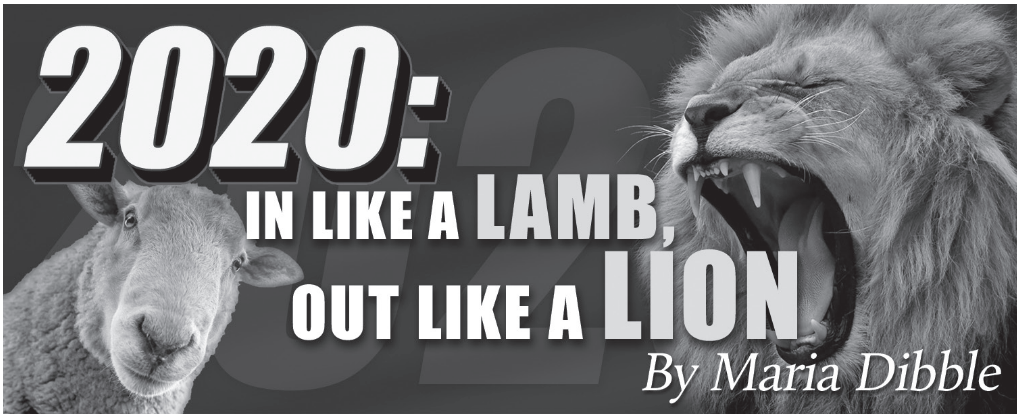
The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

AccessAbility

Winter 2020-2021
Number 141

INSIDE



2020: IN LIKE A LAMB, OUT LIKE A LION

By Maria Dibble

I clearly remember December 31, 2019, sitting before the television, watching the ball in Times Square descend, ready to usher in a brand new year. As the countdown reached zero, we hugged and wished everyone a happy and prosperous New Year, hoping for a better tomorrow.

That was then, but now we can't or shouldn't hug, we should stay parted by six feet of space, or even better, be talking via Zoom or other online mechanism.

All of us gripe about the COVID-19 restrictions, including myself. Yet how fortunate we all are that we still have our health and our lives, and the strength to complain. As I look back over this long, seemingly endless span of months, I am reminded that things can always be worse, and I worry that grim days are ahead until a vaccine is found and distributed.

What has 2020 meant for STIC?

Sadly, we had to lay off more than 20 employees, not because they weren't valued and needed for the contributions they have made to STIC, but because we have lost revenues and just couldn't afford to keep them. Yet the work had to get done, so the chores were split among remaining employees, putting a great strain on everyone. Like the troopers they are, however, they absorbed the work without complaint, even though the workload was too heavy to sustain, and we inevitably fell behind in several areas. Still, even in this I can feel gratitude for the quality of our employees and the commitment they have to STIC.

Of course, like most employers, we had to move people to working from home, a process we were not especially prepared to do. It isn't just a matter of them taking their computers and related equipment home, and working in a different setting. Staff needed to have adequate internet service, and we had to install the appropriate software on every computer so they could connect to STIC's various servers to access critical information, and that had to be done with cyber security in mind. Once again, employees met the challenge, and we moved almost 100 staff members offsite to their own homes. I have to say that it is working better than I would have imagined it could.

A few of us did remain in the building, but it became a very lonely place. Even now, though we have brought back about 25 people, it still feels empty, as we avoid one another for safety reasons, follow arrows to our destinations, and, of course, wear masks. I can hear the voices around me, but I miss the personal interactions very much.

The people we serve have probably suffered the most. Many are alone, and the forced isolation has been difficult for some to understand, and very harmful to their mental health. Services are delivered in the safest manner possible, though many employees are risking their health and safety, and that of their families and households, to continue to provide face-to-face support. They are putting their lives on the line in CDPA, Community Hab, Supported Employment and other programs, to help people with a wide variety of disabilities to weather the storm. It is very sad and unfortunate that our governor and legislature have not thought to reward them for their courage and dedication with hazard pay, though we have advocated for it throughout the pandemic. Instead, they are withholding 20% of our state contract reimbursements, which we may or may not ever get back. This isn't a cut, it simply means that for every dollar we spend, we only get back 80 cents. It won't help to cut the budget by 20%

AccessAbility

December 2020

EDITOR IN CHIEF: MARIA DIBBLE
MANAGING EDITOR: KEN DIBBLE
EDITOR: ELIZABETH SIGNOROTTI
LAYOUT: RUSSELL RICHARDSON

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

Our address is:

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

Subscriptions

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

Advertisements

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

Reprints

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

Authorship

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

www.stic-cil.org

because we'll only get 80% of the money no matter what we change. The Governor calls it a "withhold" because we "might" get it back if the federal government ever extends a hand and provides relief funds to the state. I'm rather pessimistic at the prospect of ever seeing those dollars again (see page 12 for more).

It has been a brutal year, one of the worst I've experienced in my 37 years as STIC's Executive Director, and I dare say that our employees feel the same. We've lost a lot of money, though we've been fortunate to receive other support from the federal government, through the Payroll Protection Program and other sources, preventing STIC from losing many more millions of dollars and having to lay off many more people. There is nothing more difficult to do than tell an employee s/he doesn't have a job anymore. No matter how gentle and understanding you are, the fact is that s/he is unemployed, a terrible blow to the employee and family. It literally sometimes haunts my dreams.

Let us not forget that with all the numbers and economic facts about the country's outlook, that the human factor is what drives everything. People are the backbone of what we do and what we accomplish. This pandemic has been a terrible thing. So many people died, and more are dying again. It has divided us more than we were already, and it is gaining a foothold once more throughout the country. Many people who never had mental health issues are now feeling the impact of loss, of isolation and inability to see loved ones, and the state of our economy.

Politics and the election, no matter whom you voted for, also created significant tension and stress for many Americans, and STIC employees were no different. During the election process we saw what a divided people Americans are at the moment. This is possibly an even larger disaster than the virus presents.

And amid all this, African Americans rose up against more senseless deaths at the hands of the police, and in doing so, they spoke for many Americans with disabilities as well who also died in that way, and expressed the pain we all feel over more lives lost forever. Yet all over the nation, in towns large and small, many white Americans joined them, bringing a sense of hope that perhaps we can all care for each other and work together.

We are strong as a country. We will have a vaccine and recover from the virus. It is our choice and our actions that will determine whether or not we will recover and become truly the United States of America.

In conclusion, 2020 is not a year I'd want to relive, and I know that 2021 will have its own set of problems, but I urge everyone to take a moment to appreciate what we have, our families, our friends, our coworkers and our futures. Also, let's take a moment to remember all who have fallen from the virus, and the people who have lost loved ones, and let's send them our prayers, or our thoughts and hopes that they can find peace in the new year.

Stay well, wear a mask, and be at peace.

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.

What's Next?

It's lame duck season: the period between Election Day and Inauguration Day, when people enjoy speculating about how things are going to change with a new administration. We at *AccessAbility* are not immune to that temptation, so here's our take on what the Biden Administration will mean for people with disabilities.

Although Biden, a Democrat, is known for his ability to get along, and compromise, with Republicans, his situation is going to stretch those talents to the limit. At this writing in mid-November, control of the Senate remains undecided. Two run-off elections in Georgia will take place on January 5. If Democrats win both, the Senate will be 50-50 Democrats and Republicans, with Vice President Kamala Harris as the tie-breaker. Some speculators think the odds are heavily stacked against one Democrat winning in Georgia, let alone two. But the fact that Biden won the state by over 12,000 votes (as it stood before the second recount) argues that something has changed in the Peachtree State. If both Dems win then Harris's vote will make NY Democrat Chuck Schumer the Majority Leader, but he will still have to cut deals with Republican Mitch McConnell for almost everything, including committee assignments. Also, under Senate rules most measures effectively require 60 votes for passage due to the filibuster rule.

A filibuster used to require one or more Senators to continuously hold the floor for "debate" by speaking, day after day, and night after night (as in the great old Jimmy Stewart movie, *Mr. Smith Goes to Washington*), on just about any subject imaginable, and sometimes just by reading lengthy documents, to prevent a bill from coming to a vote until its supporters gave up and withdrew it or until 60 Senators voted to cut off debate. In recent years though, nobody actually has had to do this; they just have to demonstrate that there aren't 60 votes for the bill. Oddly enough, the Dems could eliminate the filibuster rule permanently with a simple 51-vote majority (if they get one) by means of some parliamentary sleight-of-hand, and unless they do that, they'll have to pick up at least 9 Republican votes to pass anything in the Senate. Biden has sent mixed messages about the idea, but if the Democrats get rid of it they will surely regret it the next time they are in the Senate minority, so it's pretty unlikely they will do that.

The situation in the House is not that much better for the Dems, even though they have a majority and there's no filibuster rule. The majority is tiny; as of November 30, the Democrats had won 222 seats—just four more than needed—with seven seats as yet undecided. Lots of those Democratic Representatives are "moderates," and a few are pretty right-wing, and that means there will be no highly "progressive" legislation passed there.

In fact, very little of what Biden has said he wants to do may get done legislatively before the 2022 mid-term elections. No big tax increase, no massive global warming infrastructure bill, no big policing reforms, and, most likely, no comprehensive replacement for Obamacare if the Supreme Court declares it unconstitutional (more on that last one elsewhere).

However, and perhaps surprisingly to some, this is nothing new. A couple of political scientists, one from the University of Utah and one from Princeton University, published a brief description in the *New York Times* of a study they did on the effect single-party control of the federal government has had on legislation. They analyzed over 250 legislative proposals between 1985 and 2018, from both parties, and they found that only a handful of them passed with only one party's support. Because of that, nearly all of them ended up as compromise measures that didn't fully satisfy anybody. Even when single-party bills do pass, they often don't fully reflect the ideological stance of the party as a whole, because not all of the party's members actually support that ideology. ObamaCare is a great example: The Democrats jammed it through by means of a rather underhanded "budget reconciliation" process with no Republican votes in the Senate, but even then it was shorn of the "public option" and loaded up with what were essentially cash bribes to get insurance company lobbyists off the members' backs. The result was a disjointed, cumbersome jumble that helps some more people get insurance—though not all who need it, by far—at a cost of potentially making it harder for a lot of people to get really top-quality insurance, while imposing huge management burdens on employers. As the *Times* researchers put it, "Single-party partisan control of the federal government is overrated. Majority parties find legislative success especially through two paths: Either they propose something that can garner broad support in both parties, or they back down from the more contentious aspects of their legislative proposals."

So it's possible that the new Congress will pass another reasonably large COVID bail-out bill, which all Democrats and some Republicans support, but at best, McConnell will exact a very high price for it, starting with immunity from lawsuits for medical providers, nursing facilities, and pharmaceutical companies for anything that can be remotely related to the pandemic. Biden will have to grit his teeth and bear it, and keep things friendly, because if McConnell chooses to be as obstructionist as he was with Obama, then almost no legislation of serious consequence, other than continuing resolutions for appropriations, will pass.

Many have speculated that Biden will have to issue Executive Orders to get anything done, like Obama and Trump. The problem with this is that the President's legal authority to issue those orders is really quite limited. Several of Obama's orders were blocked in court, and many of Trump's were. Biden will face the same court battles and in the end may not be able to accomplish much by that method. One thing he can do is revoke Trump's orders, and it's pretty clear he'll do that for many of them as soon as he takes office.

However, the Trump Administration still has the ability to make some changes stick by issuing "interim rules," and various federal agencies have been putting on a full court press to finalize as many new regulations as possible before January 20. Under the Administrative Procedure Act, a federal agency can make a "finding" that it needs to issue final regulations without the usual 30- or 60-day public comment period for some allegedly "emergency" reason such as protecting health or safety. The agency must accept public comment after the rule takes effect and theoretically should withdraw or change the rule in response, but government agencies are really good at ignoring adverse public comments—and equally good at making up bogus "emergency" excuses (for example, the FDA indefinitely delayed implementing its rule banning the use of electronic shock devices for punishing people with disabilities at the infamous Rotenberg Center on the grounds that the psychiatrists and psychologists who would have to approve new behavior plans for those folks would be too busy treating pandemic patients; see *AccessAbility* Summer 2020). Once a final rule is issued, Congress has a pretty short window of time in which it can exercise its "review" power and revoke it—which the incoming Republican Congress did in early 2017 with some of the last regulations issued by the Obama Administration. But the new 2021 Senate may not be able to muster a majority to revoke any Trump regulations.

So what does all this mean specifically for people with disabilities?

There's a formal federal "national public health emergency" in effect for the pandemic. Under the terms of the March 2020 Families First Coronavirus Response Act, states that accept temporarily increased Medicaid matching funds to address COVID-19 cannot cut any Medicaid services or tighten any eligibility rules for the duration of the emergency—the "maintenance of effort" (MOE) requirement. The emergency was extended through Inauguration Day—January 20, 2021—in October. The MOE is allegedly the only thing keeping New York State from putting into effect the drastic changes to eligibility for personal care and CDPA services that were passed in the 2020-21 budget in April. (In fact, the state must get federal approval to make some of these changes, and as best we can tell, the state Department of Health has not yet applied for it.) But in late October CMS announced that it would issue an interim rule reinterpreting the MOE requirement to allow states to drop optional Medicaid services (such as Personal Care) from their Medicaid State Plans, or to limit the scope of services (such as by changing the eligibility rules for Personal Care) without losing the extra Medicaid funds. This interpretation directly contradicts what's in the law, and is therefore not valid, but it will take a lawsuit to establish that. It was not clear exactly when this interim rule was to start, and it may already be in effect. Several Congressional Republicans were opposed to the MOE requirement and it's not at all certain that the new Congress would use its review power to revoke this rule.

In early November, the US Supreme Court heard oral arguments on *California v Texas*, in the latest attempt by right-wingers to get ObamaCare (the Affordable Care Act, ACA) declared unconstitutional. The case is only marginally relevant to people with disabilities, because relatively few of them both have no employer-based health insurance and are not eligible for Medicare and/or Medicaid. (Much has been said about what will happen to coverage for pre-existing conditions if the Supremes strike down the law, but most of that is hopelessly wrong, as we explain on page 5.) Although the Court now has a 6-3 right-wing majority with the appointment of Amy Barrett to replace the late Justice Ginsburg, most of the Justices seemed to have serious problems with the suit. They aggressively questioned the plaintiffs' lawyers about claims that any of the plaintiffs were actually injured by the ACA in a way that would give them standing to sue, and about the notion that because Congress removed the enforcement provision requiring payment of a tax penalty for people who did not buy individual health insurance in 2017 (the "individual mandate"), the entire rest of the law was unconstitutional. It now looks like the law will survive when the Supremes issue their decision sometime before June 2021. If it doesn't, though, Biden won't have the votes in Congress to enact a thoroughgoing replacement for it. He's also proposed to add a "public option" to ObamaCare as an improvement. This would likely take the form of allowing people to buy into some form of Medicare plan on the public exchanges in the same way they can purchase private plans now. The idea's supporters believe the plan could have better features than at least some of the private plans and the competition would force insurance companies to make more attractive, less expensive, offerings. The problem with this is that a public option was part of the original ACA proposal, and it was removed because Obama couldn't even get a majority of ***Democrats*** to support it when both houses of Congress were controlled by that party. It's very unlikely to pass in 2021.

The Disability Integration Act (DIA) is still under consideration, though it will have to be reintroduced in both houses of Congress in 2021. We'll tell you again, as we did when it was first introduced (*AccessAbility* Summer 2016): It's a great idea that will probably ***never*** be enacted—and if it is enacted, it will not survive the inevitable court challenges that will follow. There are at least two reasons why: It requires states to massively increase the availability of affordable and accessible housing without giving them any money to do it. And it requires states to massively increase the amount of community-based support services available to people with disabilities without giving them any ***more*** money to do it. The latter problem would seem solvable because states can always draw down more Medicaid money to provide more of the same kinds of services they provide through that program now, but that's an illusion. The DIA deliberately avoids changing anything about Medicaid, which means that the federal Centers for Medicare and Medicaid Services (CMS) will never issue new regulations based on the DIA to fix existing stumbling blocks to expanding fully integrated services in the ways that DIA requires (for example, by excluding Medicaid funds for group homes with more than four residents, or by mandating that those residents can effectively control what goes on in those houses, or by allowing Medicaid funds to be used to pay personal attendants to provide child care or pet care). If the Medicaid regulations aren't changed in those ways, states would have to come up with 100% of the money to pay for those services. But even if they are, states would still face massive spending increases in order to comply, and it is extremely unlikely that the increasingly right-wing federal courts would override states' sovereign power to set their own budgets. Right-wing judges don't like unfunded mandates, and the US Supreme Court specifically doesn't like the federal government to threaten to cut off Medicaid funding for states that don't want to expand services—which is why the mandatory Medicaid expansion that was part of the ACA was declared unconstitutional in the same 2012 decision, *NFIB v Sebelius*, that saved the rest of the law by calling the "individual mandate" a tax.

Up to now, the DIA has seemed to have fairly strong bipartisan support in both houses of Congress. But that's only because up to now, nobody believed the law would ever really pass, or that if it did, that President Trump would sign it. We've seen it time and time again—elected officials say one thing when they're only grandstanding for public approval, but they say something else when they're actually in a position to make a law. And when it comes to disability issues, legislators have a long history of figuratively patting us on the head so as to appear compassionate in public, and then ignoring us later. This goes at least as far back as passage of the Americans with Disabilities Act, after which *No Pity* author Daniel Shapiro wondered, in 1993, what was going to happen when a bunch of politicians who thought they were just "doing something nice for the handicapped" woke up to realize they'd actually given them enforceable civil rights. (One thing that did happen was repeated attempts to remove the ability of people with disabilities to sue businesses that didn't comply with the law; another thing was repeated Supreme Court narrowing of the law's employment discrimination provisions, though some of those were corrected by the 2008 ADA Amendments Act; a third thing was the rise of a permanent and effective organized opposition to community integration for people with developmental disabilities.) It's true that for nearly the past two years the DIA was actually being held up in the House Energy & Commerce Committee by its chair, Democrat Frank Pallone of NJ. He refused to say why, but it might be because the segregationist bigots at "Voice of the Retarded" who've been campaigning against it, and their financial backers in the public employee unions, got to him. Or it might be because he understands the bill's fundamental flaws as described here. Either way, it's likely that this time around nobody in Congress is going to be bamboozled into believing that DIA will be a "safe" pat on the head for people with disabilities if it actually gets enacted. In 2021, even if the Dems get control of the Senate, I predict that DIA advocates will not get the same warm bipartisan reception they got in previous years, because if the bill passed, Biden might actually sign it—and few legislators really want that to happen.

Don't get me wrong. I would love for a bill that actually accomplishes what DIA purports to do to be enacted. But that's a fantasy. Much more than that, I would love a more modest bill that does what is really doable to be passed, and I would love the advocates to work on that instead of this unrealizable dream.

Trump's anti-poor-people CMS administrator Seema Verna will most likely be departing. That provides some hope that there will be an end to her efforts to impose nonsensical work requirements on Medicaid and provide maximum flexibility to state governments to cut services. Medicaid is a health insurance program that is overwhelmingly used by people who can't get decent jobs; lots of them have jobs, often two or three part-time jobs, none of which provide health insurance—which forces them to rely on extremely expensive taxpayer-funded hospital emergency rooms or indigent service pools for what little medical care they can get. If the Obama Administration provided a clue to what Biden will do, then we might get a much better CMS. But even Obama's CMS, which issued the groundbreaking Home and Community Based Services regulations that emphasize integrated services, declined to fully enforce those regulations in negotiations over state Medicaid plans.

Similarly, Obama's Justice Department made an effort to strongly defend the civil rights of people with disabilities, issuing guidance to states that warned them that failure to maximize community integration—even if permitted by federal Medicaid law—could result in legal action. We can hope for a similarly aggressive approach from the Biden Administration. But during the Trump years some conservative federal courts have issued opinions reducing the value of mere agency guidance (as opposed to regulations), and some judges are developing an appetite for devouring regulations themselves if they don't hew very closely to the letter of the laws that authorize them. That makes logical sense; why should judges have to enforce laws whose authors didn't care about making them stick? Unfortunately too many politicians try to make themselves look good to ordinary people while avoiding angering the rich folks who pay to elect them, and they deliberately write vague laws that sound nice but have no teeth unless they are added by the occasional bureaucrat who actually cares about the issues. If we had to depend solely on elected officials to make change in this country, very little would ever change.

In any event, the COVID-19 pandemic and its economic effects are going to dominate the activities of federal and state governments in 2021, and will likely linger into the election year of 2022 even if effective vaccines start to become widely available, as predicted, by the middle of next year. The disease hits people with disabilities harder than nondisabled people, and there's mounting evidence that it can actually create permanent cognitive, mental health and physical disabilities in some people who never had any before. So efforts focused on ending the pandemic and helping people recover from its financially and socially destructive harms can quite reasonably be considered major benefits for disabled people. It's just hard to see right now how we will get much more than that out of the only modestly changed political landscape.

What Pre-Exists What

As mentioned elsewhere (see page 3) we are awaiting a Supreme Court decision on the fate of the Affordable Care Act (ObamaCare). Most analysts now believe the Supremes will, at most, strike down the individual mandate without invalidating the rest of the law. That will do no harm because it hasn't been enforced since 2017. But the case, and the recent election campaign, raised the question of exactly how bad it would be if the law went away. Although we at STIC operate programs to help people enroll in Medicaid or purchase private insurance through the state's

ObamaCare exchange, “New York State of Health,” and would likely lose those contracts if the law was declared unconstitutional, we at *AccessAbility* have to be honest and tell you that, really, it wouldn’t be as bad as some people have claimed.

I can hear you saying, “OMG, he’s gonna talk about ***insurance*** again? BOR-ING!!” You can skip this if you want. But the advocates among you really need to understand what the truth is here. Spewing false propaganda doesn’t enhance anyone’s standing with legislators, and advocates need to ensure that their limited time and resources are devoted to the most pressing problems, instead of sweating the small stuff.

ObamaCare really has very little relevance to the most important issues faced by most Americans with significant disabilities. This is true because most of them actually have medical insurance. A relatively small number of them have it from their employers, but lots more are unemployed and/or elderly, so they have Medicaid and/or Medicare. It’s true that many other states’ Medicaid programs aren’t nearly as generous and comprehensive as New York’s, but the most important ObamaCare Medicaid provision is aimed at nondisabled poor people, not people with significant disabilities. This is the so-called Medicaid expansion, which provided a time-limited extra-large federal funding match to states that increased their Medicaid income eligibility thresholds to include more of the “working poor”—people who only rarely have employer-based health insurance. Certainly some of these people do have disabilities, but it’s a small percentage.

Some advocates would call any “pre-existing condition” a disability, and some of them are—or will be if they cause enough degeneration—but most of them are just diagnoses, such as diabetes or heart disease or a history of cancer. Just because you have them doesn’t mean they’re affecting your ability to function in any significant way. All legitimate definitions of “disability” (there are at least three in common use) require significant impairment of a person’s ability to do one or more important life activities. Most pre-existing conditions, in medical insurance terms, don’t fit those definitions. And as we said, most of the people who have ones that are actually disabilities already have insurance.

The recent propaganda around ObamaCare concerning pre-existing conditions has been pretty much completely false on both sides. The Republicans claim they support the law’s protection against denying insurance to people with pre-existing conditions, but that’s a lie. Congressional Republicans tried to repeal the entire law, including that provision, dozens of times, and neither they nor Trump have ever presented an alternative bill that does the same thing. Several Republican state governors also signed onto the lawsuit now before the Supremes, which argues that the entire law is unconstitutional.

Meanwhile the Democrats have been claiming that if ObamaCare goes away, over 100 million people will lose pre-existing condition protections. That’s also a lie. They seem to be conflating ObamaCare’s provisions with a published estimate that about 100 million people have what insurance companies would call “pre-existing conditions.” (There are several such estimates and they’re all over the map from about 50 million to more than 150 million.) But all ObamaCare does is say that when private insurance companies sell individual plans to people on the insurance exchanges, they can’t deny coverage, or impose different pricing, for people with those conditions. Over the years estimates of the total number of people receiving insurance through ObamaCare exchanges have ranged between roughly 16 million and 22 million. But most of them are people who got Medicaid through the exchanges. In 2019, only about 9 million people purchased private individual insurance plans through ObamaCare, and those are the only people who would definitely lose that protection if ObamaCare is declared unconstitutional.

There are no pre-existing condition exclusions in “original” (Parts A & B fee-for-service) Medicare or Medicare Advantage (managed care) plans. Some Medicare supplemental (“Medigap”) plans may deny coverage for pre-existing conditions if you sign up for them outside the usual open enrollment period. However, lots of people with such conditions are eligible for Medicare Special Needs Medicare Advantage plans, which have no limited enrollment period. There are a few limitations on people with end-stage renal disease also. But none of these exclusions are permanent; at worst, they impose a 6-month delay on when your plan will begin to cover those conditions.

“Straight” Medicaid does not have any pre-existing exclusions for typical medical services, such as doctor visits, surgery, lab work, therapies, or prescriptions. However, many of the services that states offer are chosen by the states, which may or may not also have waivers and/or community-based services programs that offer additional, specialized services only to people with various types of disabilities. This sort of variation isn’t what most people mean by “pre-existing conditions.” It’s true that ObamaCare provided a way for states to expand Medicaid, with its prohibition on pre-existing condition exclusions, to nondisabled people with somewhat higher incomes, by providing a higher (though steadily declining) federal match for serving them, and if the law goes away that specific program would too. But states have been able to expand income eligibility by means of Medicaid waivers for a long time (New York did it well before ObamaCare was enacted), though without the temporary increased match, so states that really want to continue coverage for those people would have a way to do it even without ObamaCare. Probably not all states would do that, but some would, and that means that a lot fewer than the 12 million or so people who got Medicaid pre-existing condition coverage through the law would actually end up losing it.

For just about everybody else—nearly all of whom get health insurance through their employers—it has been illegal for insurance plans to permanently exclude coverage for pre-existing conditions for many years—long before ObamaCare was even thought of. The federal Employee Retirement Security Income Act (ERISA) of 1974 set the maximum term of exclusion of coverage for pre-existing conditions in most employer-sponsored health insurance at 12 months for most employees (those who don’t enroll immediately when they are hired can face an exclusion of up to 18 months). ERISA defines a pre-existing condition as one that was diagnosed or treated within a six-month “look-back window” prior to when you were first eligible to enroll in the plan. For example, if you had a heart attack two years ago and haven't needed any services or medication related to your heart condition for six months, they can't delay coverage for it. ERISA's look-back window for long-term disability coverage is only 90 days.

Then came HIPAA. Most people think that the Health insurance Portability and Privacy Act (HIPAA), passed in 1996, only requires organizations to get your permission to share your health information. But the "portability" part protects people against repeating pre-existing condition exclusions. Under HIPAA if you leave an employer that provided health insurance after working there for at least a year, and you take a new job that also provides health insurance within 63 days, there can be no delay in covering your pre-existing conditions in your new job.

Note that group insurance plans like those purchased by employers can charge higher rates if large numbers of people in the plan file a lot of claims for coverage, but that's a cost borne by the employer, not the insured person, and it's not necessarily based on "pre-existing" conditions; it's just as much about people whose medical needs increase after they enroll in the plan.

Meanwhile, between 1974 and the passage of ObamaCare in 2010, many states enacted laws that further limited or completely outlawed pre-existing condition exclusions in employer-based health insurance. So the problem that ObamaCare was primarily designed to solve was how to get insurance to people who don't have it through their jobs, not how to cover pre-existing conditions for people who do, because that problem was already largely gone. The big roadblock was private insurance companies' unwillingness to offer insurance plans directly to individuals, or at least, not without huge unaffordable premiums. ObamaCare mostly created incentives for those companies to offer affordable plans, minimum quality standards for the plans, and informative online "exchanges" in which they could be sold. It was only natural that while it was doing this it would also apply the prohibitions on pre-existing condition exclusions that many state and federal laws had already applied to employer-based plans to the new individual plans.

Now, it's also true that ObamaCare required employers with 50 or more full-time employees to provide at least a minimum level of health insurance to those workers. The law also defined "full-time" as at least 30 hours a week, which led a lot of companies simply to cut everybody back to 29 hours a week, and hire more part-time workers, to avoid having to provide health insurance. Truly there weren't many companies of that size that didn't offer health insurance before ObamaCare, and it's doubtful that this provision produced a meaningful benefit.

But what about those individual plans for people who can't get insurance on the job? Aren't they a great benefit of the law? Yes, they are. But perhaps the law's greatest benefit has been educational. That is, insurance companies have learned that there really is a market for private insurance plans. When the law was passed its supporters insisted that the "individual mandate" be part of it; healthy people were forced to buy health insurance in order to keep individual plan rates down for people with pre-existing conditions. But the mandate has been gone for over three years and rates really haven't increased any faster for those plans than for employer-based plans. It's true that the federal government has been subsidizing those rates to some extent, and those subsidies would go away with the law's demise, but it's possible that the insurance companies might want to stay in this lucrative market, especially since the law's quality/coverage requirements for those plans would also be gone. We might find that if the Supremes wipe out the law, most people will still be able to buy some minimally acceptable private plans.

Of course, it's hard to explain all this in a 30-second political campaign ad. But it should now be clear that Democrats have been just as guilty of dishonesty as Republicans when it comes to ObamaCare and pre-existing conditions. Lots of insurance companies hire celebrities that people (especially older people) seem to trust to sell health insurance on TV. The idea is that somebody like William Shallert or Tom Selleck or (for some strange reason) Joe Namath is a more trustworthy "brand" than Amica or Excellus or Humana. Some people seem to consider "Democrat" and "Republican" to be trustworthy brands as well. The real lesson here is that if people rely on familiar brands or spokespeople as substitutes for actually learning the facts, they are likely to be deceived. And as citizens we have a responsibility to understand the facts before we vote on the people who make the decisions.

courts watch

***Waskul v. Washtenaw County Community*: Ambiguity is … Well … Ambiguous ...**

The Merriam-Webster dictionary defines "ambiguous" this way: "doubtful or uncertain especially from obscurity or indistinctness; inexplicable; capable of being understood in two or more possible senses or ways." We're defining our terms here because laws run into trouble in the courts when they don't.

This case is about a Michigan self-determination program for people with developmental disabilities, and was decided in the 6th Federal Circuit Court of Appeals, but it may be very significant for New Yorkers who are contending with Governor Cuomo's attempts to destroy the CDPA program by cutting its administrative rates to a level well below actual cost and by pushing managed care plans to force personal attendant wages down to the bare minimum.

Some of you know about "self-determination" disability service programs. For those who don't: "Self determination" means the person who gets the services also gets to make some decisions about how those services are provided. It's the same as "consumer direction," in a general sense. There are different kinds of self-determination programs though and the specifics of each matter for this case. The programs break down into those that give service recipients "employer authority" and/or "budget authority." Employer authority allows the person to hire, supervise, and fire the people who serve them. Budget authority lets the person decide how to allocate a personal pot of money to purchase different types of services and/or hire people to provide them. Some of these programs are available only through Medicaid waivers or so-called "State Plan" home and community-based service programs; others are available through Medicaid fee-for-service or managed care. Michigan does some things differently than New York, so we have to be careful in determining how much of this Michigan case really applies here.

The Consumer Directed Personal Assistance program (CDPA) in New York serves people with a broad variety of physical, cognitive, and developmental disabilities. It only provides employer authority, and it's funded by both managed care plans and fee-for-service Medicaid. It also only covers personal assistance services (attendants to help people with certain types of self-care and related tasks at home and in community locations). The Michigan case is about a Medicaid managed care waiver program that provides both employer and budget authority and covers a range of services that fall under the general category of "habilitation," only for people with developmental disabilities. It's similar to New York's OPWDD Self Determination program. People familiar with OPWDD tend to think of "habilitation" as separate from things like in-home attendant services, supported employment, pre-vocational services, and respite services, but those are all New York distinctions; at the federal level they're all "habilitation" services and states don't have to separate them out in their waiver plans if they don't choose to. We don't really know if Michigan's Self Determination waiver provides services similar to what we call CDPA, and that's one of the problems with deciding how important this case is to us.

The problem began in Michigan when the state changed its self-determination funding methodology. Each person's individual pot of money, or "budget," was determined by multiplying her number of hours of approved services and supports by a set rate. The person would then decide how to allocate those funds for different services and workers. However, when it came to charging costs against those budgets, the state used to break the costs down into separately-billable categories—one for wages paid to workers or fees paid to provider agencies, and another for things like workers compensation insurance, training, and transportation. Only the first category, wages/fees, was charged to their budgets. But then the state decided to incorporate all of those fees into one charge and bill all of it to people's budgets. They didn't increase the rate used to calculate the budgets though, so people either had to cut the wages/rates they paid for services, or cut the number of hours of service they purchased. They needed all of their hours of service, so a lot of people cut wages for workers. A lot of workers quit because they couldn't live on those wages, and people had difficulty replacing them for the same reason.

Some of these people's stories are pretty shocking. Derek Waskul, for example, is autistic, has "severe cognitive impairment," and needs 24/7 supports. He couldn't find enough workers at the reduced wage and resorted to hiring his father, who is only available on weekends. He's been forced to stay home three days a week; as a result he's developed "depression, worsening scoliosis, and anger management issues." Another plaintiff was "forced to hire his 77-year-old ailing grandfather"; a third opted not to lower wages, and instead his mother is paying out-of-pocket for some of his services and supports, "causing her to fall behind on her taxes and putting her at risk of foreclosure."

Federal Medicaid law has several provisions that establish states' responsibilities to ensure their Medicaid programs are adequate to meet people's needs and that home and community-based service programs like Self Determination and CDPA comply with at least minimum standards. There have been many federal lawsuits over several decades to try to enforce these rules in a meaningful way. The resulting case law has established a few things: First, in at least some kinds of cases, Medicaid recipients don't even have legal "standing" to sue states over these issues because the law doesn't provide a "private right of action" to them. Second, the US Supreme Court has been pushing the idea that courts aren't "competent" to decide technical issues about provisions of Medicaid law that it calls "ambiguous." And third, the Supremes have also said that in most cases, the only way to enforce Medicaid law is to have the federal Department of Health and Human Services threaten to cut off the money for states that don't comply, and if they won't do that, people can sue ***them***. We've covered these issues many times over the years. See *AccessAbility* Spring 2015 and Summer 2015 for *Armstrong v Exceptional Child Care Center*; there are many other articles referenced in those.

So what's different about this case? The Sixth Circuit thinks it's found a way around the standing and ambiguity problems, and it supported the idea that being forced to be "homebound" because you can't get enough services is a form of unnecessary institutionalization that violates the Americans with Disabilities Act (ADA). Why are we cautious about it? Because it's quite likely that this is just another example of a liberal federal judge trying to expand the law in ways that conservative Supreme Court judges won't approve—and maybe even have already disapproved. The distinctions are technical and involve a lot of wading through stacks of earlier decisions, which we have neither the time nor the competence to do. But we'll try to outline them for you.

This suit was filed in federal district court, and the judge there dismissed the plaintiffs' claims for various reasons. The Circuit Court looked at that decision and found several missing pieces in the district judge's chains of logic and sent the case back to be re-decided. Yet the Circuit Court left open several avenues for the district judge to rule against the plaintiffs again, as long as s/he does so in a way that dots all the I's and crosses all the T's, and that may very well happen.

But in his opinion the circuit judge made some interesting points that leave open the possibility that the case could serve as a precedent to support challenges to New York State's actions.

Previous Supreme Court decisions found that even if a law doesn't explicitly say that an individual can sue the government for failing to provide a service, there are ways to determine whether specific provisions of the law actually confer rights to a person that she can enforce by suing: Did Congress in writing the law intend the provision to benefit the plaintiff? Are those rights "so 'vague and amorphous' that … enforcement would strain judicial competence"? And does the law "unambiguously" impose a mandatory obligation on the state?

When people have been unable to get Medicaid services due to faulty payment methodologies, they have tried to sue for violations of the Medicaid law's provision that state Medicaid programs must "assure that payments are … sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area." As the circuit judge says, that provision doesn't confer a right on Medicaid recipients, because it doesn't even mention recipients. It's a provision that applies only to the behavior of state Medicaid programs. BUT, other provisions require states to ensure that all medically necessary assistance be provided to "all eligible individuals" with reasonable promptness, and such assistance "to any individual" who is eligible must be equal to the assistance that is available to other Medicaid recipients. The judge also argued that the regulations (but perhaps importantly, not the law itself) describing "promptness" and "equal assistance" are clear and not ambiguous. Finally, the law and regulations use "mandatory" language such as the state "shall" and the Medicaid plan "must," instead of "may" or "should." Whether the Supremes buy this argument might depend on whether the plaintiffs specifically said there's a problem with how promptly they are able to receive services. Very conservative "textually oriented" judges don't like arguments along the lines of, "Well, if they can't get the service at all, then they didn't get it promptly, did they?" They are sticklers for exact language. Ditto with regard to specific complaints plaintiffs bring; judges are not supposed to provide relief for harms that the plaintiffs didn't say they suffered.

So much for Medicaid law. The plaintiffs also alleged violations of the ADA. The ADA, as interpreted by the Supreme Court's *Olmstead* decision, calls institutionalization of people who don't objectively need it, and also don't want it, illegal discrimination. The plaintiffs in this case make two claims about that: First, if they can't get all of the services they need, their health will deteriorate to the point that they won't be able to continue to live in their own homes, so they are at risk of being placed in institutions. Second, even if they can maintain their health, if they must spend most of their time sitting at home, they will be effectively institutionalized there.

The first argument is easy and straightforward, and at least one plaintiff brought evidence that his health was already deteriorating. A very right-wing judge filed a dissent in this case. Among other things, he said that neither the ADA nor *Olmstead* says anything about "risk of institutionalization"; they only discuss actual institutionalization, so a mere risk is not grounds for a lawsuit under the ADA. Confusingly, he then said that if the plaintiffs want to allege that the harm of institutionalization is so profound and permanent that it wouldn't make sense to wait until it happens to them before they sue, then they could request a temporary injunction against the new methodology—but the plaintiffs did request such an injunction, which the district court did not grant. The general concept that plaintiffs don't have to actually experience a harm in order to sue, and get relief, if such harm is grave enough is well-established in case law; it doesn't depend on the language of any specific statute, and we doubt the dissenting judge's remarks on this point would hold any water. (The same dissenting judge also argued that the Medicaid regulations that the deciding judge thought were clear are too ambiguous for courts to competently interpret, without explaining what he found confusing; he apparently believes that previous cases that cite this problem should be interpreted to mean that any and all regulations are too ambiguous for judges to understand. However, the fact that a rigid right-wing textually-oriented judge may be incompetent to understand a regulation is neither surprising nor proof that another judge with a more balanced perspective couldn't understand it.)

The second argument, though, may be different. We absolutely agree with the plaintiffs' logic. The Medicaid regulations for programs like Michigan's define "characteristics of an institution" as those that isolate individuals and limit their ability to interact with nondisabled people to the maximum extent possible. But we anticipate right-wing judges writing "Those very regulations describe a person's own home as a non-institutional location. How can one federal law—the ADA— outlaw that which another federal law (Medicaid) permits or even encourages?"

There are also significant differences between the changes to Michigan's funding methodology and New York's proposed changes to paying for CDPA services. In Michigan the funding methodology was changed by combining two separate billing processes into one. In New York the proposal is to separate a single billing process into two—one for wages and benefits for CDPA workers who assist people with disabilities with self-care and related tasks, and another for the Fiscal Intermediary (FI) service, which assists people with disabilities to manage their workers. It may be possible to make the argument that the NY change will make it impossible for people to receive services promptly, because FI agencies will be extremely understaffed if that rate is cut. The "home as an institution" argument is a tougher sell for a CDPA program than it is for a habilitation program. Although both programs assist people both at home and in community locations, the primary purpose of habilitation services is to integrate people into the community, while the primary purpose of CDPA is to provide in-home attendant services.

This case might be a better fit for challenging the use of Medicaid managed care to pay for community-based services. For about a year now most of the private insurance companies (managed care organizations, or MCOs) that provide Medicaid managed care plans in NY have been trying to pressure CDPA FI programs to sign contracts with much lower rates that would force them to cut wages for attendants down to the state minimum. Many CDPA attendants have been working with STIC and other FI agencies long enough to get several wage increases; if they were cut back to minimum wage they would quit, and many would immediately get better-paying jobs in the fast-food industry or elsewhere. The risk of institutionalization if services are reduced is more imminent for most CDPA participants than it is for habilitation consumers, because the need for CDPA services is much more commonly related to physical health.

However, the managed care plan providers in Michigan are not private health insurance companies. They are regional Prepaid Inpatient Health Plans (PIHPs), public agencies that only exist to offer those Medicaid services to people with developmental disabilities. Although they receive capitated rates to serve individuals, they don't appear to have the same discretion to apply downward pressure on wages that New York's MCOs have.

The defendants in the case pointed out that the plaintiffs have several options to improve their situations without suing. They can purchase services from agency providers instead of recruiting and hiring their own people, and they can also appeal to get larger individual budgets. They may also be able to make more use of natural supports. (Most people reflexively think that last bit means, "Oh, they have to make their families help them." These plaintiffs were having their families help them and it wasn't going so well. The definition of "natural supports" is broader than that, and the real purpose of habilitation services is to get people so well integrated into the community that the ordinary folks they encounter in the places they go will befriend them and help them, especially in places where they work or volunteer, with a side effect of reducing the need for paid support.) The district judge didn't consider whether those claims were true; he dismissed the case before getting to that point. The circuit judge made it clear that it might be true that such actions could have solved the plaintiff's problems. If the district judge agrees, he can dismiss the case again and the plaintiffs might have no further recourse. A judge considering the New York situation might say that CDPA consumers could use "traditional" homecare agencies to solve their staff shortage problems. It's not true; generally speaking, at least upstate, CDPA consumers have better luck recruiting workers than homecare agencies do. Cutting CDPA wages would make recruitment just as hard in CDPA as it already is for traditional agencies, but it wouldn't increase the likelihood of people getting the services they need. But plaintiffs in a New York suit would have to be armed with factual evidence to prove that point.

So indeed, for many reasons, the question of whether this case can help us in New York is, itself, ambiguous at best.

Not Dead Yet v Cuomo: Not Decided Yet (sorry!)

As we reported previously (*AccessAbility* Summer 2020), New York State has a set of guidelines for hospitals to follow in the event of a pandemic emergency that call for taking ventilators away from people with disabilities and giving them to allegedly more "healthy" people if they show up at a hospital. Disability Rights New York (DRNY), the state's federally-funded Protection & Advocacy agency for people with various types of disabilities, filed a complaint with the federal Department of Health and Human Services Office of Civil Rights (OCR) about this on April 7.

Lots of other states had pandemic crisis policies that discriminated against people with disabilities in a variety of ways, and OCR received complaints about many of them. OCR issued a bulletin informing states that these kinds of policies were illegal under the Americans with Disabilities Act, the federal Rehabilitation Act, and ObamaCare. Later in the spring the agency announced settlements of three of the complaints, including Alabama, whose policy specifically denies ventilators to people with developmental disabilities, and the states rescinded the policies.

There's been no news on the rest of the complaints, including DRNY's. So on October 7, DRNY joined the anti-assisted suicide group Not Dead Yet and several individuals with disabilities in filing a lawsuit against the state in federal district court. The plaintiffs' complaint is detailed, straightforward, and very well argued. It should be a slam-dunk. We'll let you know if they catch any rim.

More Police Violence

After we published our last story on this topic, it was revealed that the Rochester NY police had killed Daniel Prude in March of this year. Prude was 41 years old and black. He had a history of suicidal ideation, apparent hallucinations and delusions, and paranoia, adding up to an obvious mental health disability. On March 23, 2020, he went to his brother's home and was behaving erratically, at one point leaping head-first down a flight of stairs. He was taken to the hospital for a psychiatric evaluation and released. A few hours later he ran away from his brother's home, shedding his clothes, and his brother called 911 to get some help for him. He was not armed and not behaving aggressively. Both police and paramedics arrived. A cop pointed a taser at him and told him six times to lie down on the ground. Prude did so, and he also put his hands behind his back and allowed the officer to cuff him. He said "Yes, sir," and he also repeated "In Jesus Christ I pray. Amen," and other things. A few minutes later he became agitated, shouting "Give me that gun!" According to the police he began spitting at them, and according to the Boston *Globe* this could be seen on the police body camera video. The police put a "spit hood" on his head and put a knee on his back and forced his head down onto the pavement. He demanded that they remove the hood and tried to stand up but didn't succeed. Eventually he stopped struggling, then he stopped breathing, and then he died.

The coroner's autopsy report stated that he died of "complications of asphyxia in the setting of physical restraint." It also said that "acute intoxication by phencyclidine, or PCP," was a contributory factor. Prude's sister said that he had smoked a joint soaked with PCP before going to his brother's house.

An internal investigation in April cleared the police officers of any wrongdoing. These events were not publicly revealed until September 2, at a press conference that featured the body camera video. The news generated multiple protests over more than a week in Rochester, most of which began peacefully but were eventually marred by acts of vandalism. In response, the police used tear gas and pepper spray on the protesters. Then on September 4, seven police officers involved in the death were suspended. New York Attorney General Letitia James announced she would empanel a grand jury to investigate the events. Then Rochester's Chief of Police and two other high-ranking people in the department resigned. There has been little news since then.

As we reported last time (*AccessAbility* Fall 2020), substance abuse is itself a disability and it is usually a type of self-medication by people who have some form of mental health or cognitive disability, whether PTSD, psychiatric illness, or brain injury, and are trying to relieve pain, anxiety, fear or depression. Prude's brother sought medical help for him but the hospital released him within a few hours, even though his action in diving down a flight of stairs was clear evidence that he presented an immediate danger to himself and should have been grounds for holding onto him until they could get him some effective ongoing supports and services. Having no other way to help him, his brother called 911.

The fact that paramedics came along with the police may perhaps be an improvement over the usual police-only response to such situations. But the response ultimately failed and it may have been because the paramedics, who should have been trained in defusing situations like this, did not take the lead when they arrived. People in these situations can often be "talked down" by someone who knows how to do it. Even if physical restraint becomes necessary, there are well-understood safe ways of doing it that don't risk the person's life. Instead the police were allowed to take over and they applied the knee-in-the-back, hand-on-the-head approach, which is known to be dangerous (it's what killed Eric Garner and George Floyd). In retrospect there doesn't seem to have been a need for police to be on the scene at all.

As we also said last time: This is why people shout, "Defund the police!" It doesn't mean abolish the police. It means stop using them as first responders for people in crisis, and transfer the money we pay them for that to organizations and trained professionals who actually know how to help people without hurting them. And it means reduce the size of police forces dramatically as a result, and with them, the size, wealth, and power of police unions that pay our elected officials to perpetuate this insane approach to crisis intervention.

Where are the Missing Nursing Home Residents?

On November 2, ABC News reported that by late October, more than 82,000 people in 41 states had died of COVID-19 in nursing homes and other long-term care facilities. As of October 31, about 230,000 Americans had died of the disease, total. Various media have reported that the ratio is consistently about 40%. But this may be a dramatic undercount.

As we've reported, we know that many people in New York contracted the disease in nursing facilities but died in hospitals, a statistic that the state Department of Health (DOH) still refuses to publish although most other states have done so from the beginning of the pandemic. In August the Associated Press reported that DOH surveys show that nursing facilities in the state had 13,000 more empty beds than expected this year—which was more than twice the number of nursing home COVID deaths reported by the state at that time. Some of those are due to family members pulling people out of these death traps and others who wisely decided not to go in. But it's quite likely that many of them died in hospitals after being infected in those "homes."

It's also likely that there's another explanation for some of those empty beds.

On November 6 the Albany *Times-Union* reported that there has been a dramatic rise in deaths due to Alzheimers disease and other forms of dementia, in New York and across the nation, in 2020. These deaths were 21.4% higher in NY and 16.6% higher for the United States.

Experts said that if this was because COVID-19 itself, as a physical disease, was contributing to earlier deaths of people with dementia, the expected rise would be more like 5%. There's something else going on.

One thing would be that these people received much less medical care in general due to the pandemic. Nursing homes, always short-staffed, lost a lot more workers due to the disease, and the amount of neglect of their residents skyrocketed as a result. But some hospitals have also been periodically overwhelmed with COVID cases and less able to provide prompt and consistent care to other patients, including those with dementia.

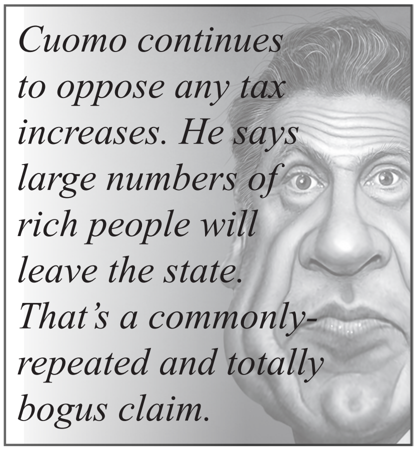
And there's another theory. People with these conditions seem to benefit from lots of personal attention. It slows their rate of deterioration. It's quite likely that, denied frequent attention from employees, and deprived of any visits from family and friends, many of them went downhill rapidly and died much sooner than they would have if there were no pandemic.

Keeping people with disabilities in places where there is forced togetherness among strangers and paid staff, instead of helping them stay in their own homes and avoid contact with people who are a potential danger to them, is not good social policy.

The Incredible Shrinking Deficit

According to TheCity.NYC, by early October the Cuomo Administration had recouped almost all of the projected state budget deficit caused by the pandemic economic depression.

Cuomo has claimed the deficit was anywhere between $6 billion and $20 billion at various times since the spring. TheCity used a figure of $14.5 billion to start with, which was the difference between Cuomo's early, pre-pandemic budget proposal, and his most recent projected loss of state revenue due to federal cuts and decreased tax payments. But the budget passed in early April didn't include everything Cuomo had originally wanted to spend, and that brought the number down to $10 billion.



Cuomo continues to oppose any tax increases. He says large numbers of rich people will leave the state. That's a commonly-repeated and totally bogus claim.

Then the state came up with $3 billion in legal settlements, a lot of it from disputes with banks related to the financial crisis. And Cuomo borrowed $4.5 billion to cover the delay in income tax payments between April and July. As of October 1 he'd gained another $2 billion by withholding 20% of planned payments to local governments, schools, and not-for-profit organizations like STIC. That takes the number down to $500 million. And he apparently still hasn't spent all of the $5 billion he got from the feds for pandemic aid either.

Which should theoretically leave the state in pretty good shape. The problem with that is there is a major economic depression under way. Lots of people are out of work, and lots of people are spending less money, and that's going to mean dramatically reduced sales and income tax revenue for the state, especially next spring. Without another federal bailout specifically aimed at state governments, the situation will be very dire next year.

Cuomo's budget director has said quite plainly that those 20% withholds on state payments will turn into permanent cuts if the feds don't come through pretty soon. As bad as that would be, we have to tell you it would actually be better for STIC if that happened than if he continued to withhold promised payments indefinitely.

You see, the withholds are not really mere 20% cuts to our budget. We could at least plan for that, since we'd know how much money we were going to get. They are actually cuts to our reimbursement for money already spent. So it doesn't help us at all to cut our spending by 20%. Suppose we were promised $100. If we actually spend $100, we will only be reimbursed for $80. But if we only spend $80, then we will be reimbursed for $64. If we spend only $64, we get back only $51.20. Get it? We can't escape, and we can't plan. The only way to stanch the bleeding is to shut down completely and spend nothing.

If there's a federal relief package, we would get the missing money repaid—or at least some of it, depending on how big a package it is. But if that doesn't happen, we'll be left holding the bag. This is insane and unnecessary. It's just as easy to announce a 20% cut and then if the feds come through, restore the cut along with an extended period of time to spend it. However, the reason Cuomo isn't doing that is because an actual proposed cut triggers a ten-day period in which the legislature gets to meet and propose an alternative, something Cuomo doesn't want to face.

And that's because the alternatives could include stopping wasting money on pie-in-the-sky "economic development" schemes that Cuomo and his cronies like (you know, where they promise some business huge tax breaks in return for creating hundreds of new jobs, and then the business creates only a handful of jobs, if any, and still gets the full huge tax break), ending subsidies for the richest school districts, and increasing the state's taxes on its wealthiest citizens. Amazingly, even the right-wing fanatics at the Citizens Budget Commission support the first two ideas, and the only slightly less obnoxious Empire Center for Public Policy favors at least cancelling a planned tax cut for people earning over $100,000.

Cuomo continues to oppose any tax increases. He says large numbers of rich people will leave the state. That's a commonly-repeated and totally bogus claim. According to the Tax Policy Center, historically, when places that people find attractive for other reasons raise taxes, only a tiny number of wealthy people move. Between the end of World War II and 1963, the top marginal income tax rate in the US was 91%. Very few people left the country to escape those rates. Much more recently, even after Congress applied sharp limits on federal deductions for state and local income taxes in 2017—a feature allegedly much valued by the rich—the number of "ultra-rich" New York City dwellers continued to rise. Many of the wealthy people who do leave in these situations are near retirement and would pay less in taxes if they stayed anyway. And people who can afford to move will also leave if the state lets its infrastructure and services deteriorate due to spending cuts. By some measures, New York City and its suburbs is the most attractive place to live in the country; very few people with the means to live there are likely to move to less desirable places as long as they can continue to afford it. And if you make $2 million a year and have that cut to $1.8 million, you can certainly still afford it.

Meanwhile, there are lots of rank-and-file Democrats in the state legislature calling for tax increases. The problem is with their leadership, which still seems mesmerized by the completely undeserved reputation for god-like wisdom that the governor amassed during the early part of the pandemic, a performance that has been deemed Emmy Award worthy, political stagecraft that it was. Even if they did go along with raising taxes, Cuomo would veto the measure. Although early returns suggested the Dems didn't do so well in either house of the legislature, after the absentee ballots were counted, they emerged with supermajorities in both the Assembly and the Senate. This means, they can override any Cuomo veto. It remains an open question if they will have the guts to do it though.

STIC NEWS

Xscapes Holiday Special

20% off all Xscapes Bucks purchases until 1/1/2021

Buy as much or as little as you need for your holiday gifts.

To Purchase

Call (607) 760-3322

email info@xscapes-stic.com

Xscapes Bucks along with a holiday certificate will be mailed to you or your family as requested.

Brand New 60-Minute Escape Room Experience

By Todd Fedyshyn

You have entered one of our high-level field offices. This location maintains data and gathers intelligence on a large network of foreign operative assets. Recently we have determined that this unit has been compromised and is at extreme risk of enemy penetration. We have issued a data extraction and purge order to the operative in charge, but he has not responded or acknowledged this action. It will now be your responsibility to locate the high-level documents stored in the facility and secure them. You will also be charged with initiating the self-destruct sequence which will neutralize all remaining intelligence and prevent it from reaching enemy hands. For your protection during your mission, we have remotely secured your location. Unfortunately, it will be impossible for you to exit unless you achieve your objective. It has been determined that enemy assets will arrive at that location in one hour. If you have not successfully retrieved all data, we will have no choice but to remotely detonate and eradicate the facility. Good luck agents.

To book your next escape room experience visit: www.xscapes-stic.com

Xscapes is only offering private bookings at this time. You pay one flat price for up to five players. Whether you have 2 players or 5 players, the cost is the same. The only exception here is the $100.00 paid at time of booking only covers the hour-long games, which are Valley of the Kings and Exit Protocol.

There will be an extra $25.00 due at time of playing the game if you desire to play the hour-and-a-half games Twilight Zone or Wizard and Dragon. Once you have booked your time slot please call (607) 760-3322 to let our team know which one of our four games listed above you would like to play for the time slot you have booked online. We also do take calls for last minute bookings and are happy to work your team into our schedule.

Please be mindful that masks must be worn while visiting Xscapes.

When Big Companies Come Through Big!

By Rachel McHugh

As an organization, we at STIC would like to express our deepest gratitude for the donation made from Joe Rusin at NYSEG. With so many people out of work and our ability to fundraise hampered by the pandemic this donation couldn't have come at a better time! It has allowed us to keep providing critical unfunded services to the people we serve in the disability community. So often it is easy to lay blame for financial hardships on large companies because we think they don't have a heart. In this case Mr. Rusin and NYSEG came together and recognized the valuable services we at STIC offer and chose to support us during this difficult time, showing us not only do they care about their community but they have a very big heart.

"*We must find time to stop and thank the people who make a difference in our lives.*" – John F. Kennedy

You Can't Touch This: Advocacy in the Time of COVID

By Maria Dibble

As many of you may know, STIC has always been a strong advocate for the rights of people with disabilities, supporting and advocating for legislation that serves their needs the best.

We've always had several methods of advocating. In the early days we used phone and letter-writing campaigns to legislators and other public officials, with the goal of educating them on our issues and hopefully garnering their support.

Additionally, from our first days to the pre-COVID-19 present, we met face-

WE NEED YOUR HELP

By Sue Ruff, Advocacy Director

STIC has been part of the State Systems Advocacy Network, or as abbreviated the SSAN, for many years. Systems Advocacy "happens" when a group of people work together to change conditions for people with disabilities. Disability advocates work in several areas and the *AccessAbility* newsletter regularly describes those areas and efforts.

Finding housing that is both affordable and accessible, finding jobs and receiving adequate wages, getting personal assistance in your own home, accessing health care and mental health care, attending inclusive school classes, being able to travel from one place to another (especially if you live in a rural area), knowing the emergency shelter will be accessible if you are suddenly homeless are just some of the issues and challenges we face.

People with disabilities may be very patient but we have to be persistent. In this time of reduced opportunities for us to gather, share, plan, educate, advocate, and work with those who can help with housing, education, employment, health care, transportation, mental health services, personal assistance, emergency preparedness, and many more areas, we NEED YOU! Is there an area or issue that touches you deeply? Please reach out to me and join our group of systems advocates.

My email is advocate@stic-cil.org. My phone number at STIC is (607) 724-2111, extension 343.

I won't fill your email box. You can tell me what areas or issues touch you and how you want to help. Sometimes we send email action alerts, sometimes we ask people to call policy makers to explain how certain proposals will affect them, and sometimes we meet (it can be digitally or by phone if you don't have internet access; see below for more ideas). Please join us by adding your voice, your passion, your concerns, and a little of your time. Thank you for helping.

to-face with legislators, brought people with disabilities to Albany to share their stories, and when necessary, held protest rallies or even took over a legislator's office. We rallied several times to try to save CDPA from the draconian cuts the Governor wanted, up until March 15.

When COVID hit in March, we were not well prepared to continue our advocacy efforts for the budget and our many areas of concern. We were trying to arrange for our employees to work at home, with all that involved, to ensure that the people we serve were safe and had what they needed, and so on. But this was at a key point in the legislative session, the last two weeks, where all sorts of deals are cut, and you either get what you need or more often are thrown under the bus.

This year, we definitely felt the wheels of the bus roll over us, with little regard for our interests (which are your interests) and concerns. Our legislature gave everything to Governor Cuomo that he asked for, throwing everyone under the bus because he was given almost unfettered power over the budget. He was handed the power to change budgets or take other budgetary actions, with only a short period in which the legislature could respond. Why the legislature did this to themselves, just handed over their governing responsibilities to the governor, I can't fathom, but they did.

I promise I'm not rambling (well maybe just a little); this all relates to my point about advocacy. That was in March, and we missed precious opportunities to try to have an impact on the 2020-21 budget, a loss for most New Yorkers.

Come January of 2021, the Governor will be releasing his 2021-22 budget that will go into effect on April 1. I know we won't be showing up in large numbers to speak to or try to convince legislators to support our agenda, but we must find a way to reach them.

This is where we all come in. We're living in a time of social media (Facebook, Twitter, etc.). We will ask people with disabilities and others to help us spread the word on our issues and send Twitter, Facebook, Instagram or other messages to our politicians. This can work well if they hear from enough of us.

If you're like me and don't use Twitter or Facebook or Instagram, an ordinary email is just as useful, and the old-fashioned phone call or letter is even better.

The other method we must adopt is Zoom meetings with legislators. But for the meetings to be effective, sometimes we will need their constituents to join us (meaning you) so they will hear the message loud and clear. We vote and we want xxxx. Of course STIC staff will all engage in activities to advocate for our priorities, but sadly legislators are not as impressed by our pleas; they really want to hear their constituents speak up in whatever venue.

We are going to have to be creative to get our messages across, and I'm sure we will come up with some new and unique strategies to reach them.

I can't emphasize enough that we will do our part, but we absolutely need you to make our efforts successful. There is a lot at stake this year. The state has a huge deficit in the many billions. The governor will have the hatchet out to slash our budgets, but we can't survive without funding. There is only so much of the pie to go around, and we just want a fair slice.

People with disabilities and our issues are usually last to be considered and first to be discarded. Help us to reverse this trend, and make the concerns of people with disabilities a top priority. Together, our numbers can control the discussion if we all participate in some way.

If you wish to join us in our advocacy efforts, Please call Sue Ruff at 724-2111 Ext. 343. You won't regret it.

Accessible COVID Testing

If you don't have medical insurance you can get free COVID-19 tests from New York State or Broome County.

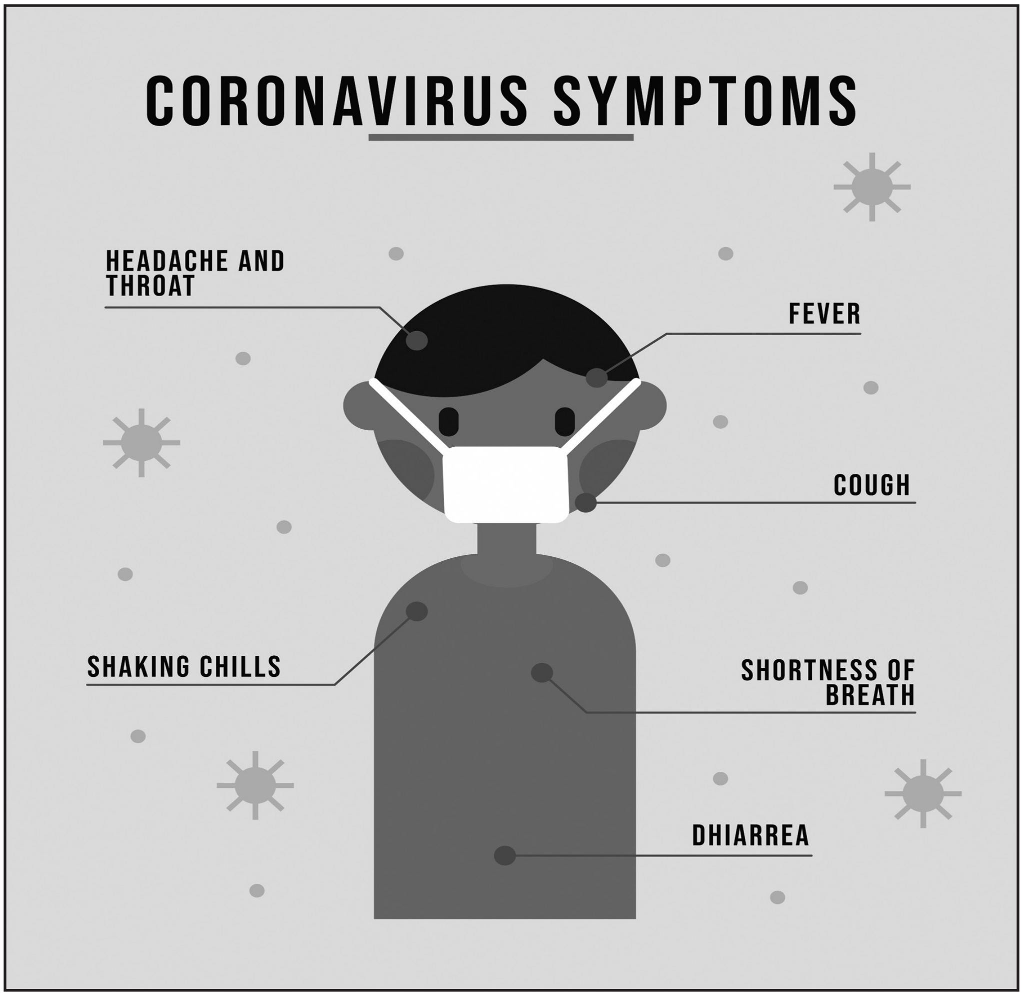
The state has drive-up testing at Binghamton University. Assuming you can drive or have someone drive you, there should be no issue with physical accessibility. We don't know what provisions have been made for sign-language interpreting, but you must get an appointment before you can be tested. You must also meet certain criteria in order to be approved for testing (such as having possible symptoms or reason to believe you've been exposed to the virus). When you call for an appointment you can ask about interpreters or other accommodations. Call (888) 364-3065 for an assessment and possible testing appointment.

Broome County has a mobile testing site that travels around the county. It's only available to people who have possible symptoms of the disease. Most of the time the site will be on a fixed bus route so it should be easy to get to. If you can walk up to the site, that's fine. If not, and you're in a vehicle, they'll come to you. Again, we have no information about sign language or other forms of communication accessibility. You'll need an appointment here also; you can register online or call 211. Check them out at: www.gobroomecounty.com/hd/coronavirus

CVS, UHS, and Lourdes/Ascension also all have testing sites; you'll most likely need insurance for them as well as appointments, and you'll need to pass an assessment screening.

Depending on what kind of homecare you have, your doctor may be able to order in-home testing by your worker, who can collect the specimen and deliver it to a local lab for analysis and quick results.

More information on finding test sites is here: https://coronavirus.health.ny.gov/find-test-site-near-you



NY Medicaid Removes Visit Limits

In 2011 the first Medicaid Redesign Team imposed limits on the number of therapy visits (for physical, occupational, and speech therapy) a person could have annually. This was always illegal under federal Medicaid law, which requires that all services available in the state's Medicaid Plan that are deemed medically necessary by an appropriate authority must be provided without arbitrary limits.

After nearly ten years of advocacy the state's Department of Health finally got the message. As of October 1, 2020, there are no more visit caps on these therapies. The number of visits covered will be determined by an assessment of medical necessity.

Congratulations, Medicaid advocates for this big win!

STIC's offices will be closed for the holidays

Thursday, December 24—

Sunday, January 3

We will Reopen

Monday, January 4, 2021

Happy Holidays to All!

STIC
Southern Tier
Independence
Center
Access your world.

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

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

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

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.

❑ Individual	$5	❑ Contributing	$100
❑ Supporting	$25	❑ Complimentary	$________
❑ Patron	$50	❑ Newsletter Subscription	$10/year

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

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

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

THANK YOU!

Southern Tier Independence Center

EXECUTIVE DIRECTOR
Maria Dibble

ASSISTANT DIRECTOR
Jennifer Watson

ACCESSIBILITY SERVICES: Frank Pennisi

ADA SERVICES: Frank Pennisi

BEHAVIORAL CONSULTING:
Yasmin Van Veronica Wallen
Rachel Schwartz

DEAF SERVICES: Heather Shaffer

EC-FACE: Karen Lawrence
Beth Kurkoski Leigh Tiesi

EDUCATION SERVICES: Stephanie Quick

HABILITATION SERVICES: Cathy Sostre
Daniel Schwartz Hannah Hickox
Catherine McNulty Brittany Lynady
Katie Trainor-Leounis Lucretia Hesco
Jacquelyn Granato

HEALTH EXCHANGE NAVIGATORS:
Christy Sodan Joy Stalker
Michelle O'Hare Theresa Askew
Loretta Sayles Chad Eldred
Theresa Kircher Patricia Lanzo
Brittany Pritchard Brittaney Carey

HOUSING SERVICES:
Michael Phillips Kim Kappler

INTERPRETER SERVICES:
Stacy Seachrist

MONEY FOLLOWS THE PERSON:
Krystal Pierre Millien Marcy Donahue
Michael Phillips

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

NY CONNECTS: Amy Friot Eileen O'Brien

PEER COUNSELING: Jane Long
Danny Cullen Robert Deemie
Richard Farruggio Susan Link

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

PSYCHOTHERAPY:
Charlie Kramer Jane Long

SA-FACE: Shannon Smith Tara Ayres

SELF DETERMINATION FI: Rhonda White

SUPPORTED EMPLOYMENT: Brian Roth
Kandi Stevens Michelle Dunda
Rachel Barton Crystal Musshafen

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER:
Belinda Turck Sara Brhel
Ellen Rury Cortney Medovich
Lori Wilmot Valerie Soderstrom

TECHNOLOGY SERVICES:
Jessica Kendricks Sam Robinson