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

AccessAbility

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The Last CATCH-22

by Ken Dibble

Here's a conundrum of modern life for people who are elderly and disabled:

Suppose you don't want to live in a nursing facility. That's pretty much like saying, suppose you want to breathe. But it's worthwhile elaborating just a bit on this.

If you are starting to need some help, and you don't mind the idea of moving somewhere that is not your home and not fully under your control, and you have a lot of money, you may be able to get into a pretty upscale place. You know, one of those "senior communities" that can provide flexible levels of services and supports, so that the setting slowly morphs into "assisted living" and then gradually ramps up the hours of personal care and nursing visits as your needs increase, while you continue to live in a very nice little apartment. The staff are reasonably well-paid, well-trained, courteous and respectful, and it may be "just a fantastic place to be," as an elderly gentleman has recently been telling us on local TV commercials.

Trouble is, most of us who are growing older aren't going to have the kind of cash it takes to get into those places. In *Atlantic* magazine just over a year ago, Neal Gabler, a relatively successful author, bemoaned the fact that neither he, nor a very large number of his fellow Americans (47% of respondents to an annual federal survey), could come up with $400 in an emergency. You might think that's just about cash on hand, but it's not. About half of American households have a net worth of less than $54,500. People don't save like they used to.

But even those who have reasonably large middle-class nest eggs would have a hard time paying for one of those "fantastic places" for very long. According to SeniorHomes.com, in 2015, monthly rates charged by assisted living facilities in New York for a one-bedroom unit ranged between $1,100 and $11,100. You can imagine what sort of care you would get for $1,100 a month; that's not much more than the rent for a decent-quality one-bedroom apartment, without any services, in a lot of places. In 2014 half of assisted-living residents in the United States were paying more than $3,500 a month. How long do you think you could afford that?

INSIDE

If you can't afford that, there's always Medicaid. In 2013, in the Binghamton region, the highest rate New York State Medicaid paid for an assisted living program (ALP) was about $2,830 per month, for people who need daily rehab. The lowest rate paid in our region, for people with somewhat reduced physical functioning, was $1,490 a month (information at: https://www.health.ny.gov/facilities/long_term_care/reimbursement/alp/assisted_living_program_rates_january_2013.htm).

However, you can't be admitted to an ALP if, for some reason, such as using a ventilator, you need 24/7 care, or you have a condition, like a severe bedsore, that leaves you "bedridden". If that's your situation, and you can't stay home, you're going into a nursing facility.

In 2014, the lowest rate that NYS Medicaid paid for a skilled nursing facility in Broome County was around $4,885 per month (from https://www.health.ny.gov/facilities/long_term_care/reimbursement/nhr/2014/nursing_home_rates_jan_2014.htm). The lowest rate they paid for someone on a ventilator was about $15,750 a month.

What, you may ask, is going on here? This is a STIC editorial and you haven't once mentioned homecare?

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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.

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Okay, here we go. NYS personal care rates (the Consumer Directed Personal Assistance program is "personal care") are all over the map. Each agency gets its own state fee-for-service rate based on very complicated paperwork it has to submit to the state. But these days most people get personal care through Medicaid managed care, and each managed care insurance company also negotiates its own rate with each provider. Plus, the rates are usually hourly, not daily as they are for nursing facilities and assisted living. But here's a number: The lowest rate for CDPA "live-in" service (the attendant lives with you and is supposed to provide 24/7 service, but in fact must be allowed five hours of uninterrupted sleep daily, as well as some time off) in NY in 2015 was about $5,090 per month (at https://www.health.ny.gov/facilities/long_term_care/reimbursement/pcr/2015_pc_rates.htm). If you can get live-in service authorized at all, you must have very high needs; you would be similar to the people who rate $15,750 in a skilled nursing facility. But if you actually need attention more frequently than every five hours during the night—say, to be turned every two hours due to a bedsore—you won't qualify for a live-in attendant.

To try to get closer to what actual 24/7 homecare would have cost in the same time-frame, let's do some arithmetic: In 2013, the NYS minimum wage was $7.25 an hour. 24/7 care is 8760 hours a year, times ... hmm... hmmm... carry the six... Turns out it would have cost at least $7,620 a month just to pay staff to provide 24/7 care to you in 2013. If you add in required withholding and a somewhat better hourly rate, you get something around $9,000 a month.

Now, the regulations governing these things are inflexible: If you qualify for $9000 homecare, you are also going to qualify for $15,750 nursing facility care, so if you don't stay home that is what you will get, and that, not $4,885, is what NY will pay, even if in reality all you need is some reliable way to get help at any time of day. Actually, that's "allegedly reliable," but hold that thought for now. Point being that for those with the most needs, assisted living is not available, and homecare is still far less expensive than the equivalent form of nursing facility care.

There's another regulation governing homecare that you need to know. Homecare still operates under the New York State fee-for-service Medicaid regulations, even though much of it is now provided through managed care. Those regulations were intended to give county government a lot of control over what you can get, because counties are responsible for coming up with half of the state share of Medicaid money. When you apply for homecare, these regulations require the county to try to find some reason to deny your request, or to reduce the number of hours you receive. If, for example, the county thinks you have relatives who can help, they can require you to rely on them. Or if the county thinks you are dying, it can require you to use hospice services instead of homecare. Or if the county thinks you are not "safe" at home, it can tell you it will only pay for a nursing home.

Now, there are other state regulations that require the state's Medicaid program to provide as many hours of homecare as are medically necessary to people found eligible for it and deemed able to benefit from it. These regulations should take precedence over any decision made by the county, and the state is supposed to enforce them. (Hold that thought until you get to page 6....)

In our new world of managed care, most New Yorkers can substitute "managed care plan" for "county" when they think about this. There are still some people on Medicaid waivers who don't have to enroll in managed care, but it doesn't much matter. Although there are no actual regulations on the books that explicitly say this, a Medicaid managed care plan has the same authority to determine need and approve services that counties have, and the regulations for counties are the only guidelines that are available for them to follow, and they follow them. (For policy wonks

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.

who want to talk about how much better the Community First Choice (CFC) regulations are than those for NYS personal care: The CFC regulations are federal, not state. Although the federal regulations legally trump those of the state, as a matter of practical reality, the feds will not actively enforce them, and it has not really dawned on the state that it must do something about following them. The contracts with managed care plans point to the state personal care regulations, and until the state writes its own regulations for CFC, the personal care regs will control this system. If you think the state is going to produce CFC regulations quickly, remember how long it took to get the CDPA regulations issued.)

Now, suppose you are an elderly and very severely disabled person with considerable physical and cognitive issues, and you're dependent on Medicaid, but you know that you are comfortable, and feel safe, in your own home with, say, 12 hours a day of service provided by CDPA attendants whom you have chosen and trust. You know for sure that you do not want to leave your home to place yourself at the mercy of strangers in a residential facility. You would rather die than do that. And suppose you live in a county, like Broome, that takes full advantage of the Medicaid regulations to resist providing 24/7 homecare. What do you suppose will happen if your condition worsens? Perhaps you lose the ability to control your bladder or bowels. Perhaps you develop a very severe bedsore. Perhaps you begin to die, as we all eventually must do.

You had better hope the person responsible for assessing your needs doesn't find out about it. You may think you should request more service, but that may be a very bad idea. If you can no longer get out of bed, and you need somebody to turn you every two hours, and to keep you clean despite your incontinence, and to encourage you to drink and eat enough, you might need more service than you're getting. But asking for it triggers a new needs assessment. And the county assessor may easily conclude that you aren't safe at home because you need 24/7 care, but you can't get it because the county won't approve it. Catch-22! Then they make a finding that you need to go into a nursing facility. And then, my friend, you are done.

No, you say, I don't need 24/7! My last aide leaves at 10 pm, and the next one comes in at 8 am, so I just need somebody to come in at midnight, and stay until 6, to turn me. That's only 18 hours. But the assessor says, "under the regulations, we only cover 16 hours without special procedures. If you want 18, you'll have to ask the medical director to approve it, and you'll have to prove that you would be okay if something happened during those six hours when nobody was there, and you don't really look to me like you can handle that." (The math works out, trust me; there's a break between 1 pm and 3 pm with no aide.)

And you might conclude that this was just hard-nosed economics masquerading as concern for your safety. Lots of people think it's too expensive to provide 24/7 homecare for everybody and that some people are just going to have to go into nursing homes. Sad but unavoidable.

Except that I've just shown you that it isn't economics. The county will pay almost twice as much to put you in a nursing home as it would to keep you at home with 24/7 homecare. That's true in the example I've given here, and in almost every other example you can think of.

It's ***not*** "always about money." Sometimes it's about something much harder to combat: fear.

In Medicaid-funded institutional settings you will get no more personal attention than you would get with 16 hours of homecare. If you don't believe me, go in unannounced and spend some time on a Medicaid-funded floor of one of our local nursing facilities. Listen to the constant alarms and call-bells going off. Observe the staff, if you can find them, sitting around the nursing station, chatting. You can call for help to go to the bathroom or get a drink of water, or to ask for pain medicine, or to say you're having trouble breathing, all you want. Nobody will come immediately, or even soon, especially at night, or if there's a staff shortage, which there nearly always is. And if you don't have the ability to yell very loudly, or press a call button, nobody is going to come at all until the next scheduled "rounds." Therapy? One of the most common complaints about nursing facilities is that people who were admitted because they needed therapy never got any, even though the facility often billed for it. Safe? What's one of the most commonly reported "serious incidents" in nursing facilities? People getting injured because they fell out of bed or while trying to walk when there are no staff nearby. Sometimes they lie on the floor for a good long time before they are discovered. If you complain, prepare to be disrespected, handled roughly, perhaps even slapped or pinched. Do you have concerned relatives who, seeing this, become enraged and want to file a lawsuit on your behalf? So sorry; remember, you were required to sign a binding arbitration agreement as a condition of being admitted. Do you want to file a complaint with the state health department, which, by law, has responsibility for overseeing these places? Do you think that will help? Not necessarily. According to a 2014 federal audit, the New York State health department failed to follow up to find out if nursing facilities had corrected problems found by state inspectors 72% of the time.

But people who have never lived with a disability cannot conceive that you might be safer in your own home surrounded by people whom you've chosen, whom you can trust, even if they can't be there all the time, than you would be in a place where "24/7 service" means only spending every single last hour of your life in the same large building with people who don't know you, don't respect you, and don't pay attention to you.

It's really difficult to get people to even think about this. We all hope that when our time comes it is quick and we don't spend weeks or months slowly fading, in pain and fear. But that's how more and more of us are living our last days. Improved medical technology improves our ability to stay alive, but it does **NOT** improve the lives we must endure for those extra days.

This fear, this refusal to face what we are all coming to, causes legislators, regulators, and bureaucrats to keep the system the way it is. To mask the fear they tell themselves these "hard decisions" are necessary for financial reasons. They are lying to themselves. These decisions are only necessary to hide the suffering of our elders and the future that awaits many of us.

I have been watching my severely-disabled mother-in-law slowly dying for several months. We have fought the attempts of the county and the hospice service to drive her into a nursing home, a place she has been in before, and to which she would rather die than return. I have been forced to face what is happening to her, and what is likely to happen to me. I know some of you are living that experience right now as well.

Face it, and learn from it. Consider what you have learned when you are asked to vote for politicians who want to destroy Medicaid, or who want to take us away from our homes to keep us "safe".

There is little hard news to report about Trump Administration or Congressional action on the disability healthcare front. There's been a lot of speculation and political posturing, of course.

The available funds do affect federal healthcare programs. Congress has passed a "budget" for the current federal fiscal year, but a federal budget bill is loosely binding. What really matters are the separate appropriations bills, which authorize the actual spending of money. They can differ radically from what's in the budget. At press time no such bills had been passed, but there were some "continuing resolutions" in effect to keep the government running. Also at press time Congress was facing a self-imposed deadline to get a tax-cut bill to Trump before Christmas.

As of now, nothing is "for sure," but one thing we do know is that right-wingers want to weaken the federal government's power to keep people from treating each other badly when that might conflict with their beliefs about religion, gender, or race, or when it might cost them money. Many of them believe that a good way to do that is to cut the amount of money the government has. If these right-wingers really control the government, they certainly will do this.

The question is whether they really do control it. Among Republicans there are a lot of far-right people and near-right people, and a few middle-of-the-road people ("moderates"). So far these groups have been, surprisingly, unable to cooperate, even though Republicans control the House, the Senate, and the Presidency. There is no majority of Republicans in the Senate that is in favor of seriously damaging Medicaid or Medicare, and there may be no majority that supports really destroying the Affordable Care Act ("ObamaCare"). When it comes time to spend money, there may not be a majority in favor of deeply cutting things like food stamps, housing vouchers, transportation subsidies, or other things that affect the lives of Americans with disabilities.

Some pundits have suggested that, of all of the things dearest to the hearts of Republicans, tax cuts are the most beloved, so surely they will agree on that. And some people have argued that big tax cuts should be feared because they will inevitably lead to spending cuts.

It's not inevitable at all. The federal government routinely runs budget deficits because it doesn't collect enough taxes to cover its expenses. The last balanced federal budget occurred during the Clinton Administration. When Republicans are not in power, they attack Democrats by claiming their spending causes deficits. When Republicans are in power, they excuse cutting taxes by claiming that deficits don't really do any harm. (They also claim that cutting corporate taxes induces companies to create jobs. That is fake news. No modern corporate tax cut in history in the United States has ever had a significant effect on jobs. Rather than investing the extra money to expand the business, most corporate executives just pass it on to stockholders or stuff it in their own pockets. Corporations make decisions to expand based on projected revenues from sales, not on their cash on hand.) When it comes to taxing and spending, the federal government can and will do anything that it can get agreement on, regardless of what's in the budget, or how much money is actually in the treasury. While you may be philosophically opposed to various kinds of tax cuts, if your concern is about people with disabilities, the time to worry is when Congress is considering specific appropriations bills.

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For those who are interested, we'll get into the weeds a bit here. Medicaid is an "entitlement," meaning that all those a state deems eligible are "entitled" to receive all necessary medical benefits that the state has agreed to offer, and the federal government is committed to pay a fixed percentage of those costs, whatever they are. However, it's an "appropriated entitlement," which means that Congress must actually authorize the spending of these funds every year. These appropriations don't contain dollar amounts; they say something that translates to, "to New York, 50% of valid claims for basic Medicaid services, 90% of valid claims for Community First Choice services ..." Even if Congress does not end the Medicaid entitlement, it can cut Medicaid spending by saying something like: "to New York, 90% of 50% of valid claims". We're not saying Congress won't do this; they will probably try very hard to do it. We're saying they haven't even started talking about it yet. You should pay attention and take action when they do.

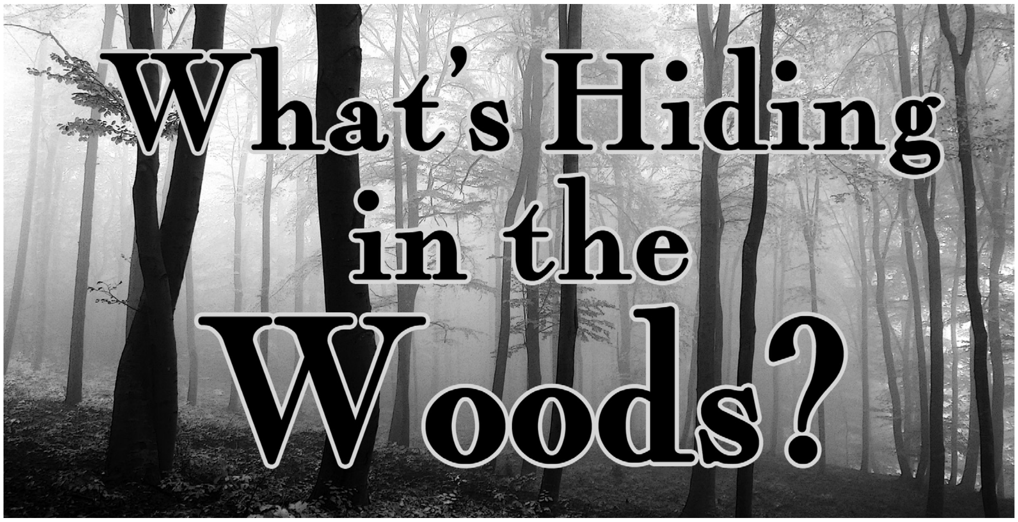
Meanwhile, the Republican adoration of tax cuts may not be enough to overcome the hardcore ObamaCare haters in the Senate who, at press time, were promising to include a provision to repeal the "individual mandate" in their tax-cut bill. That might be a big enough poison pill to get three moderates to withdraw support, and that's enough to defeat the bill. Or it might not.

Three is a small number. This fragile balance could be affected if Senator John McCain, a near-right guy who has brain cancer and has blocked attacks on Medicaid, becomes incapacitated or worse. It could also be affected if Roy Moore, the recently scandal-damaged far-right Republican candidate for the Senate seat vacated by Attorney General Jeff Sessions, loses the special election on December 12. There was a write-in campaign underway for the slightly less right-wing Republican that Moore defeated in the primary. If the overwhelmingly conservative Alabama electorate splits its vote, the Democratic candidate could win. On that one, by the time you read this, we will know.

There's also been a fairly scary ruckus over Congress' failure to renew the Children's Health Insurance Program (CHIP), a special form of Medicaid that is known in New York as Child Health Plus. This failure has cut off the funding for the program, though various states will actually spend their last CHIP dollar at different times over the next several months. Some already have, and Congress has granted them special emergency funds. New York says if the program hasn't been renewed by some time in December, it will have to start sending letters to families announcing that the program will end.

There is virtually universal support for CHIP in Congress, so it will be renewed eventually, to a point. ObamaCare expanded eligibility for CHIP. There aren't many, if any, Republicans who are down with that. The Congressional leadership doesn't view any form of CHIP renewal as a real emergency since, so far, nobody has actually run out of money. They can renew the program retroactively to the date it expired, which will turn on the cash spigot, any time they want. Right now they are focused on their fear that if they don't enact any of the things they promised to their political base, like a tax cut, they will be in deep trouble in the 2018 elections. So when that issue is resolved, they'll get around to renewing CHIP—except that they are unlikely to renew the ObamaCare expansion. Not even Democrats are holding out hope for that.

If you use Child Health Plus, your children are enrolled in a private insurance plan whose premiums are heavily subsidized by Medicaid. When the cut-off date arrives, your kids will still be insured, but your premium will go up—way up. Although the state is talking about sending you a warning letter, the first thing you get may be a bill for the new, higher premium. There are several different sellers of these plans. The plans are identical, but the unsubsidized premiums are not. If your subsidy is not renewed, you may be able to get a cheaper rate. DON'T PAY such a bill until you consult with the experts, such as a New York State of Health navigator—but don't delay that consultation either.



What's Hiding in the Woods?

Woods Services is a private institution for people with developmental disabilities in Langhorne, Pennsylvania, near Philadelphia. It houses more than 650 people of all ages, who come from more than 31 states and the District of Columbia, including well over a hundred New Yorkers, most of them school-aged children. The facility thus qualifies as a "residential school" under New York law and regulations.

Federal and state laws require local school districts to serve children with all disabilities, and when those children have behavioral issues, schools are required to carry out functional assessments and develop individual positive behavioral support plans for them. "Positive behavioral support" includes treating people with disabilities as though they have as much value as nondisabled people, and giving them meaningful things to do that interest them, so they have alternatives to "acting out." But lots of schools refuse to do this, and instead seek any excuse to send students to segregated day programs such as BOCES or an "alternative school." Sometimes they go further and send them to residential schools. Woods Services is one such place.

It is a frightening throwback to the days of Willowbrook and Rome State School. When Disability Rights New York (DRNY) inspectors visited, a housing unit for adults smelled of urine. Lights burn out and are not replaced, leaving common rooms dark. In those rooms people peer at dim TV screens, or sit and rock, or bang their heads without staff intervention. Dirt and debris, including coins, rubber bands, and broken pieces of toys were scattered on the floor throughout the school building, easily available to people who have "PICA," a disorder that causes them to compulsively put non-food objects in their mouths. There is no privacy in the bathrooms or bedrooms, which have no door locks. Staff brought DRNY inspectors into a bedroom where a resident stood naked, having just come from a shower. The inspectors passed by a bathroom whose door was open to the hall, in which an adult was using the toilet. There was an infestation of bedbugs in October 2016; two New York children were "covered in bug bites."

The place is not just filthy and demeaning, it is dangerous. In 2009 a student was run over by several cars and killed because the staff tasked with watching him weren't paying attention. In 2010, another child suffocated in a hot car because the staff thought he had gotten out and didn't bother to check. In 2013 the New York State Education Department (NYSED) and OPWDD found that adult residents were having sex with students in the facility. They also found that people were being illegally restrained or doped up, and were being abused and injured. The facility often failed to notify state officials or family members of these incidents. Despite the frequency of these events, NYSED continued to approve sending children there. When the children "age out" of school at 21, OPWDD is supposed to bring them back to New York and provide services to them, but even though the agency knows the facility is substandard, it has made very little effort to do so.

According to DRNY's report:

"A culture of abuse and neglect, which goes unreported and unaddressed, exists because Woods has failed to address system-wide problems. This failure places all residents at significant and on-going risk of abuse, neglect, and injury. ... Only when DRNY brought these issues to the attention of OPWDD and NYSED did those agencies schedule site visits to Woods in 2017. NYSED's site visit substantiated 34 separate violations of New York State's Special Education regulations. …

Despite this monitoring, residents were still not protected from further abuse. In May 2017, a resident with autism was beaten with a shoe. On February 27, 2017, a staff member was arrested for punching a thirteen year-old in the face which fractured his nose."

The Woods staff and administration appears to have learned to depend on New York State agencies' failure to act. Instead, they intimidate and retaliate against residents who complain, and falsify incident reports, or simply refuse to report incidents at all. For example, in December 2014, the light bulb in a student's bedroom blew. He complained to the staff and asked to call the maintenance department to have the bulb replaced. For some reason the staff person told him not to call maintenance. When the kid did so anyway, the staff person pushed him to the floor and punched him in the back of the head. Students who complain have "behavior plans" created to punish them for complaining. Two students who were interviewed by DRNY investigators were called into a program administrator's office and "interrogated" about what they had told the investigators in an intimidating way, and for a while afterwards refused to talk to DRNY.

In more than one case, when a charge was made that an employee had physically abused a resident, and the resident had obvious physical injuries, and other staff who witnessed the events corroborated the abuse, the internal Woods report said that abuse could not be "substantiated." It was also common to report incidents of clear neglect as "accidents," or misrepresent the extent of injuries. For example, a 78-year-old man who was unsteady on his feet and who needed help in the shower was left alone by staff and was later found on the floor with a gash in his head that required two staples. The incident was not deemed to be possible neglect. An autistic student who was repeatedly allowed by staff to jump off desks and otherwise try to hurt himself was reported to have suffered a "cut on [his] bottom lip," when in fact his jaw had been broken and two teeth were lost. Woods was supposed to notify New York authorities when events like this occurred, but the investigators discovered numerous internal documents indicating that the Woods administration knew about many incidents that they never reported.

Woods also operates a sheltered workshop that violates federal law by paying subminimum wage to people whose disabilities do not affect their ability to do productive work. For example, an autistic resident worked two days a week doing data entry for Woods at minimum wage. He spent the rest of the week in the workshop, getting less than minimum. Another worker who worked at an in-house cafe for minimum wage and complained to his supervisor that it wasn't enough was fired and sent to the workshop as retaliation, where he was paid less. And like all sheltered workshops, a lot of what goes on at the Woods facility is not "work" at all. In October and December 2016, DRNY inspectors observed almost half the workshop "employees" either sleeping or looking at magazines because there was no work to do.

To summarize: Woods Services is a hellhole. NYSED and OPWDD knew it was a hellhole but they continued to allow New York children and adults to live there. The Woods administrators have covered up serious incidents, deliberately ignored complaints and orders to make improvements, and practiced retaliation against those who speak up, for at least seven years. They are probably snickering even now because they believe nothing but a bit of unfavorable press coverage will result from DRNY's investigation.

DRNY released its report of that investigation on October 30, so it is much too soon to make a judgment. If anything more happens, we'll let you know.

courts watch

Scofero v Zucker: And Yet Again!

Remember *Caballero v Senior Health Partners*? We reported that one in the fall of 2016. Some downstate managed care plans were sued for routinely cutting or denying homecare services. As of July 2017, documents were still being filed in that case; it had not yet gone to court (and we don't have any more recent news on it).

Meanwhile, people were having similar issues upstate, and in March 2016 the Empire Justice Center filed this case in federal district court for the Western District of New York. It's another class action suit. Due to their documented medical needs, the three named plaintiffs were all found eligible by the state's "conflict free" enrollment broker, Maximus, for 24-7 homecare, a service that, by law and by contract, is available from the state's mandatory Medicaid Managed Long Term Care (MLTC) system, but no managed care plan would agree to serve them.

New York's Medicaid system for people with disabilities was largely "fee-for-service" before 2012. That means that a doctor decides what services you need, including homecare; the provider submits bills for that amount of service to the state; and the state pays the fees to the provider. Federal Medicaid law and regulations say that a state's managed care system, in which the state pays a limited lump sum to an insurance company, out of which all your medical costs must be covered, must not provide less service than its fee-for-service system does. 24/7 homecare has long been available from the fee-for-service system. Some people think the state is trying to shift responsibility for cutting services, and the associated bad press, to managed care insurance companies. But the state is still legally responsible for ensuring that all medically-necessary services are provided to all of those who are eligible for them. There's no doubt about that.

Under the state's contracts with managed-care insurance companies (MCOs), while those companies must provide all of the services for which participants have a documented need, including 24/7 homecare, the company does not have to enroll people whom it doesn't think it "can" (read "doesn't want to") serve. So people can be told that they must enroll in managed care in order to get services that are vital to their health, only to find that they can't actually enroll at all. Then New York can say, "It's not our fault. Blame the MCOs!"

Actually, people who can't find an MCO to take them are supposed to remain in the fee-for-service system. Under that system, counties are supposed to approve services. But with so many people mandated into managed care, some counties have dismantled their Medicaid processing systems and for that reason—or simply because they don't want their own bottom lines to be affected—are telling these people they can't help them.

All of which looks like yet another ridiculous NY State government snafu concocted by idiots who don't know what they're doing, but that's not it at all. Cuomo can't directly and officially cut the amount of services that are provided; federal Medicaid law requires that all medically-necessary services be provided, period. And he can't remove politically popular services entirely from the state's Medicaid program; the state legislature would have a cow. Yet Cuomo believes he gets political mileage out of his 2% Medicaid growth cap, and some people think he plans to use that mileage in the 2020 presidential election. So how can he rack up that mileage?

Ridiculous snafus cut Medicaid spending, and they are a deliberate part of the Cuomo Administration's political strategy. Snafus delay the pay-out of funds that people are entitled to have spent for their services. Eventually, through a lengthy process of Medicaid fair hearings and/or court cases, the people entangled in these delaying tactics—if they are still alive—will be granted the services they were supposed to get, and the money will begin to flow. But it will have been prevented from flowing for some months or years, which helps keep spending under the cap. There are no retroactive Medicaid payments to cover "mistakes" or give you "back" the hours of homecare you lost. And if the state had to pay lawyers to defend against lawsuits—well, that isn't Medicaid-reimbursable, it comes out of the General Fund, so it can't be counted against the cap. This can't go on forever either—but it only has to go on until Cuomo runs for President. The people responsible for New York's Medicaid system know this; they've planned it that way. That makes it Medicaid fraud, though very hard to prove.

What we actually need is a law that criminalizes playing these games with the Medicaid system, so that the next time a court case like this is lost (the state always loses), the Commissioner of the NYS Department of Health (DOH), Howard Zucker, isn't just instructed to fix the problem; instead, his replacement is instructed to fix the problem because Zucker (and maybe his boss, Andrew Cuomo) goes to jail. Yeah, good luck with that. But that's what's really going on here.

As for what went on in this case, it's almost beside the point, but we'll tell you anyway:

Gail Logan was a 68-year-old woman with cerebral palsy living on her own in subsidized senior housing in Erie County. She sprained her ankle and somehow (perhaps a simple paternalistic, and wrong, assumption about the effect of CP, a developmental disability, on one's ability to care for oneself) ended up in a nursing facility, where she was supposed to receive physical therapy before returning home. She got no therapy there, a common story. In fact, at one point she was left in her bed for 21 days straight. She was there for a total of two years, while her muscles atrophied until she lost the ability to walk and do many other things for herself.

She always wanted to return home though, and eventually was referred to Maximus, which found her able to benefit from, and eligible for, 24-7 homecare. She was denied enrollment by three different MCOs. A Fidelis assessor visited her then vanished. She eventually called them and was told they could only cover 6 hours a day and therefore would not enroll her. They never sent her a written notice. VSNY Choice evaluated her and told her the same thing, verbally. They followed up with a written letter stating that they would not enroll her because she had voluntarily withdrawn her application. She had done no such thing. Then Wellcare assessed her and said they would not serve her because she could not transfer without a Hoyer lift and because she had no family to help her. They also sent her a bogus letter claiming she had voluntarily withdrawn.

Logan pursued a fair hearing with Wellcare. At the hearing a Wellcare representative told the administrative law judge that Wellcare had no objection to serving her and they were working on a care plan. The judge adjourned the hearing, but then Wellcare sent her a letter saying they couldn't serve her "safely in the community." The judge reconvened the hearing, at which point Wellcare claimed that there were no providers in its network that offered 24/7 care. The judge asked if they would go outside their network to seek providers in that case, as their contract with the state requires. Wellcare refused to do so. (There is no indication of whether they considered using multiple providers to assemble a 24/7 care schedule, a sometimes-workable strategy in larger cities such as Buffalo.) The judge ruled in favor of Logan and ordered Wellcare to serve her; they refused. She filed a complaint with DOH; DOH did nothing. (Picture Commissioner Zucker staring at her with a stony smirk, as the Medicaid funds to which she was entitled slowly piled up in the state's coffers.) At the time the suit was filed, she was still in the nursing home that injured her, but had lost her housing voucher, making it likely that if she ever gets the services, she will have no home in which to receive them.

STIC's Offices Will Be

CLOSED FOR THE HOLIDAYS

December 25, 2017– January 1, 2018

We will re-open at the usual time on Tuesday, January 2.

Happy Holidays Everyone

Joseph Scofero, also age 68, from Wayne County, was placed in a nursing facility following a stroke. Maximus approved him for 24/7 homecare. A nurse from iCircle assessed him and agreed that he needed 24-hour care, but then she said that "Medicaid" would not approve more than 24 hours a week and that "nobody gets 24-hour care." iCircle did not follow up with a written notice. iCircle being the only managed care option in his county, he applied to the county Department of Social

Services. DSS gave him a verbal denial but nothing in writing.

Barbara Lane, age 83, was in Monroe County. She experienced an anoxic brain injury, and as a result was unable to walk, talk, or breathe independently. She was placed in a nursing facility, where she developed pressure sores. Fortunately, she had some family members who were able to provide some care, and they helped her get fee-for-service Consumer Directed Personal Assistance (CDPA) approved by the county DSS. With this help, her pressure sores finally healed. But then she was told she must enroll in managed care in order to continue to get the service. She needs, and was approved by Maximus for, 24/7 care, and was enrolled by Home First. But that company dropped out of the managed care system in her county, so she had to find another plan. She was visited and assessed by iCircle, then never heard from them again. VNA Homecare Options evaluated her and offered 48 hours per week. But her family members were aging and could no longer contribute as much care for her. They objected, at which point VNA declared that it could not serve her.

Not only did all of these companies lie to these people, they mostly did it verbally or in bogus letters. They all violated contractual requirements to issue clear written notices explaining the medical reasons for denial of services, and to provide information about the right to appeal.

We should point out that STIC was a founding member of iCircle and our Executive Director sits on their board. These events occurred in 2015. Some people in STIC's CDPA program were and are enrolled in iCircle, and at least one of them had a similar experience around the same time. When iCircle was getting started, they hired experienced managed care insurance people who did not necessarily understand the agency's mission to ensure that people with disabilities can live in the community. We "educated" them. Since then, the agency has had a better attitude about approving needed services. We don't know if there are more recent similar problems in other parts of iCircle's service area. The fact that some blunders like these can be blamed on poor training rather than malice doesn't really matter. From Cuomo's point of view, blunders that delay spending are good.

In any event, these are just the three named plaintiffs in the case. There are others, but the case has not yet gone to trial. The Empire Justice Center wants more plaintiffs. If you or someone you know had a similar experience, please contact Geoffrey Hale at (585) 295-5730, or ghale@empirejustice.org.

Myers v Schneiderman: Another Finger in the Dike

This is the assisted suicide case on which we last reported in *AccessAbility* Summer 2016. Some people with disabilities and doctors, supported by national assisted suicide activists, sued New York State to have its law against assisted suicide overturned. Their arguments were that what they call "aid in dying" isn't really assisted suicide, and that the US Constitution's "equal protection" clause requires that if people are allowed to refuse medical treatment in order to die, then they should also be allowed to have a doctor administer a medical treatment in order to die.

Having lost in the Appellate Division of the NYS Supreme Court, the plaintiffs took their case to the highest court in the state, the NYS Court of Appeals. On September 7, 2017, they lost there.

There isn't anything new in this latest decision. The plaintiffs always had a very low chance of prevailing, because the only significant legal consideration is whether the state can show that its laws prohibiting assisted suicide are "rationally related to any conceivable legitimate State purpose." That's pretty easy to do. It is a legitimate state purpose to prevent desperately tired, stressed, and frustrated caregivers from murdering their relatives, for example. It is also legitimate for the state to wish to avoid creating a new legal alternative to spending a lot of money to enable poor people with significant disabilities to stay alive.

This question has not only been decided before by New York State courts, it's been decided, twice, by the US Supreme Court. *Vacco v Quill* was the Supremes' answer the last time some of these plaintiffs raised the question (yes, some of the same plaintiffs in *Myers v Schneiderman* were involved in that 1997 case). Then there was *Washington v Glucksberg*, also in 1997, which demolished some of the same arguments presented in the NY case.

But a "legitimate state purpose" is a very low bar. Suppose a state legislature decides that it's a legitimate state purpose to address the fact that, as stated in Judge Rivera's concurring opinion in *Myers*, "as medical science indicates, palliative care is not always an option for a terminally ill patient in severe pain approaching death."

Because of that fact, legislatures have now legalized assisted suicide in five states and the District of Columbia, and bills to do so keep coming before legislatures in other states. This is happening because there is something fundamentally lacking in the status quo.

New York State's homecare system is unreliable and inadequate. As a result, people with very significant disabilities constantly face two equally unacceptable choices: Be institutionalized, where, although you will likely not receive quick or appropriate levels of attention when you need something, at least you can probably count on somebody discovering your dead body before it starts to stink; or, stay in your own home with inadequate hours of service, and maintain your "freedom" to do virtually nothing until you die in your own bed.

Judge Garcia, in his concurring opinion, quoted a "friend of the court" brief submitted by disability rights advocates: "Research demonstrates that 'suicidal feelings in terminally ill people' are often 'remediable through other means, including pain management, hospice services and counseling,' notwithstanding the patient's impending or imminent death." First, it's not just about imminent death. Second, "research" doesn't equate to readily available, reliable, and affordable services.

Certainly we want to fix this system. However, we must be honest with ourselves and each other. Advocates have been trying to fix the homecare system for 30+ years. Although some improvements have been made, it remains inadequate, especially in smaller cities. The solution, which is to make providing homecare a more highly-respected and well-paid profession, is not on the horizon in an era where all of the political focus is about cutting healthcare and long-term care spending. This is not just about right-left politics. This is a "structural" problem: The American population is aging and using more long-term care, but there are fewer and fewer younger, working taxpayers available to pay for that care. And as predicted, a lot of them are growing resentful about having to pay for it.

There is resentment in the other direction also. Older people with disabilities who are not near death but are facing years of chronic, unrelievable pain, as well as gradual loss of abilities that the homecare system cannot, and will not, compensate for, are beginning to object to the rigid stance taken by younger disabled activists who are diametrically opposed to any form of assisted suicide for any person. People ought to be asked if they really want to be martyrs to this cause.

It's one thing to be relatively young and actually have years of productive and fulfilling activity to look forward to. It is another thing entirely when you are old and facing inevitable decline and increasing pain. Palliative pain relief and deep sedation are technically possible but only theoretically available in many cases, and then only to those who are considered to be near death. After decades of shrugging at the perpetual suffering of poor people of color struggling with drug addiction in the inner cities, white America is suddenly all about the "opiate crisis" affecting white suburbanites. Part of their response has been to make it a lot harder to get effective treatment of severe chronic pain for those who must live with it for years or decades.

This is not going to go away. These cases will keep being filed, and efforts at legislation will be repeated, until something changes. If disability activists keep refusing to be a constructive part of an equitable solution, the changes they get will be those they most fear.

We'll keep reporting the changes, whatever they are.

Gil v. Winn-Dixie Stores, Inc.: Infelicitous Facilities

Last time (see *AccessAbility* Fall 2017) we reported that a federal district court had ruled in this case that Title III of the Americans with Disabilities Act, which governs public accommodations, requires websites available to the public to be accessible. The case was notable because the judge recognized that there is a set of widely-accepted standards for web accessibility, known as WCAG, that experienced website developers can easily understand and follow in order to comply with the law.

The losers, the Winn-Dixie supermarket chain, appealed to the federal 11th Circuit Court of Appeals. An impressive list of business associations representing shopping centers, hotels, theaters, realtors, the always-dependably-right-wing National Federation of Independent Businesses, and others filed a "friend of the court" ("*amici*") brief in support of Winn-Dixie.

That brief begins with: "If this Court affirms the lower court's decision at issue on this appeal, *Amici*'s members will be forced to do the impossible and try to 'comply' with nonexistent, undefined, and potentially ever-changing standards of website accessibility."

There's a saying in the IT industry: "I love standards; there are so many of them to choose from." But website accessibility is actually one of the few areas in IT where there is broad agreement on how things should be done—by website developers. The reason why businesses aren't in broad agreement with these standards is that the standards describe things that should not be done—things that business website operators want to do, like make things as confusing as possible in order to trick people into clicking on stuff that they don't really want, and making annoying advertising "pop up" when you are in the middle of trying to find useful information.

Beyond that, there's an obvious logical inconsistency in the *amici* brief's opening salvo: If a thing is "nonexistent," then it can't be defined or undefined, nor can it be "ever-changing."

These points are evidence that the lawyers who wrote the brief are simply parroting their employers' uninformed opinions about the state of website technology. The WCAG standards clearly exist, and have existed for more than 20 years. They do change, but only to the extent that website technologies and fashions change. If they didn't change for those reasons, businesses would complain that they can't be followed because they are outdated.

The brief argues that ADA Title III only applies to "physical" locations because the law refers to "places of public accommodation," and Merriam-Webster's dictionary defines "place" as "a physical environment" or "particular region, center of population, or location to visit" or "a building, part of a building, or an area occupied." Then the brief discusses the *DOJ ADA Title III Technical Assistance Manual*, which defines places of public accommodation as falling into one or more of an "exhaustive list" of twelve categories such as "establishments serving food and drink" or "places of exhibition or entertainment."

First, DOJ's manual is not a set of regulations, but merely advice and not legally binding.

Second, both sides can play the dictionary game. The manual defines a public accommodation as a "facility" that falls into one of the twelve categories. Dictionary.com's definition of "facility" includes this: "something designed, built, installed, etc., to serve a specific function." Things that are not "physical" can nevertheless be "designed" and "installed." Google has a "define" feature; if you type "define: facility" into Google, you get "1. A place, amenity, or piece of equipment provided for a particular purpose. ... Synonyms: provision, space, means, potential, equipment." The words "amenity," "provision," "means," and "potential" all can refer to non-physical things. In fact, the Google "define" feature is itself a "facility."

The actual Title III regulation says, "Facility means all or any portion of buildings, structures, sites, complexes, equipment, rolling stock or other conveyances, roads, walks, passageways, parking lots, or other real or personal property, including the site where the building, property, structure, or equipment is located." One might argue that "sites," "equipment," and "personal property" could all refer to websites.

A better way to look at it in the case of Winn-Dixie is this:

The regulations parrot the actual law in stating that "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation." This is the heart of the matter, and legally the controlling language.

Suppose you operate a supermarket that is a physical store. Suppose you provide a website that lets customers order food sold in the store that will be packed for them and which they can either pick up at the store, or have delivered to them by employees of the store. Or suppose the website allows you to print out a coupon that you can use at the store. Such websites would certainly be services, facilities, privileges, advantages and accommodations of the physical store. The responsibility to not discriminate ultimately falls on the owner or operator of the place of public accommodation, not the place itself. The owner/operator must make such a website accessible.

How accessible a public accommodation is required to become is governed by the "readily achievable" standard. That is, that making the site accessible is "readily achievable without much difficulty or expense" in relation to the total resources available to the company. For a company the size of Winn-Dixie, making its website accessible is without a doubt "readily achievable."

This is actually a tougher sell in the case of a company like Amazon, which, at least until recently, did not have any physical stores. (Amazon may have shot itself in the foot by purchasing Whole Foods, which does have stores.) If the company does not have any physical locations to which its website adds value, then you would actually have to make the argument that a website is a "site," "equipment," and/or "personal property" of the company. That may be a reasonable strategy, but to our knowledge, so far it has not been tried.

We'll keep you posted on the appeal.

Justice Center Prosecutions: Another One Bites the Dust

Last time in our editorial we mentioned that there were two cases in which a judge found that the Special Prosecutor for the NYS Justice Center for the Protection of People with Special Needs cannot prosecute people for neglect or abuse because the state constitution requires criminal prosecutions to be conducted only by elected officials. Now there's a third such ruling.

According to the Albany *Times-Union*, Nicole Hodgdon, "a counselor at Albany's Hope House drug treatment center, was charged in December [2016] with rape as well as misdemeanor sexual abuse and misconduct for allegedly having sex with a client." Although the local elected prosecutor had formally consented to the Justice Center taking over the case, the local Supreme Court judge said that wasn't good enough; the local prosecutor should have remained in charge while using the Justice Center prosecutor as a consultant.

The Justice Center could appeal this or the other decisions but so far there has been no announcement that they will do so. It is possible that they don't want to risk a higher court setting a precedent that would effectively make the Special Prosecutor useless.

The reason why the Justice Center has a Special Prosecutor is because there is a long history of local prosecutors refusing to take these cases. They tend to assume that any person with a disability is automatically an unreliable witness.

They also think the cases are difficult to win because defendants can put on a strong defense by talking about how difficult their jobs are, what with mandatory overtime and how nobody understands how devious and violent people with disabilities can be. Sound familiar? It should; it's the same defense used by police officers charged with wrongful use of lethal force—often, we need to keep repeating, against people with disabilities. Those cases are hard to win too.

For these reasons we don't think that getting rid of the Justice Center's Special Prosecutor and relying on the discretion of local elected officials would be a good idea.

The judge's ruling in the Hodgdon case leaves open the possibility that the Special Prosecutor could operate under the authority of the state Attorney General, who is elected. Disability Rights New York, the independent not-for-profit agency whose job is to keep various state agencies serving people with disabilities honest, including the Justice Center, has called for the entire Center to be moved out from under the Governor and into the Attorney General's office to make it more politically independent. The *Times-Union* reported that Attorney General Schneiderman has "taken an interest in the question" of taking over prosecutions.

CCO CCO Achoo!

Last time, we told you that New York's plan for health homes for people with developmental disabilities included the expectation that your doctor(s) and other hard-core health professionals would take an active role in your service planning, and would be available to your "Care Coordinator" for instant consultation and problem-solving. In our comments on that plan we politely stated that this expectation was ridiculous. So did lots of other people. The plan's authors were stung. In their response, they said that doctors won't actually be required to do that stuff, but they still refused to remove language from the plan saying that they will.

The apparent actual requirement will be what it already is: Reports of examinations and orders and such from doctors and others must be collected by Care Coordinators and stuck into that big thick binder known as your "chart," and should be reviewed as part of your planning meetings.

We're tempted to yawn, since the state's Department of Health (DOH) and Office of People with Developmental Disabilities (OPWDD) routinely issue requirements that they don't actually intend to enforce. But when you think about it, this is a form of corruption. In this case, failure to enforce the written requirement will probably benefit you, since we don't think most of you want a lot of doctors and other medical providers at your service planning meetings. But when it's something like the requirement that managed care companies can't cut your services without a valid medical reason and proper advance notice (see page 6), you may be very seriously harmed.

So we'll say it again, for emphasis: Issuing written requirements that the state has no intention of enforcing is corrosive and corrupting. It fosters cynical disrespect for the authority of the state not only by service recipients, but by the employees of the state and organizations the state hires to do its work. It encourages those people to violate state and federal laws in important ways that hurt people. It must stop.

Another issue we had with the health homes plan was the apparent expectation that an ordinary managed care insurance company (MCO) would be just as good at doing what we now call "Medicaid service coordination" as experienced developmental disability service agencies. We all know that's absurd. Yes, the plan is to have such agencies form "Care Coordination Organizations" (CCOs), but the state does not believe there will be enough of them to "cover" all of the OPWDD-eligible people who will eventually be forced into managed care. The way the plan was written, it looked like these relatively small specialized CCOs would be placed in direct competition with very large, very rich insurance companies, with disastrous results.

DOH has clarified that it doesn't intend to allow ordinary MCOs to get into this business unless a "coverage" shortage actually appears. This is comforting only if you trust these people. A better response would be that the state won't force people into managed care unless and until there are CCOs available to serve them. We may have to go to the state legislature to get that now.

Our third major concern was about rates paid to the CCOs. We think that lots of OPWDD-eligible people will not actually want Big Medical Brother constantly pestering them to eat their vegetables and lose weight, and so will opt out of the Health Home benefit. (Remember, the health home is not a place, it's an "enhanced" type of service coordination. All service coordinators will eventually have to work for a CCO that offers Health Home, but you don't have to accept Health Home to get your service coordination from a CCO, so you may be able to keep your service coordinator even if you don't want Health Home.) The rates for Health Home Care Coordination have been published, and seem reasonable. DOH has now acknowledged that rates for non-Health Home service coordination will be lower, but they are still refusing to say whether they will be the same as today's service coordination rates. They could be a lot lower; if they are, CCOs may not actually have enough money to operate, which will open the door to somebody like Excellus becoming your service coordinator. Be afraid. Be very afraid.

Regarding the TBI (Traumatic Brain Injury) and NHTD (Nursing Home Transition and Diversion) waivers: The process of forcing people on those waivers into managed care won't begin before January 2019. Those waivers must still comply with the new federal "conflict-free case management" rule (the same one that led to OPWDD's plan to create CCOs), but all we know is that the feds have approved a DOH corrective action plan. That plan seems to be a plan to make a plan; the service coordination provider agencies must submit an explanation of how they will put "interim firewalls" in place to address conflicts of interest until managed care begins. The Regional Resource Development Centers (STIC operates one for each waiver) must provisionally approve those explanations, which must then receive final approval from DOH. "Firewalls" are nonsense; self-dealing corruption never occurs on the record, and no paper procedure will prevent the top-level authorities at any agency from verbally ordering service coordinators to only refer people to other in-house services. Ultimately, the advent of managed care is supposed to somehow "resolve" this issue—but we have no details on how.

A better solution would have been to hand over service coordination to the RRDCs; they are already forbidden to be housed at agencies that provide other NHTD or TBI waiver services. The federal rules do allow for a geographic scarcity exception to the conflict-of-interest regulation. If there aren't enough service coordination agencies within the region to ensure that your service coordinator doesn't have to work for the agency that provides your other waiver services, then the rule doesn't apply, in which case the "firewall" thing has to be done. This is probably the path DOH took. But the result is yet another cynical instance of regulatory corruption—on-the-record requirements that can't effectively be enforced.

STIC NEWS

Southern Tier Housing Coalition Summit: "There's No Place Like Home"

by Maria Dibble

Southern Tier Independence Center, in collaboration with community partners, hosted the Broome County Housing Summit: There's No Place Like Home, on October 4, 2017. The summit was a free one-day conference to examine the growing housing shortage in Broome County, understand the causes and impacts, and explore community-based solutions.

On the evening of Oct. 3, we held a dinner for local and state officials and other key stakeholders to discuss the housing goals we have for Broome, the perspectives on what we have now versus where we want to be, and much more.

The event's keynote address was delivered by Christopher Coes, Vice President of Real Estate Policy and External Affairs at Smart Growth America. Mr. Coes has led Smart Growth America's national and regional public policy and advocacy efforts on a range of issues.

He was an extremely knowledgeable and engaging speaker, discussing, among many things, the creation of "walkable communities." This concept involves neighborhoods planned with those who don't drive in mind. It ensures that stores, services and other necessities are located in proximity to one another, so that they are accessible to all who live in the walkable area. However, one of the components critical to the success of such an endeavor is the availability of adequate public transportation. Transportation was one of the issues identified as a barrier to the establishment of such a community in Broome. Almost every year, transportation is cut, when economically it would be much more effective for it to increase, according to Mr. Coes.

Several panels that explored barriers and solutions from the perspectives of consumers, providers, building contractors, and public officials followed the keynote. We discussed various funding options for affordable accessible housing that is not segregated by age, disability, or any other demographic. The numbers of individuals seeking an apartment or home is growing, and affordability is a huge issue. Not all people with disabilities need physical accessibility, but a good practice for newly constructed housing units would be to make them "adaptable," meaning 36-inch doors, a large enough bathroom for a wheelchair, walls that can support grab bars, and the like. This adds very little, if anything, to the final cost, and such units are easily made accessible if the health and needs of the occupant changes.

Approximately 100 people attended from a variety of agencies and entities, and the feedback was overwhelmingly positive.

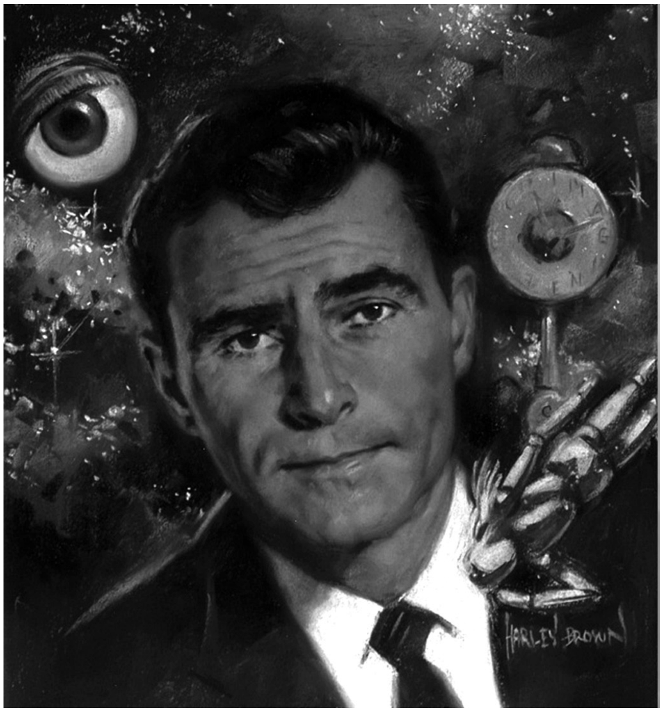
The Southern Tier Housing Coalition is taking the suggestions and information acquired at the event to develop a plan to address the issues. We know that these issues exist in other counties, but we are first going to focus on Broome.

To make our efforts a success, we need people who are interested in working on housing issues. Professionals, public officials, people with disabilities, and others who wish to participate are needed. Simply contact Joanne Carlyle at benefits@stic-cil.org, or call her at (607) 724-2111.

I would like to thank Community Bank for their generous sponsorship of this event, without which we would not have been able to afford the keynote speaker, dinner, and refreshments for the day. In other words, the event would likely not have taken place.

I would also like to express my appreciation to everyone in the Coalition who contributed to the planning and implementation of the summit.

Now, the real work begins! Won't you join us?



Don't Spare the Rod

by Bill Bartlow

"Everybody has to have a hometown, Binghamton's mine. In the strangely brittle, terribly sensitive make-up of a human being, there is a need for a place to hang a hat or a kind of geographical womb to crawl back into, or maybe just a place that's familiar because that's where you grew up.

When I dig back through memory cells, I get one particularly distinctive feeling—and that's one of warmth, comfort and well-being. For whatever else I may have had, or lost, or will find—I've still got a hometown. This, nobody's gonna take away from me."

—Rod Serling

STIC is proud to announce that in conjunction with the Rod Serling Memorial Foundation, we are designing our third escape room: "TWILIGHT ZONE: The Rod Serling Experience." The rights to use "Twilight Zone" have been graciously granted by CBS at the urging of Andrew Polak, President of the foundation's board of directors, and the intercession of Anne (Serling) Sutton, board member and Rod's daughter. A special thanks to them for their effective efforts.

You will begin your Twilight Zone experience in Mr. Serling's writing room at his cottage on Cayuga Lake. There you will become familiar with Rod's career.

Unlock the Twilight Zone using the key of imagination and solve a series of five challenging sections filled with interactive fun. It is a dimension of sight, a dimension of sound and a dimension of mind. It's a land of shadow and substance. You'll be asked to make an important decision, only to arrive at the surprising ending.

We hope to open by June 1, 2018, or possibly even sooner. It will be an engrossing adventure into STIC's version of the Twilight Zone, with fun snippets from the programs. No worries though, it can be enjoyed by newcomers to Serling's world, as well as longtime aficionados of the show. It's full of mysteries, twists, and turns, and will challenge all of your senses to finish on time. Keep watching these pages for more updates and perhaps a secret or two.

And don't forget, we still have our first two rooms open for your enjoyment: "Valley of the Kings," a puzzle-filled sojourn in the land of ancient Egypt, and "Pulse," where you are charged with stopping terrorists from releasing a pulse that would destroy much of our infrastructure. Six to eight players per experience is recommended but not required.

If this sound fun and you wish to volunteer to plan puzzles, assist with constructing rooms, or other related activities, call Bill Bartlow at (607) 724-2111. You'll never regret you did.

For more info on Xscapes, call Bill or visit our webpage at www.xscapes-stic.com.

That's the signpost up ahead – our next stop, the Twilight Zone!

UNCLASSIFIEDS

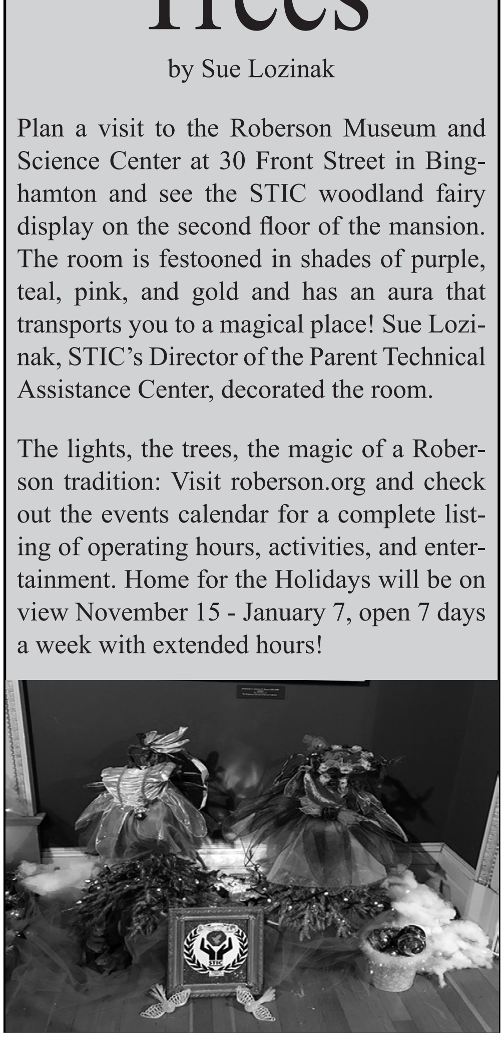
For Sale: Walk-In Whirlpool & Air Bathtub - American Standard 48" long x 28" wide x 37" high with built-in seat, grab bar and extension kit to fit 60" opening. Purchased new, never installed - $2,750. Call (607) 724-7039

Roberson Trees

by Sue Lozinak

Plan a visit to the Roberson Museum and Science Center at 30 Front Street in Binghamton and see the STIC woodland fairy display on the second floor of the mansion. The room is festooned in shades of purple, teal, pink, and gold and has an aura that transports you to a magical place! Sue Lozinak, STIC's Director of the Parent Technical Assistance Center, decorated the room.

The lights, the trees, the magic of a Roberson tradition: Visit roberson.org and check out the events calendar for a complete listing of operating hours, activities, and entertainment. Home for the Holidays will be on view November 15 - January 7, open 7 days a week with extended hours!



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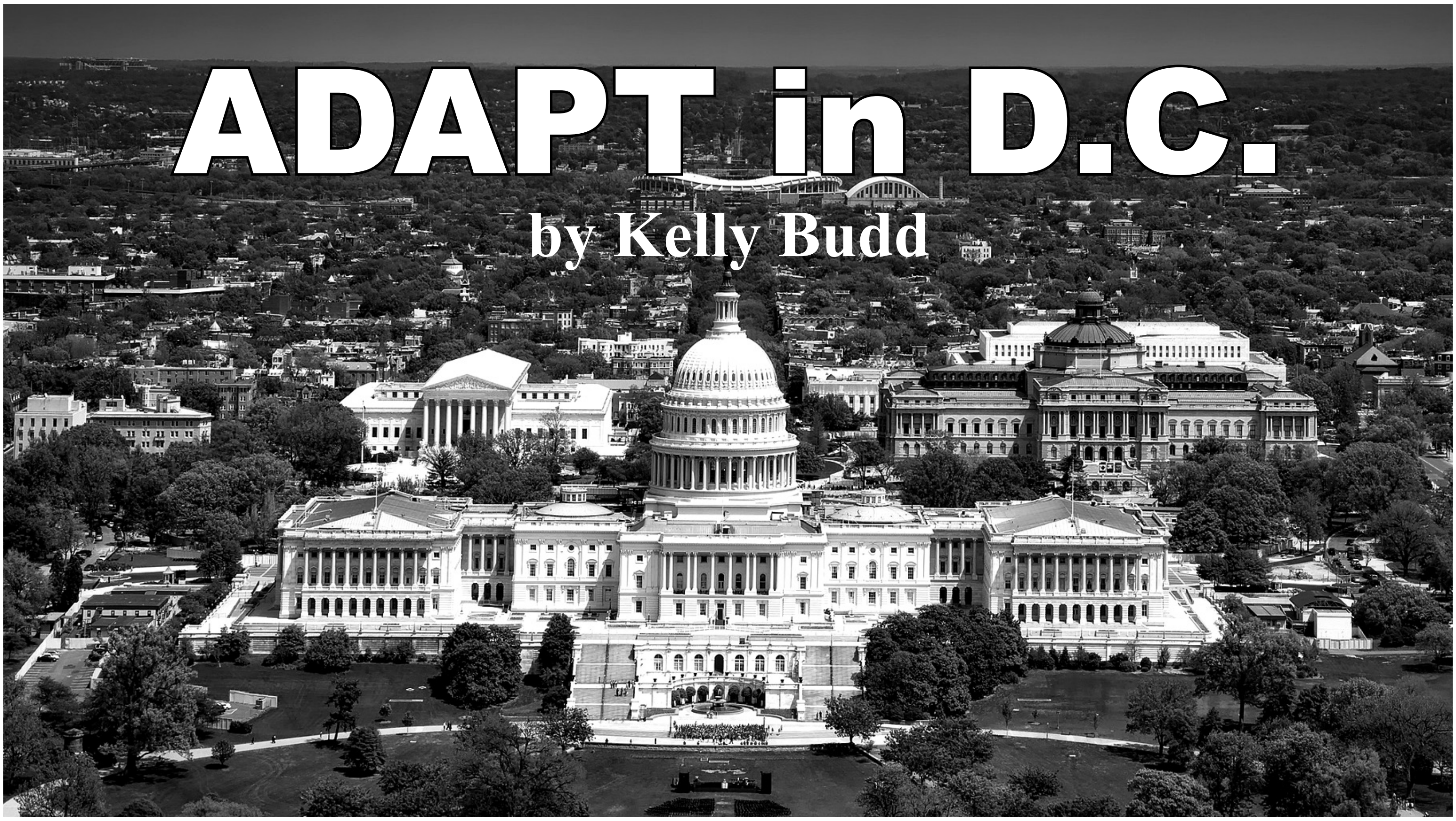
ADAPT in D.C.

by Kelly Budd



Nicole Hakes and Kelly Budd participated in an ADAPT action/protest in Washington, D.C., from September 23-28. While there, we protested on the front step of the home of the Attorney General of the United States, Jeff Sessions, to encourage him to enforce the US Supreme Court's *Olmstead* decision. The *Olmstead* decision requires that the mandate contained in the Americans with Disabilities Act concerning integration be enforced, and that public agencies provide services to individuals in the most integrated settings appropriate. Sadly, many individuals with disabilities are being forced into nursing homes and denied the most basic human right of their freedom to choose where they want to live, as well as being denied the opportunity to be productive in their communities.

We also attempted to attend the Senate Finance Committee hearing that was being held to discuss the proposed Graham-Cassidy bill, designed to repeal and replace Obamacare, which would leave millions of Americans without desperately needed healthcare. We left our hotel at 4:30 am and marched several miles to the Hart Senate Office Building, arriving before the building opened for business. Once inside, we joined hundreds of other concerned Americans, many of whom were in wheelchairs, many of whom this bill would directly adversely affect, and lined the halls to wait for the 2:30 pm hearing. There was a large Capitol police presence in anticipation of the frustration that would occur once the doors opened. While in line, we received support from several senators who were also opposed to the bill, one of whom brought pizza for the people in line to help them keep their energy up. Once the doors opened, we were told that only approximately 14 people could attend the "public" hearing! This brought an eruption of loud chanting both in the hearing room as well as outside in the halls. In the halls, we were advised by Capitol police to cease chanting or we would be arrested. Many could not contain their frustration with the fact that so many came to express their concern over the bill but were not allowed into the hearing, and were arrested. Approximately 123 people were arrested that day, including Kelly Budd. This was an important day, as the bill was eventually "killed."

As Americans, we have the right and a duty to let our government know when it is doing something that is detrimental to the neediest of Americans, and we did, but we didn't stop there.

The following day, we protested in the office of Senator Lindsey Graham to let him know how his bill would affect Americans. Capitol police again threatened to arrest us if we did not leave his office, so we left. However, Mr. Graham came down the hall as we were leaving, and the chants of "Shame, Shame, Shame!" could be heard reverberating through the hallway. Mr. Graham scurried into the sanctuary of his office and did not stop to speak with us. Later that day, his bill was removed from a vote in the Senate and died.

When we left Mr. Graham's office we marched to the Health and Human Services office to demand a meeting with then-Secretary Tom Price. We surrounded the building carrying signs and chanting that we wanted a meeting. Again, the Office of Homeland Security arrested another 43 people. Mr. Price declined to meet with us to discuss enforcing the *Olmstead* decision.

Our last day of action began with a march to Tom Price's home, in another attempt to encourage him to meet with us to discuss *Olmstead*. Our protest closed the street in front of Mr. Price's home as we chanted, "Tom Price, Tom Price, Come on out! We've got something to talk about!" After several hours, it became clear that alas, Mr. Price was not inclined to speak to us. On a side note, Mr. Price resigned his position two days later. I'm not saying we were responsible but… After leaving Mr. Price's home, we lobbied members of Congress to co-sponsor the Disability Integration Act. This resulted in over a dozen Congress members agreeing to co-sponsor the bill and many others agreeing to review the bill and consider co-sponsorship.

Overall, this action was an eye-opener to the struggles that Americans with disabilities go through on a regular basis just to have the freedoms afforded all other Americans. We would like to encourage everyone to support ADAPT and its causes because when we live in a completely integrated society, everyone benefits.

AIN'T NO POWER LIKE THE POWER OF ADAPT CUZ THE POWER OF ADAPT DON'T STOP!!

Should Supported Decision Making be Formalized?

"Supported decision making" very accurately describes how ALL of us make decisions about things that we aren't experts on. We talk to people we trust who know more than we do, we consider their information and suggestions, and then we make our own decisions.

People whose disabilities affect their ability to learn or reason can do this too. But too often they aren't allowed to make their own decisions because somebody assumes, wrongly, that they can't.

There's a particular form that these unjustified assumptions take in New York; it's called Article 17A guardianship. This is a law that lets the families of adults with developmental disabilities consign their children to "legal death" merely by filling out a form, getting two doctors to sign it, and sending it to a judge. All the doctors have to sign-off on is the diagnosis of developmental disability. There is no requirement for a court appearance, no requirement that anybody prove that the person actually can't make his or her own decisions, no requirement that the person even be told that his civil rights are going to be taken away or be given an opportunity to oppose it. This is an abuse of parental and legal power that is arguably unconstitutional. Disability Rights New York, the Protection & Advocacy agency for New York, has filed a lawsuit to have it stricken from the books (see *Access-Ability* Winter 2016-17). If someone actually does have a demonstrable problem with making decisions, there is a better way to set up a legal guardianship in New York; it's called "Article 81." But most advocates for "supported decision making" believe that if its principles are followed, there is no need for any formal guardianship process at all for most people. So how do we do that?

We take steps to ensure that the person has people who respect her rights, who s/he can trust and talk to. Then when important decisions must be made, those people talk with him or her. At first they may need to initiate the process, but as it becomes more familiar, the person will naturally seek out their friends and associates to get advice. It's a very natural process that doesn't need much specialized tinkering except to ensure that it does happen, instead of somebody taking over and making decisions for the person without consulting them. A few people may need more structured training, but again, no one should assume that's necessary for everyone.

If a person knows what they want to do, or not do, but has difficulty dealing with the details of complex issues, the appropriate option is a durable power of attorney. This lets somebody else handle those details without taking away decision-making power from the individual.

But then, apparently, some lawyers got involved and you can guess what happened. Now there's a pilot project to demonstrate how supported decision making can become a formalized legal thing—a sort of "guardianship lite." In this process, the person identifies specific people who agree to be part of their "circle" to help them make decisions, and they all sign a document saying that they will follow this process.

There's a website for the pilot project (http://sdmny.org/); its operators seem to be suggesting that no one will take this seriously without legal documentation to back it up. They think that courts and state agencies like OPWDD are going to want to see these written agreements before they will accept decisions made by people with disabilities.

It is a legal fact that ALL adults have ALL of their rights unless and until they are taken from them by a formal legal procedure. Courts and OPWDD MUST accept EVERY adult's decisions at face value UNLESS there is a legal guardianship. We should never take the position that there are people who must have a piece of paper to prove they DON'T need a guardian before their decisions are respected. Please don't let anyone convince you that we need to do that.

Tony Phillips, a well-known disability rights advocate in New York and a former president of the Self Advocacy Association, recently told a United Nations-sponsored panel of experts in New York City, "It can't become just another service. It has to be something that persons with disabilities can do on their own, without agencies."

A perhaps more balanced approach to this issue can be found here:

http://www.supporteddecisionmaking.org/

As this site explains, "You may want to, ***but don't have to***, create a written plan saying the people who will provide support, when they will provide it, and how" (emphasis added).

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