their conversation in real time.

At Bethesda, if the VRI malfunctions or isn't providing adequate interpretation, the supervising nurse on the hospital floor is supposed to get permission from a hospital administrator to bring in an in-person interpreter. Not only did Bethesda's VRI frequently fail to work, but when it did work, many deaf patients were dissatisfied with the quality of the interpreting. So much so, in fact, that the hospital posted a sign saying that deaf patients who didn't want to use the VRI must pay for an interpreter.

Beyond that, the hospital often didn't even follow its own policy. Sandra Sunderland, for example, had a heart attack and was subsequently scheduled for a cardiac catheterization procedure. She asked for an in-person interpreter before the procedure. The nurse neither provided one nor brought in the VRI. The doctor performed the entire procedure while doing nothing more than making incomprehensible gestures.

Deaf people have had numerous complaints about VRI devices. They frequently freeze or provide blurry pictures; at times the screen goes blank or the device simply doesn't activate. These issues seem to occur when the required internet connection isn't fast enough. Or the headphone used by the interpreter doesn't work so she can't hear the speech she's supposed to interpret. Or, bizarrely, the camera suddenly zooms in on the interpreter's face, so that her signing hands can't be seen. Or the interpreter just isn't very good. Or there's no interpreter available from the system at all.

It's important to note that there are technical situations for which just-any-old-interpreter

won't work. Court cases are one; medical procedures are another. In both, specialized vocabularies are required, as is extreme attention to detail and accuracy. A mistake in these situations can have dire consequences. Courts and hospitals are not only required by federal civil rights law to provide interpreters, they are required to provide interpreters who are qualified for the particular job they're tasked to do.

Another patient illustrated this point nicely. D. John Virgadaula came into the hospital for shoulder surgery. You know how, when you go in for surgery, they make sure to ask you which body part they're supposed to operate on? They don't do that to be funny (although they often smirk when they ask the question); they do it because there have been many cases where the surgeon performed the wrong operation. The nurse couldn't get the VRI to work for Mr. Virgadaula, who reported, "While they were [trying to fix the] VRI ... the doctor was getting frustrated, ' ... and then the doctor says, You know what—he looked at me and kind of gestured—Okay is it the right arm, right shoulder or the left shoulder? So he's gesturing to me, asking which shoulder it is. ... And [then] he's gesturing this to me, sleep, you, and then shot in my shoulder."

Sunderland, Virgadaula, and several other deaf patients sued Bethesda Hospital in federal district court, arguing that the hospital violated their right to an interpreter as a reasonable accommodation under both the Americans with Disabilities Act and "Section 504." For largely technical reasons the court threw out the case, so the plaintiffs appealed.

In April, the Eleventh Circuit Court of Appeals reinstated the case for some, but not all plaintiffs. The court ruled that those patients for whom the alternative of written communication was adequate, and those patients who didn't actually complain at the time, did not have standing to sue. But the others, for whom the VRI wasn't satisfactory and no reasonable alternative, such as writing, was offered, have a "try-able case." So the case was remanded back to the district court to hold a trial and issue a decision.

This is a promising result, but please note that the decision only says that the plaintiffs have an arguable case. It does not say that hospital patients who can't use, or don't like, the VRI are entitled to in-person interpreters. It's not time to celebrate yet.

## Website Accessibility Cases

The Trump Justice Department (DOJ) has created a new category of regulatory review: the "inactive list." Formerly the department had the "regulatory plan," listing regulations it planned to issue within the coming year, and the "long-term actions," including issues on which regulations would be forthcoming, but not as quickly. The new inactive list includes issues of which the department is aware, but for which it has no plans for regulations. Regulations for website accessibility for "public accommodations" (stores, entertainment venues, etc.) had been in the "regulatory plan" for 2018, but Trump's anti-regulation bureaucracy has moved them into the inactive group.

That, fortunately, is not stopping a growing number of federal courts from ruling that the Americans with Disabilities Act requires public accommodations to make their websites accessible.

All of the cases below concern accessibility for people with visual disabilities who use screen-reader software to access websites.

*Gil v. Winn-Dixie Stores, Inc.* (Southern District of Florida)

This case is unique and especially important because it was the first to say that in the absence of federal regulations for Title III public accommodations, the ADA can be held to require websites to comply with the WCAG 2.0 web accessibility standards. WCAG (Web Content Accessibility Guidelines: <https://www.w3.org/WAI/intro/wcag>) are standards developed by the Web Accessibility Initiative over more than two decades, through an open process that accepts input from a broad swath of those interested in the issue. The decision is based on the facts that the federal government has already adopted the WCAG standards for all of its agencies, and DOJ has proposed regulations for websites operated by state and local governments (ADA Title II) that defined WCAG as a "model standard."

The WCAG standards are widely accepted internationally. They discuss all aspects of web accessibility in minute detail, down to the level of how each type of item appearing on a website should behave. Most modern web development tools have the capability to produce WCAG-compliant websites, but merely using them to put up a website does not make the site accessible. The developer must understand the standards and know

how to configure the tools to ensure that the resulting site actually functions in an accessible manner.

*Lucia Marett v. Five Guys Enterprises* (Southern District of New York)

*Andrews v. Blick Art Materials* (Eastern District of NY)

These cases are interesting because both judges said that ADA Title III applies to website-only businesses that have no physical "nexus" to brick-and-mortar businesses.

*Gorecki v. Hobby Lobby Stores, Inc.* (Central District of California)

The judge in this case demolished the argument that courts should not order businesses to make websites accessible merely because DOJ has not yet issued regulations on the topic. The ADA has been understood to require website accessibility in some form since it was signed into law in 1990, while DOJ has been dragging its feet on the issue for almost that entire time. The fact that no regulations exist to explain a law does not make the law any less a law that must be obeyed. In the intervening decades just about every expert on website design has come to agree on what web accessibility means and how to achieve it; it is long past time that site owners should be held to account. This will be an essential precedent to get enforcement of accessibility requirements in the coming years.

***A.T. v Harder: Educating a Local Dinosaur***

This is a class action suit filed in federal district court for the Northern Region of New York in July.

A. T. is a minor child with bipolar disorder and ADHD (attention-deficit hyperactivity disorder) who was placed in solitary confinement in the Broome County Jail, under the auspices of County Sheriff David Harder.

This case raises all of the same issues that were aired in *Peoples v Fischer* (see *Accessibility* Summer 2013), whose settlement required the use of solitary confinement in New York State prisons to be drastically curtailed. That was a legal endorsement of the fact that long-term solitary confinement causes mental health disabilities in people who never had them, and makes them much worse in people who were already mentally ill. In the last few years there has grown an almost complete consensus among not only

mental health professionals and disability rights advocates, but prison administrators, in both Europe and the United States, that solitary confinement is harmful and must only be used as a last resort for very brief periods of time. Twenty-one states and the federal prison system now completely ban the use of solitary confinement as punishment for juveniles. Many local jails have followed suit; most recently the Onondaga County jail (Syracuse) agreed, as part of a legal settlement, to ban solitary for children earlier this year.

Yet the BC Jail continues to use it routinely, not just for adults but for children aged 16 and 17. As in *Peoples*, teenagers in the jail are placed in solitary for minor infractions such as speaking loudly, singing, and refusing to clean their rooms. Some of the infractions that land them in “the box” are things that teenagers commonly do, such as engaging in “horseplay,” or playing with snow. A. T. spent 30 days in “the box” for writing on a sweatshirt; he has spent over 150 days in solitary in total. As with adults in state prisons, consecutive short sentences are routinely piled on kids in the jail, resulting in stays of many weeks. Unlike prison inmates, though, many of the people in “the box” in jails have not been convicted of any crime; they are merely being held for trial because they cannot afford bail. (The issue of ordering high bail amounts for poor people accused of minor crimes is another travesty of American justice, yet another case of unequal treatment based on social class or race.) Children with known disabilities are also locked up in solitary solely for behaviors that are caused by their disabilities; sometimes the reason given is “protective custody” or “observation” rather than disciplinary infractions, but kids locked up for such reasons are not treated differently from those placed in “the box” for breaking a rule.

Children in the BC Jail solitary have no access to radio or TV. For the first three days of confinement they are only permitted one religious book. If they don’t have such a book, then they have nothing to read—nothing to do at all—for the 23 hours daily that they are locked up. They get one hour of recreation per day (which may mean being let out into an empty, walled, concrete-floored area), but for the first week all teenagers in solitary are shackled during the recreation period. During that period adult prisoners are also in the recreation “yard,” where they frequently threaten and victimize the

children. Children in jails are supposed to continue to receive education, but those in solitary aren’t allowed to attend classes. At most, a teacher visits them for ten minutes once a week, and may, or may not, leave a packet of worksheets for them to complete. This clearly violates the federal Individuals with Disabilities Education Act (IDEA), which requires that children with disabilities have an Individualized Education Plan (IEP) tailored to their needs, and which applies to children educated with public funds regardless of where they are being schooled. IDEA also requires educators to assess children with disabilities to determine whether their negative behaviors are caused by their disabilities, and if so, to develop a positive behavioral intervention plan to address them. Sending kids to jail, and placing them in solitary once there, does not qualify as a positive behavioral intervention.

Bipolar disorder frequently causes negative behaviors, including arguing and fighting, distorted beliefs about one’s abilities, paranoia about others’ intentions, and depression and suicidal ideation. ADHD often requires that school assignments be broken down into brief sections that can be completed quickly; a sheaf of worksheets is almost the exact opposite of such an educational strategy.

The harmful effects of solitary confinement are more dangerous in children, whose brains are still developing and more vulnerable to psychological trauma. Several studies have shown that it weakens children’s ability to trust adults, and often leads to depression and attempted suicide.

Permitting only religious books for the first three days is especially offensive, not only to atheists but perhaps also to thoughtful religious people who might object to this apparent effort to conjoin religious instruction and inhumane punishment, thus equating them. It is also a probable violation of the principle of separation of church and state, though this is not mentioned in the complaint.

There is much more, all of it sadly familiar to anyone who has an interest in the issue of solitary confinement.

It is also familiar to Sheriff Harder, who has repeatedly heard from advocates and attorneys who have advised him that solitary confinement for juveniles is definitively known to injure them, that it is considered unacceptable by a broad array of experi-

enced professionals in the corrections field, and that the national agency that accredits jails (jails not accredited can be prohibited from accepting new inmates and denied government funds) frowns upon the practice. Yet in response to the lawsuit, Harder told a reporter that A. T. and another teenager with disabilities included in the suit “didn’t follow the rules in jail, just like they didn’t on the streets.”

But the tide is turning against those who insist on being “tough on criminals”—even kids only accused, not convicted, of crimes—at any cost. Sheriff Harder will have to learn this lesson the hard way, but he will no doubt learn it.

## **New York State Needs Help**

The federal Department of Education has placed New York’s special education system in the “Needs Assistance” category for the second year in a row. The determination is made by assigning points to various compliance and educational outcome issues, and doing some boring math on them to arrive at a “Results Driven Accountability percentage,” or RDA. If the RDA is between 60% and 80% for two years in a row, the state is designated “Needs Assistance.”

New York’s score for the most recently calculated school year (2015-16) was 62.5%. We don’t know the score for the 14-15 year, only that it was also between 60 and 80. We can tell you where the state went wrong in 15-16, though.

Although NY school districts made progress on correcting most previous issues of regulatory compliance, including disproportionate representation of people of color in special education, they did not do so well on reducing their unfairly high rate of suspensions and expulsions of minority children with disabilities.

Those who’ve seen the John Waters movie *Hairspray* will understand what we’re talking about. Early-60s Baltimore high-school girl Tracy Turnblad likes her big teased hair-do, but she is sent to the special-ed class because her teacher thinks it’s a “hair-don’t.” There she meets a bunch of black kids who were sent there to segregate them from white students and keep them from competing academically with them. John Waters didn’t make this up; he based it on his own childhood in Baltimore.

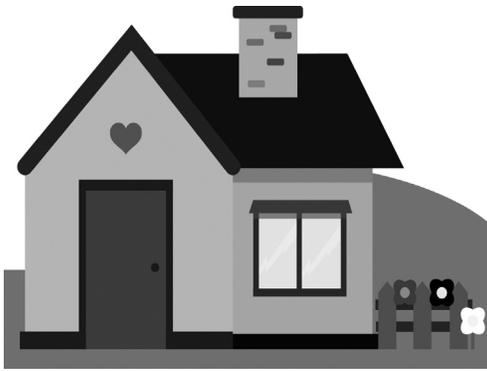
When the US Supreme Court declared school segregation unconstitutional, many school districts conceived a strategy of labeling black students “disabled” and banishing them to the “special class.” This didn’t just happen in the south; it was common all across the United States, and it is still continuing today. The Education Department scores show that New York schools aren’t doing that as much as they used to. But they also show that they continue to apply harshly different standards of treatment to disabled children with behavioral issues based on their race or ethnicity. A disabled black kid in a New York school who behaves badly is far more likely to be suspended or expelled than a white disabled kid who does the same thing.

On the academic results side, New York did even worse. Only 26% of fourth grade students with disabilities, and 39% of eighth grade disabled students, got a score of “basic or above” on the standardized National Assessment of Educational Progress test, even though 93% of children with disabilities at both grade levels took the test.

Lest you believe that low test scores for children with disabilities are inevitable, we’ll remind you that we’ve reported that only about 19% of children receiving special education services are in disability categories that could potentially reduce their ability to learn even with special accommodations, and a much

smaller number actually have learning limitations (see *AccessAbility* Spring 2015).

The federal “Needs Assistance” designation is supposed to require the Department of Education to demand that New York’s State Education Department (SED) do something. As best we can tell, the feds have elected to direct SED to obtain “technical assistance” on how to get schools to do better, and to demonstrate that they are using that technical assistance. That doesn’t sound like a very big deal to us, but education advocates are encouraged to demand specifics from SED on what it plans to do and when.



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# A HOME is Not a HOUSE

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As we reported last time, Medicaid Service Coordinators will have to leave the agencies that employ them and go to work for regional Care Coordination Organizations (CCOs) in order to comply with the new federal conflict-of-interest rules. This will theoretically begin sometime in the second half of 2018, but don’t hold your breath. It’s coming, but we don’t know how soon.

The CCOs must be controlled by organizations that have experience in providing a broad range of services to people with developmental disabilities.

Southern Tier Independence Center has formally signed up to own a share of PrimeCare, the Care Coordination Organization (CCO) being formed by many of the same agencies that established the iCircle managed care company a few years ago. STIC’s Executive Director, Maria Dibble, is on the board of iCircle and will also be on the PrimeCare board. Several STIC staff members, including Service Coordinators Jo Anne Novicky and Emily Neville, are serving on the PrimeCare committees that are working on issues such as salary and

benefit packages for Care Coordinators, and defining high-quality care coordination procedures. We believe that this will give STIC a lot of influence over how PrimeCare operates.

When service coordination for people with developmental disabilities moves over to the CCOs, you’ll be offered the option of receiving “Health Home Care Coordination.” A “Health Home” is not a place to live; it is a form of care coordination that is focused on keeping people physically healthy. Other Health Homes in New York State have aimed at things like ensuring that people with serious mental illness and diabetes check their blood sugar, take their medications, and get to their doctor appointments. Health Homes also work to improve a person’s “social determinants of health.”

“Social determinants of health” is a big mouthful of words. Here’s what it means: Disability rights and health care advocates have long argued that people who live less stressful and more satisfying lives are healthier than those who don’t, and that when it comes to healthcare, prevention is much cheaper than treatment. People who

are homeless, for example, are constantly under physical and psychological stress, and they have high rates of physical illness as a result. Give them a decent place to live, their stress goes down, and they need less medical treatment. People who have meaningful employment have both more money and a greater sense of self-worth; this also leads to healthier bodies. So another function of Health Homes is to assist people to find and keep places to live, and to find and keep jobs. The record of Health Homes in New York on this is uneven; some are much better than others.

But for people on the OPWDD Medicaid waiver, this will sound familiar—much like Medicaid Service Coordination. In fact, it comes from a much older source—Centers for Independent Living like STIC, which have been providing “wrap-around” support to help people with disabilities establish, and keep, lives in the community with peer counseling, independent living skills training, and housing and benefits assistance since the mid-1970s.

Under the Affordable Care Act (“Obama-Care”), states get a much higher federal

Medicaid matching share for providing Health Home services. This is why OPWDD wants CCOs to get certified to provide Health Home Care Coordination.

This is *not* “managed care” in the technical sense. Managed care is about how insurance companies pay for health care, and Medicaid managed care is about how the state pays and oversees those insurance companies. New York still plans to move OPWDD services into managed care, but that is not expected to happen around these parts before the early 2020s.

But OPWDD seems to be basing its version of Health Homes on the FIDA managed care demonstration that’s been going on in New York City for the past three or so years.

FIDA stands for “Fully Integrated Duals Advantage.” It’s a way for states to provide both medical and long-term care supports and services to people who are eligible for both Medicaid and Medicare, the so-called “dual eligible.” New York’s FIDA demonstration is exclusively for people with developmental disabilities who volunteer to participate. Health Home Care Coordination is an option for the participants, but even if they don’t choose it, their person centered planning process and their service plans (called “Life Plans”) are supposed to include all of their medical health needs and services along with things like habilitation and supported employment.

The thing about FIDA, though, is that it’s a failure. After three years, only about 8% of those eligible have signed up. There are at least two important reasons for this. First, the program is run directly by managed care insurance companies, not experienced developmental disability service providers. If you’re on the OPWDD waiver and you want to be in the FIDA demonstration, you can’t keep your OPWDD service coordinator; you have to use one who works for the insurance company. Second, very few medical service providers—doctors, etc.—have agreed to participate in FIDA. Ideally, in the Health Home model, your doctor and nurse and physical therapist are all supposed to sit around the table with you

and the people who provide habilitation and employment and housing supports, and help you develop your integrated service plan, using a person-centered process that you control. And in between meetings, the doctors and nurses and PTs are supposed to take phone calls from your hab DSP and your service coordinator to discuss issues and work out solutions to problems that crop up. When was the last time your doctor came to one of your service planning meetings? Can’t remember such a time? Exactly. How many of you have a doctor you can talk to on the phone? Ditto. From the doctors’ point of view, this sort of thing takes up a lot of time, and results in a lot of extra paperwork, for which they are not paid any extra money. So, many people who wanted to try out the FIDA quit when they learned that they not only couldn’t keep their service coordinators, they couldn’t keep their family doctors either.

OPWDD thinks the CCOs will solve the first problem, because they will employ people’s existing service coordinators.

(There’s no actual guarantee that you can keep your service coordinator; that will depend on how well the CCOs treat those employees in terms of salary, benefits, and working conditions, and also on the case-load limits they set.)

But OPWDD doesn’t have a solution for the second problem. Even if CCOs eventually morph into managed care organizations somewhere down the road, which is what OPWDD is hoping, and their provider networks are big enough to include your doctor, there is no way your doctor is going to come to your meetings or take your phone calls unless she is specifically paid a reasonable rate to do so, and that’s not likely to happen.

Now, you can get perfectly good medical care without that. And having a bunch of medical professionals at your planning meetings may be more intimidating than helpful. But we are uncertain about how all of this is going to work in detail.

The main problem is money, sadly. Once the CCOs are up and running, the only service coordinator you can have will be one who

works for the CCO. But the Health Home benefit is optional; you don’t have to take it. Once managed care arrives, then if your CCO becomes a managed care organization, it will be managing both your medical care and your disability support services. If you opt out of the Health Home benefit, then it may be two different sets of people managing your medical and your long-term supports. And that may be fine. As we’ve suggested, it may be a lot harder for you to control your own planning process if it’s dominated by medical providers. And you may not want people looking over your shoulder and pestering you to take your meds or attend smoking cessation programs or eat your vegetables or go to the gym and work out. Or, to save money, the CCO may integrate your medical and support service planning whether you use the Health Home or not.

The state will only get that extra Medicaid percentage if you choose the Health Home benefit. If you do, the CCO can get a rate to serve you that is higher than what the state pays for Medicaid Service Coordination today. If you don’t, then the state will pay a different rate, but so far it has refused to say what that rate will be. Notably, it has refused to say it will be at least as high as the current service coordination rate. It could be lower than that, even much lower.

Right now we don’t see very much that is attractive about the Health Home benefit for people who already have OPWDD waiver services. A lot of you might choose not to take it, as will be your right. If that happens, though, the CCOs may not have enough income to operate. What will happen in that case?

According to OPWDD’s plans, if that happens after managed care is introduced, then you’ll be shifted into developmental disabilities service plans run by ordinary managed care insurance companies—just like in FIDA. You won’t be able to keep your service coordinator, and you may not be able to keep your doctor.

We don’t want that to happen. OPWDD has requested public comment on this plan and we’ve responded. Unfortunately, the deadline for comment has already passed, so there’s nothing left to do right now except wait and see. When we see, we’ll tell you about it.

*Give them a decent place to live, their stress goes down, and they need less medical treatment.*

# STIC NEWS

## STIC's Honor Roll

Each year Southern Tier Independence Center gives special recognition to a few select people. While we know many, many people who do very good work in the fields of disability rights and disability services, only a very small number truly go far beyond the call of duty to render invaluable assistance to people with disabilities, STIC, or the cause of disability rights.

These are among those people. We thank them very much.

### OUTSTANDING AGENCY SUPPORT

#### Dr. James J. & Pamela Vincens

This couple has been consistently supportive of, and highly generous to, STIC, year after year, for decades.

### OUTSTANDING CONSUMER SUPPORT

#### Susan Buegler

Susan is a social worker for very young children with disabilities. She helps children make the transition from Early Intervention to Medicaid waiver services at home, and from pre-school to primary school special education. She works tirelessly to teach families to advocate for their children's inclusion and independence. She is truly dedicated to improving the lives of children and families and often continues to work with them even when they have left her "caseload".

#### Laura Riker, Resource Network

Laura is the Family and Fiscal Director for the Resource Network, which provides funding for "goods, services, or other needs not funded by other sources." The program exists to prevent people with unique needs from "falling through the cracks" of the developmental disability service system. Laura is extremely creative and helpful; she's arranged for families to get emergency respite, to pay for driving lessons, and funding to attend a summer musical workshop. If a need doesn't fall within the usual Resource Network bounds, she will look outside the program to try to find other resources to help.

#### Eric Schneiderman, NYS Attorney General

Over several years New York's Attorney General has done exemplary work to identify and prosecute people who abuse or neglect people with disabilities in segregated environments, especially in nursing facilities.

### OUTSTANDING EMPLOYMENT ASSISTANCE

#### Jill LoVuolo, Community Options

Jill LoVuolo is Community Options' Employment Director. She has helped that agency develop a full array of OPWDD-funded integrated employment services, including Pathways to Employment, community prevocational services, ETP, and supported employment. Her program will work with anyone, including those with behavioral issues or a criminal background. She explains options in depth to people with disabilities and their families so they can develop a truly individualized approach. Constantly thinking "outside the box", she has helped many people develop customized employment situations, and they've been very successful.

### OUTSTANDING SYSTEMS ADVOCACY

#### Diane Coleman, Not Dead Yet

Diane is an energetic and passionate national leader working to oppose legalization of assisted suicide. She has testified before the US House of Representatives and appeared on Nightline, CNN, MSNBC and others. Working out of Rochester, she has been effective in preventing legalization in New York, and she is now working on a bill to improve pain relief and palliative care.

### Susan Oakes, Legal Aid Society of Mid-New York

Bigotry toward parents with disabilities is a major remaining barrier to full social equality. Susan has poked a hole in that barrier by bringing the Americans with Disabilities Act (ADA) to the Broome County Family Court room for the first time ever. She used it to assist a mother with disabilities who was devastated when the Department of Social Services removed her child from the hospital days after he was born. Susan spent countless hours researching, communicating and networking with people in Albany, Vermont, Maryland and Canada to educate herself and use the ADA to support the case and going way above and beyond for this mother.

### OUTSTANDING VOLUNTEER SUPPORT

#### Benjamin Houck

Benjamin is a recipient of STIC services who loves to contribute and help out; He's always available to do document shredding, weeding and maintaining our flower beds, and more.

#### Cynthia Shapley

#### Francis Shapley Jr.

These amazing people helped with every single Haunted Halls of Horror performance in 2015 and 2016. They performed as "scare-actors", and helped with wardrobe, makeup, and crowd control.



STIC Executive Director Maria Dibble presents the Vito Sirotkin Humanitarian Award to Reva Reid

# New STIC Sensory Room Dedicated

by Maria Dibble

On July 26, 2017, STIC introduced a new service to the community, a “Sensory Room”, which we dedicated to beloved former employee Vito Sirotkin, who passed away suddenly last year.

The plaque outside the room reads:

We dedicate this room to the honor and memory of Vito Sirotkin

For his love of children and humankind  
Thank you Vito for the gifts you gave,  
For the kind and generous man you were,  
For being the wind that fills our sails,  
Guiding us through our hopes and dreams,  
As we journey to our destiny.

The dedication featured words from Assembly Members Donna Lupardo and Clifford Crouch, Binghamton Mayor Richard David, and representatives from County Executive Jason Garner and Senator Fred Akshar. The event was moving and emotional for everyone who knew and loved Vito. His wife, children and other family members attended, with flowers being presented to Heather Sirotkin, along with our fondest memories.

## First Vito Sirotkin Humanitarian Award Winner

The ceremonies for the event were facilitated by Maria Dibble, STIC’s Executive Director, and included the presentation of a very special award, newly created in Vito’s honor, the “Vito Sirotkin Humanitarian Award”, a plaque which read:

Vito Sirotkin Humanitarian Award

Reva Reid

“For selfless dedication to children and adults with disabilities,  
and for the betterment of the community and humankind.”

It was given to Reva Reid, an occupational therapist who goes beyond the call of duty to assist children and adults with disabilities to live fulfilling and more independent lives. She also designs adapted bicycles for children with disabilities so that they may experience the joy of riding as nondisabled children do, and she offers them for very low cost. Her generous spirit and caring represent what this award means to us at STIC.

## What is the Sensory Room?

The Sensory Room is a place where children and adults with sensory disabilities can experiment with and be exposed to a wide variety of visual, tactile, auditory and cognitive experiences, by using the equipment and technology we have available. People can determine if any of the items on display and for use would meet their needs and improve their abilities to cope with various types of stimulation and activities, before they decide if any would be beneficial in their daily lives. People will have an opportunity to explore, with their own senses,

multiple textures, lights, colors, sounds, and much more, through devices, computer software, static and mobile displays. They will learn about themselves, and they or their families and/or therapists can determine if these things can help them live more full and independent lives. While we don’t sell any of this equipment, we’d like people to have a chance to try before they buy, and their experimentation in our room will allow just that.

Tours and use of the room must be scheduled. For an appointment, call Kevin Jackowski at 724-2111.





Advocating for  
Differing Abilities:  
**STIC's 2017 Americans  
with Disabilities Act  
(ADA) Celebration.**



*See page 14.*



## Back on the Campaign Trail

Each year we send out letters asking for financial support. We know, some of you read those letters and laid them aside, planning to respond later. Later is now! There's still time if you would like to send in your contribution with the form and envelope we provided. If you do, you have the option of seeing your name or the names of people you care about here in our newsletter, like those below.

THANK YOU!

**Gordon and Alice Allen**

**Muriel App**

*in memory of Douglas App*

**Diane J. Button**

*in memory of Dale A. Button*

**Gerald L. Day**

**Kristine A. deVente**

*in name of Emily Neville*

**Denny and Lynn Graham**

*in memory of Olga Barron*

**Wayne and Faline Howard**

**Susan Hoyt**

*in memory of Carl Richard Brennan*

**Stan and Bonnie Kauffman**

*in memory of Peter Putano*

**Charles and Charlotte Kramer**

**Michael & Rachel Leonard**

**Sam Liberto**

*in name of Saverio Liberto and Filomena Liberto*

**Dorothy Martens**

**William and Helen Mizera**

**Karyn Ann Petracca**

**John and Rita Sejan**

**Jennifer Watson**

**Robert and Dawn Watson**

*in name of Kevin Watson, Jr.*

**Jody Weidemann**

## ADA All the Way

by Maria Dibble

On July 26, 2017, STIC celebrated the 27th anniversary of the Americans with Disabilities Act (ADA), or as we called our event, "Advocating for Different Abilities".

The ADA is the most important piece of civil rights legislation ever passed for people with disabilities, affecting public accommodations, communication, employment, transportation, and state and local governments. The sweeping legislation was all about our rights, not about "special privileges" or special programs. It was about making our country a more accommodating, receptive, accessible place, and it has gone a long way in promoting a more level playing field. Many strides have been made in accessible stores and other facilities, provision of sign language interpreters, more curb cuts, accessible buses and trains, and so much more. We have a long way

to go on employment still, but none of us is giving up on that either.

Each year, STIC marks the anniversary of the ADA's signing by President George H. W. Bush in 1990 with both fun and educational activities. The law should be celebrated, and we do!

This year, our goal was to educate the public about STIC, our services, and how to be advocates for issues. We hosted a wide variety of activities including: an advocacy tree, where people placed a leaf for what they had, or wanted to, advocate for; an advocacy suggestion box to guide us in future advocacy efforts; an accessible voting machine and voter registration table (because the best advocacy tool is to vote!). We also featured a guide dog demonstration, therapy horse, face painting, adaptive bike display, assistive technology, STIC department info, sensory integration activities, and food and fun. More than 300 people attended and it appeared to be a great success.



Book your Valley of the Kings or PULSE experience here:

[https://www-1554a.bookeo.com/bookeo/b\\_xscaapes\\_start.html?ctlsrc=1495468589081&src=02r](https://www-1554a.bookeo.com/bookeo/b_xscaapes_start.html?ctlsrc=1495468589081&src=02r)

We've added daytime hours! Monday through Saturday at 1:00 pm, 3:00 pm, 5:00 pm, 6:30 pm, and 8:00 pm.

The word 'PULSE' is written in large, white, block letters with a glowing, electric effect. The background is dark with white lightning bolts striking across it.

The words 'VALLEY OF THE KINGS' are written in a stylized, textured font. The word 'OF' is smaller and positioned between 'VALLEY' and 'THE'. In the center, there is a detailed illustration of the Great Sphinx of Giza.

## David: One Year in the Community and Still Going Strong!

by Dacia Legge

David—3 ½ years in Bridgewater—moved to a beautiful, accessible apartment through First Ward Action Council in August of 2016 and is still going strong.

David is a 67-year-old man who was admitted into the Bridgewater Center for Rehabilitation and Nursing after experiencing a stroke. His friends and family in the community were skeptical that David had the capacity to care for himself, and some thought he didn't have enough cognition to direct his services. However, by using the Nursing Home Transition and Diversion waiver (NHTD) services, he is living independently in the community with 8 hours a day of staffing (split into two 4-hour shifts) and with the help of service coordination.

David is a free spirit who loved to travel on his motorcycle before his medical event. After his stroke, his health continued to deteriorate and he was relying on help from his elderly, frail parents. Once that was no longer feasible, he was admitted to Bridgewater in January 2013.

In October of 2015, David's facility social worker made a referral to the Open Doors Program, on his behalf. Open Doors met with him and made a referral to the NHTD waiver and to the Open Doors peer program. The peer program connects participants with peers who have also experienced stays in nursing or rehabilitation facilities. The peer is someone who can relate to what the participant is experiencing and feeling. David's peer met with him weekly and he was empowered to make more of his wishes and wants known to the staff.

Next, Open Doors made a referral to the Olmstead Housing (OHS) Program and the housing coordinator was able to assist David with finding a beautiful, accessible subsidized apartment that was renovated by First Ward Action. David's service coordinator used waiver funding to buy furniture and household goods to set the apartment up. One of his favorite things about his apartment is that it is right next door to a large Bingo hall, and this is one of his favorite things to do. He goes there twice a week, and spends time with new friends he has made and participates in the community meal there.

David's discharge was a successful collaboration between the nursing home, Open Doors, the peer program, OHS and the NHTD waiver

coordinator. David was also assisted by his aunt, who was one of his strong advocates in believing that he deserved a chance to try and live in the community independently, again.

The Open Doors Program is here to assist individuals, by supporting their wishes to return to their community, with the supports they want, after a stay in nursing homes, rehabilitation or developmental centers. Often people have to battle a medical model mentality and other attitudinal barriers that suggest most people leaving a facility need 24/7 services or supervision. However, this mind-set ignores the fact that people have the right to self-determination, the dignity of risk and to be in the least restrictive setting they choose. Open Doors staff will advocate alongside you or your loved one, to provide a voice for what individuals want for their supports and how they want to live their lives.

If you or a loved one would like more information on the Open Doors Program, please reach out to:

Dacia Legge, LMSW  
Open Doors Regional Lead Coordinator  
Southern Tier Independence Center  
dacial@stic-cil.org  
(607) 724-2111 x 329 (phone)  
(607) 772-3606 Attn: Dacia (fax)

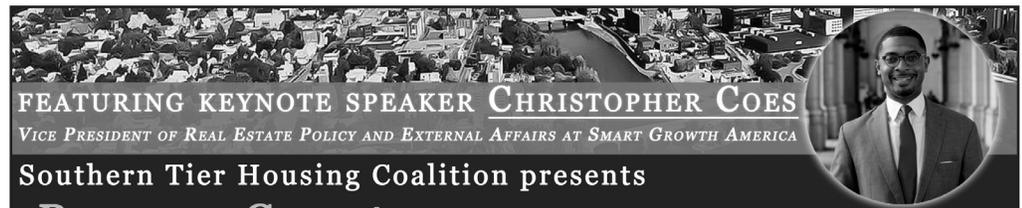
## Free Smoke Alarms

The Red Cross distributes free smoke alarms to people in our area. Their volunteers will be making a concerted effort to assist people between September 23 and October 15. However, they can help at other times of the year as well.

They are able to order and distribute smoke alarms for people who are hard-of-hearing or deaf.

Renters as well as home owners can request this service.

Their phone number is (607) 785-7207.



FEATURING KEYNOTE SPEAKER **CHRISTOPHER COES**  
VICE PRESIDENT OF REAL ESTATE POLICY AND EXTERNAL AFFAIRS AT SMART GROWTH AMERICA

Southern Tier Housing Coalition presents  
**Broome County**

# Housing Summit:

## There's No Place Like Home

**OCTOBER 4<sup>th</sup> FROM 9:00-4:30 | SOUTHERN TIER INDEPENDENCE CENTER**  
**Registration 8:30 - 9:00** 135 EAST FREDERICK STREET, BINGHAMTON

*Join us for a free public summit to examine the growing housing shortage in Broome County, understand the impacts, explore community-based solutions, and learn about funding/grant opportunities.*

**The summit will include panel discussions focusing on:**

- Personal experiences of people with disabilities obtaining housing
- Local developers sharing successes and challenges they have had on housing projects
- Government officials and community leaders discussing their role in the development of safe, affordable, and accessible housing

**The day will conclude with participants taking part in small group brainstorming sessions and identifying next steps.**

*Lunch and light refreshments provided at no cost.*  
Pre-registration is required by September 22<sup>nd</sup>  
Email registration to [housingsummit@stic-cil.org](mailto:housingsummit@stic-cil.org)  
Please call (607) 724-2111 with any questions related to the summit

**Special thanks to our premier sponsor**

**Community Bank N.A.**



This newsletter is also available in large print, on cassette, and online, at:  
[www.stic-cil.org](http://www.stic-cil.org)

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## 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.**

- |  |      |  |           |
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| <input type="checkbox"/> Individual              | \$5  | <input type="checkbox"/> Contributing            | \$100     |
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**MAIL TO:** Southern Tier Independence Center, Inc.  
 135 E. Frederick St.  
 Binghamton, NY 13904

Name \_\_\_\_\_

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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

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