

AccessAbility

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Empty the Warehouses

By Maria Dibble



In this throw-away world in which we live, are human beings included among the old, worn-out items that should be trashed?

This is a question that we must examine in the full light of honesty and truth. We all likely agree 2020 is a pretty awful year, and that's for those who have been fortunate enough not to be touched by COVID-19 directly, or to have lost a treasured loved one. But for the tens of thousands who have experienced such losses, it must be an unimaginable hell. And to add to the burden, many could not be with their loved ones when they passed.

I am talking about people languishing in nursing homes, suffering with fever, cough, and the ravages of the disease, confused and alone. I understand that there may have been no way to allow visitors into the facilities once everyone realized the extent of the spread, but what if they'd realized sooner?

President Trump has taken a lot of flak, including from Governor Cuomo, for not recognizing the disease's impact on the US until it was far too late, criticism with which I agree, but the same could be said of NY and Cuomo, who instead of ensuring that nursing homes had enough Personal Protective Equipment (PPE), and that employees were properly trained in its use, as well as on other disinfecting practices, he put out an order requiring nursing homes to take people back from hospitals, even if they were sick. This gave the virus a foothold into the nursing homes, and

this highly contagious germ took advantage of the opportunity, as it usually does, spreading almost without check. So many people located in one building was a recipe for disaster, and we followed the recipe to the end, resulting in the death of over 6,500 humans, each of whom was someone's mother, father, brother, sister or child. (The NYS Department of Health has denied that Cuomo's order caused the contagion but that claim is not credible; see page 5.)

Meanwhile, the nursing home residents could do nothing to protect themselves, and the families didn't know what was going on behind the walls of the facilities, with officials never answering families' questions, and in some cases outright lying to them. Yet the Governor still continues to say that people who are elderly and/or have disabilities are safer in the nursing homes than they would be in their own homes in the community.

Eight years ago, the *New York Times* and *Poughkeepsie Journal* printed exposés about abuse and neglect of people with developmental disabilities in group homes and developmental centers that seemed to shock everyone. Sadly, I wasn't overly shocked, because I knew then as I know now, that any warehousing of people for whatever reason, including in nursing homes, will inevitably result in a culture of secrecy, leading to cover-ups of neglect, abuse, rape and other crimes that were described in those articles. I was definitely appalled, but not too surprised.

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The very term “warehousing” should evoke an unpleasant picture in our minds. I know it does in mine. I see a bunch of items we don't want or need, stored in a large cold empty building, waiting to be disposed of at the earliest convenience. Is this what we want for the people we know and love?

I have to wonder, when will we decide that we've seen enough neglect and abuse, we've seen enough disposing of people in institutions where they will be “out of sight, out of mind”? When will we decide that it is time to embrace these people as the human beings they are, each contributing or having contributed what they could to our society?

This state and country are in a real fix, most of us know that. But the answer isn't casting away and devaluing the people around us! We need to look at where our resources are going. Should we renovate a stadium, or should we fund a food bank? Should we give tax breaks to huge corporations, or should we fund personal care services? Where are our priorities? I know where mine are, how about you?

AccessAbility

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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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Hands Off Hands-Off Personal Care!

As we reported last time, the state's 2020-21 budget contains major changes to Medicaid personal care services (see *AccessAbility* Summer 2020). Most of those changes were designed by Governor Cuomo's Department of Health (DOH) and some of his cabinet-level officials, in close collaboration with health industry executives. They were sent to Cuomo's rubber-stamp "Medicaid Redesign Team" (MRT), which was controlled by big-time contributors to his political campaigns, for a fake show of public involvement and approval. Then they went on to the state legislature for passage into law.

In order to carry out those changes, DOH must issue new regulations, and also get changes to the Medicaid State Plan approved by the feds. As best we can tell, nothing has been officially sent to the federal Centers for Medicare and Medicaid Services (CMS) for approval. But in July DOH published proposed regulations and requested public comment. We ... er ... gave it to them. Here's what we said, in non-technical terms.

1. You can't ignore people's personal physicians.

The new regulations would prohibit an individual's own treating physician from making the determination that personal care services are needed by that individual. Instead there will be so-called "independent" physicians (actually, working for Maximus, the state's contractual Medicaid managed care broker, at least for the next few years) who will evaluate people and recommend services.

The people on the MRT seem to believe that people's own doctors are biased and will just rubber-stamp whatever they want. We can see why they would think that; after all, that's what they did for Cuomo. It apparently didn't occur to them that some (maybe even most) doctors take professional ethics seriously.

Federal Medicaid law requires that services be based on an objective needs assessment. However, the US Department of Justice (DOJ) issued guidance to states almost ten years ago about this. DOJ said that if a state ignores a treating physician's recommendations for personal care and instead requires a person to enter a segregated setting that s/he doesn't want, the state may be charged with violating the ADA.

2. You can't nickel-and-dime people into nursing "homes."

Some people don't know that New York's personal care regulations have, for decades, required counties to consider cost when deciding to approve people for personal care or CDPA services, and if something else would be less expensive—such as a hospice, assisted living or a nursing facility—for a particular person who needs a lot of hours of service, then they must accept that segregated option. This rarely happens in New York City, which has a long history of providing live-in or 24-7 personal care, and that's where most of the state's influential disability rights activists are. It did happen frequently in many counties upstate until homecare was largely taken over by big managed care organizations (MCOs), which

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.

have seized on the low-cost CDDA program as a way to keep spending down across the state. But a lot of the early downstate media coverage reported people up in arms about this as though it was a new thing.

The proposed regulations tightened up these “cost-effectiveness” rules, added segregated day programs (such as “adult social day care” and PACE managed care) to the list of supposedly cheaper alternatives, and clarified that MCOs must follow the same regulations as counties.

What very few people know is that the DOJ guidance, as well as the US Supreme Court’s famous *Olmstead* decision and other federal court cases that came after it, all say that forcing individuals into segregated settings that they don’t want because it’s cheaper than homecare violates the ADA.

Pound-for-pound, homecare, and especially CDDA, is nearly always less expensive than segregated services. But these individual cost-comparisons are very dependent on specific details, not only how many hours of service a person needs but also what rates are currently paid to the local providers for various types of programs, and which of those programs have openings. STIC’s CDDA program has one of the lowest rates in the state. It may be cheaper for a person to get, say, 18 daily hours of CDDA from STIC than from one of the big for-profit providers in the area, but a local nursing facility may actually charge a daily rate for that person that is less than the highest local 24/7 CDDA rate. Depending on who is able to serve the person soonest, s/he may be able to stay home or may get packed off to an institution. And if that person moves over to, say, the Hudson Valley, her local rate and provider situation may ensure that she stays home. This kind of thing is discriminatory on its face, which is one reason (though not the only one) why DOJ and the federal courts say that a state must take into account *all* the money it spends on long-term care and not just specific rates paid for specific services, and the total amount that can be saved by maximizing use of the most integrated options—including downsizing and closing nursing facilities and transferring the money to homecare—before it decides that personal care or CDDA is too expensive. A state that denies personal care to one person but provides it to another because they live in a different county or have slightly different needs is violating the ADA—and has always done so, long before these proposed regulations were issued.

It’s also violating federal Medicaid law, which requires that when states decide to offer a service to people everywhere in the

state, that service must actually be *equally available and provided* everywhere in the state. (States can get waivers for this rule, but NY doesn’t have one.)

We’re using “homecare,” “personal care” and CDDA interchangeably here because the likely effects of the regulations on them are the same. The state does not pay uniform rates for these services, or for segregated programs for that matter. Rates are individually negotiated by each provider with the state based on actual costs—or, in some cases, indefensibly inflated statements of actual cost. So program costs very much depend on where you live. But since we at *AccessAbility* value honest accounting, we’ll clarify the differences among these programs here.

Homecare – This is a generic term for all forms of paid assistance a person with disabilities can get in their homes or in community locations. In NY, in addition to private-pay homecare, people can get some forms of these services through Medicare, Medicaid, the Veterans Administration and the state Office for Aging.

Personal Care – This is a specific Medicaid service available to people with permanent disabilities in NY, including those who regularly work or do other things in the community. Unlike some other services, Personal Care is “optional”; state Medicaid plans don’t have to include it. Until the new budget passed, NY had two “levels” of Personal Care: Level 1 includes assistance with things like cooking, cleaning, shopping and other errands that don’t involve touching a person’s body. Level 2 is hands-on help with using the toilet, getting in and out of bed, periodic turning in bed (to prevent bed sores), dressing, bathing, and walking. (Correction: Last time we reported that walking was a Level 1 task, but we were wrong; it’s Level 2.) If you needed help with anything on the Level 2 list, you would get Level 1 help automatically, but people could get just Level 1 if that’s all they needed. The new regulations eliminate Level 1-only service, and you must need help with at least three Level 2 tasks to get any Personal Care at all (unless you have dementia; then two tasks are enough). Personal Care can be provided up to 24 hours a day by multiple workers, or by a live-in personal assistant (who must get at least 5 hours of uninterrupted sleep and three one-hour meal breaks daily).

Note: In a special session in July the state Senate passed a bill that would add TBI, visual impairment, cognitive impairment and developmental disability to the list of disabilities that only require two Level 2 tasks to qualify for Personal Care, but the bill did not pass the

Assembly before it adjourned.

Certified Home Health Aides (CHHAs) – This is NY’s name for a Medicaid service that is, unlike Personal Care, not optional; all state Medicaid programs must offer it. However, it is, by definition, “skilled medical” care and involves tasks such as special positioning, range-of-motion exercises, wound care, maintenance of medical equipment and other things that Personal Care attendants aren’t allowed to do. In order to receive it you must also need some type of ongoing medical therapy (such as physical, occupational, or speech therapy or nutritional or “medical social” services). If you are eligible, CHHAs can do Personal Care-type tasks as well though typically they don’t for Medicaid recipients because Personal Care is cheaper. Also it’s part-time only, and it’s not available to people who are able to work or go to school outside the home (though you can get it if you want to spend your time in a segregated day program).

Medicare Home Health Services – These are very similar to CHHA services but are funded by Medicare and must be reauthorized by a physician every 30 days. People who aren’t eligible for Medicaid but have Medicare are the most common users of this service. Lately it’s being promoted by advocates as an alternative form of homecare, but it’s really not comparable because it’s not available to people who want to be active in the community.

Private Duty Nursing – NY Medicaid funds this service, which provides medication administration, including injections and infusions, complex wound care, periodic medical evaluations, and other things that require nursing expertise. Services are brief in duration and not necessarily daily.

CDDA – Consumer Directed Personal Assistance services are considered a type of Personal Care in NY. They are largely funded by Medicaid but the federal Veterans Administration and the NYS Office for Aging have some limited funding available for people who don’t have Medicaid. It’s not available for private pay. It can be provided up to 24/7, or as a live-in service. CDDA personal assistants (PAs) can do anything Personal Care attendants and CHHAs can do, and some things Private Duty Nurses can do. No education, certifications, or formal training in how to do those things are required; instead the consumer trains them in how s/he wants things done. Consumers also hire, schedule, supervise, and fire their own PAs, and anyone who does not have custodial or financial responsibility for the consumer can be hired. Consumers are assisted in managing the program by a Fiscal Intermediary (like STIC). If

a consumer is not able to handle the responsibilities involved (is not “self directing”), then s/he can appoint a Designated Representative to do it for him or her. All of this is provided for one low rate, which is why CDPA is usually the least expensive form of home care; the other types all charge higher rates. As we’ve said, though, there are outliers.

3. Medicaid managed care must have person centered planning and community-based settings.

A few years ago CMS released new regulations for Medicaid managed care. Those regs say that all forms of long-term care (whether segregated or community-based) must be provided only if required by a genuine person-centered plan. The person being served must control the planning as much as possible and be able to include anyone they want. Medical evaluations are only one part of making the plan; the person’s wishes and goals are just as important, and the process is intended to help them achieve those goals, not thwart them. The person must agree to the plan or it can’t be carried out, and the person must also be given free choice of where to live.

The new regulations describe a home care planning process almost completely controlled by doctors and nurses, and only those “others” the doctor wants to involve, and the medical evaluation is the primary determinant of the service plan. The individual does not control the process and their choice of where to live can be overridden. This is an obvious violation of federal regulations.

For community-based long-term care, the managed care regs include requirements that services only be provided in the person’s own home or locations that meet the definition of “community based.” The definition is flexible, but the person must have substantial ongoing involvement with non-disabled community members who are not paid to work with them, and their autonomy to come and go and make decisions must be restricted as little as possible. Locations where services are provided must be free of “institutional characteristics,” including isolation from the community and physical environments similar to those of hospitals or nursing facilities.

Many if not most “day programs”, and assisted living and other adult care residential facilities, funded by Medicaid in NY don’t pass the institutional smell test and would not be legal places to spend Medicaid managed care funds earmarked for community-based services.

4. This will actually cost the state more money, not less.

There are two factors here: First, federal law requires all state Medicaid plans to pay for nursing facilities, but does not require personal care. Second, the new regulations block people with certain types of needs from getting any form of personal care, period, before the “cost effectiveness” step is taken. That means that people who only need help with, say, walking safely can never get personal care of any kind. But since not being able to walk safely without help can get them admitted to a nursing home, that’s most likely where they will end up, at considerably higher cost than the state would have paid for their personal care if it hadn’t been so irrationally bull-headed about cutting that particular program.

Also, there’s nothing stopping a nursing facility resident from leaving that place on a daily basis to go to work or school, but if you want to do that while living at home you can’t get CHHA services even though there is currently no arbitrary minimum task assistance requirement for those. So if the new rule doesn’t put you in a nursing home, it may well cost you your job.

Wait, you’re probably saying, not being able to walk is enough to get into a nursing home? What about wheelchairs? What about ramps? What about family members?

Ultimately the determinant for nursing home admission is: can this person take care of herself and all of her health needs alone? If not, then she can be admitted. Wheelchairs are only useful in environments that are accessible to them. Lots of people with limited walking ability have wheelchairs that they can’t use everywhere in their homes because their bathrooms, kitchens, and entrances aren’t accessible. Certain types of Medicaid waivers will pay for some accessibility improvements, but many people who only need personal care don’t qualify for those waivers, which are usually intended for more significant disabilities.

Also, suppose you only need what used to be a Level 1 service—help with shopping, cooking, and other errands. Now you can’t get that help. What’s going to happen to you? Where will you get your food or clothes or household paper products? Okay, you can do all that online now, right? Not so much. Is the plan to have these people eat nothing but delivered meals from now on? Where’s the online laundry? Oh, you can probably hire some Uber-equivalent service to do your laundry for you—but how will you pay for it? Remember, these people are on Medicaid; by definition they are mostly very poor. And people who can’t maintain a balanced diet or clean bedding will end up in nursing homes, sooner or later.

As for help from family, a lot of these people are elderly and they have no local family to

help them. Family members have to work and get paid in order to avoid becoming dependent on government programs themselves. There are tens of thousands of “unpaid caregivers” who have had to quit their jobs or go part-time in order to take care of disabled relatives already in NY. Would we rather give them food stamps and welfare and HEAP assistance so they can do that, instead of simply paying for home care? Maybe our leaders would; after all, those things are all federal money, and they’re trying to cut state spending instead of raising taxes on the rich people who pay for their campaigns. But do you, as an ordinary not-rich taxpayer, really care which pocket they take your money out of? It all comes from you eventually.

5. You can’t discriminate on the basis of disability... period.

That should be obvious, it’s what the ADA is all about. If states provide services aimed at people with disabilities at all, they must provide them in the most integrated settings appropriate to their needs and wishes.

For example: two groups of people with disabilities need support services to survive and prefer to get them in their own homes. Both groups will end up in nursing facilities if they can’t get them there. New York says to one group: you can get home care and stay in the community, and to the other group says, don’t bother asking for home care; go to the nursing home. Perversely, the second group actually needs less home care than the first group, but it does need home care.

That’s just flat-out illegal discrimination. Not hard for anybody except Cuomo and his financial backers and the right-wing media to understand. But to make sure they get the point, we made it very clear in our comments that they will undergo a flood of federal civil rights complaints and lawsuits like they have never seen if they try to put these regulations into effect.

And they will eventually lose, but as we’ve said before, that doesn’t matter, because the flow of money will have been temporarily slowed down, and won’t have to be repaid, and that’s all they care about, because that’s all the rich people whose pocketbooks they are protecting care about. Until it becomes a criminal act, leading to expulsion from public office and fines or jail time, to deliberately and knowingly violate Medicaid law and the ADA, this stuff will continue.

None of these changes can take effect until at least January 1 of next year, because the Medicaid “maintenance of effort” requirement on states that take the extra federal COVID help

was extended another three months, along with the national pandemic emergency, by the US Secretary of Health and Human Services.

DOH has also so far not responded to comments it received on its destructive plan for a per-member-per-month payment system for CDDPA fiscal intermediaries (FIs) like STIC, and it has continuously delayed announcing the winners in its competition for CDDPA FI contracts. No news is good news in those cases, but eventually there will be news, and we'll report it.

Institutional Death and Destruction Continues

Part 1: The Nursing Home Saga

In mid-August the national media reported that roughly 40% of people who have died from COVID-19 nationwide were in "nursing facilities." It's not clear whether this means they all died in those facilities or if it includes those who contracted the illness there and died in a hospital.

A major focus of hearings conducted in August by the Democrats who run the NY State legislature was on that question. The state's Department of Health (DOH) has reported that about 6200 New Yorkers were either known to have, or presumed to have, died of COVID-19 in nursing facilities between March 1 and early August. (On August 11 the *ProPublica* website said that figure was over 6500.) On August 17, the state's fatality total was about 25,200. That makes NY's nursing home death rate about 26%, much lower than the national one. However, DOH Commissioner Howard Zucker repeatedly refused demands to provide data on how many people contracted the disease in nursing facilities and then died of it in hospitals.

(We, like most media, are using "nursing facilities" to include assisted living facilities and other "adult care homes" not specifically for people with developmental or mental health disabilities; for those groups, see below.)

Zucker's behavior is actually rather new. Early on in the pandemic, NY's reports of nursing facility COVID deaths included people who died in hospitals. But in April, as the nursing home death rate skyrocketed, Cuomo stopped counting those deaths, claiming he was worried about people being counted twice. In August Zucker told the legislature he won't release those numbers until he's sure they're accurate.

Most of the news stories we've seen indicate that only NY and a handful of other states

don't report those numbers. One story said that if those states are excluded from the count, then a whopping 70% of US COVID-19 deaths in the other states are nursing-facility related. Extrapolating the non-reporting states back in, the national percentage is probably around 60%.

There are some clues as to what NY's actual nursing-facility-related rate could be on the DOH COVID-19 tracker website (<https://covid19tracker.health.ny.gov/views/NYS-COVID19-Tracker/NYSDOHCOVID-19Tracker-Fatalities?%3Aembed=yes&%3Atoolbar=no&%3Atabs=n>):

Fully 85% of New Yorkers who have died from the disease were age 60 or older. 90% of all those who died in the state had "co-morbidities," the top three being high blood pressure, diabetes, and high cholesterol.

In August 6500 deaths represented about 6% of NY's total nursing facility population according to *ProPublica*. According to *Kaiser Health News*, in 2019 NY had almost 90,000 people in "certified nursing facilities." We've been unable to get a total for people in "adult care facilities," which doesn't include nursing homes, but we are guesstimating that to be about 15,000. So about one-half of one percent of New Yorkers live in nursing or adult care facilities. Most, but not all, of them are elderly. According to DOH, about half any given time are not permanent residents; they are there for post-acute rehab following a hospital stay. Such stays didn't start out to be permanent, but many definitely ended that way.

It's difficult to get accurate data about this stuff. As we reported last time, in late March Cuomo issued an executive order forbidding nursing facilities to reject transfers of people with COVID-19 from hospitals. Following devastating media coverage about the rising nursing home death toll, a growing number of public officials and activists began demanding more accountability for the role his order played in the disaster. He has consistently claimed this was partisan politics, but criticism has come from both Democrats and Republicans from the beginning.

In July DOH released a report that argued the order played no role. A high percentage of COVID-19 cases, perhaps as many as 40% according to some sources, are transmitted by people who show no symptoms, and DOH said most of the cases were caused by infected nursing home staff who unknowingly brought the virus to work. DOH claimed the proof is that the nursing home COVID death rate peaked a week before the rate of transfers from hospitals did. But the report's death rate did not include that all-important number of

people who got the disease in a nursing home but died in a hospital. In mid-June *ProPublica* reported a clear nationwide trend: NY was not the only state with such an executive order. Other states with similar orders had similar or higher nursing facility death rates: In Michigan, 5% of nursing facility residents had died of COVID-19 up to that point; in New Jersey it was 12%. But in Florida, which prohibited transfers of coronavirus patients from hospitals to nursing facilities from the outset, the COVID death rate in those facilities was just 1.6%, and California, which began by encouraging transfers but quickly reversed course, by mid-June had a 2% nursing facility death rate. In NY, the Rensselaer County Executive, a Republican who has pugnaciously attacked Cuomo at every opportunity, pointed out that because he defied Cuomo's order and would not permit the transfer of COVID patients to the county nursing home, nobody had died of the disease there, while privately-owned facilities in the county that followed the order had many deaths.

According to *ProPublica*, the DOH report said that the "vast majority of the roughly 310 homes that accepted those [COVID hospital] patients had already had a case of COVID-19 among their staff members or residents." But the report also said that 58 nursing facilities had no COVID-19 sufferers before they accepted transfers. After the report came under multiple attacks from public health experts, DOH suddenly said that figure was in error, and only 6 facilities had no COVID prior to hospital transfers. *ProPublica* said, "The department would not answer an array of questions about how and why it had changed the data in its report, one it had used to defend its controversial policy. It would not say how what it had called a peer-reviewed study had relied on erroneous or incomplete data; it would not say how the new information had come to light."

The report was blasted at the August legislative hearings. We can't say it better than *ProPublica* did on August 11:

"Addressing Zucker in one exchange, State Senate Investigations Committee Chair James Skoufis ... said: 'It's my opinion that your administration's definition truly misrepresents the scale of this crisis as a result. So let's try and get the full picture here and now: How many of New York's nursing home residents died in hospitals?'"

Zucker insisted the state couldn't say because it didn't yet have a fully accurate count. 'You don't have a ballpark that you can give? So the total official number is about 6,500. Are we talking with the hospital deaths: 8,000?'

10,000? 15,000? What are we looking at?' Skoufis countered.

'I'm not prepared to give you a specific number. We are in the middle of a pandemic obviously, we always forget about that sometimes,' Zucker said. 'We are looking at all the numbers, we are looking at the data, when the data comes in and I have an opportunity to piece through that, then I will be happy to provide that data to you and to the other members of the committee.'

State Senate Health Committee Chairman Gustavo Rivera ... suggested a final count wasn't needed to see what the administration was doing. 'It seems, sir, that in this case you are choosing to define it differently so you can look better,' he said. 'That is a problem, bro.'

ProPublica asked [DOH] if it had ever excluded fatalities of residents transferred to hospitals in counting deaths of nursing homes residents during outbreaks of the flu or other infectious diseases. The state did not directly respond but said in a statement, 'This is a global pandemic, the likes of which we have never seen before. There is no precedent.'

Elaine Healy, acting president of the New York Medical Directors Association, said it shouldn't be hard for the state to have an accurate count of how many nursing home residents died of COVID-19 in hospitals. They'd counted these deaths in the nursing home totals early on, she said, and 'the numbers would be quite easy to get from the hospitals.'"

DOH was hard-hit at the outset of the pandemic. But the bureaucrats who work there don't provide medical care or run hospitals and nursing homes. Their job is to analyze healthcare needs and plan how to address them. It's hard to see how, even in an unprecedented pandemic, they could be facing any task more important than getting accurate data about what's going on.

Meanwhile, other ugly facts remain undisputed: Prior to the pandemic about 82% of nursing facilities nationwide had been dinged by inspectors for poor infection-control practices; "about half had multiple citations," according to an August article at *The Nation* website (we reported similar numbers in June). During the pandemic many facilities had difficulty obtaining PPE (masks, gloves, gowns and other equipment to prevent disease transmission), yet were previously required by federal regulations to have plans in place to address potential pandemics (including, presumably, stockpiling PPE) and they just ... didn't ... do it. Now they're on a frenzied national tear, demanding immunity

from lawsuits for negligence and claiming none of this is their fault. They got US Senate Majority Leader Mitch McConnell to demand a grant of immunity in exchange for financial aid for medical providers, laid-off workers, schools and state governments, and President Trump has indicated he's on board. In NY, the 2020-21 budget granted immunity to nursing facilities, hospitals and other providers against most types of lawsuits concerning care provided to *any patients*, not just COVID-19, during the pandemic.

It's been difficult to avoid the conclusion that the main thrust of Cuomo's and DOH's responses to criticism over the summer has been to defend nursing home administrators and owners, who are big campaign contributors, at all costs.

The August legislative hearings (two staged by Democrat-run Assembly and Senate committees, and an "alternative" hearing run by the Republican minority) have scorched Cuomo and Zucker in lively theatrical moments, and have provided an outlet for many rightfully aggrieved family members demanding answers for the deaths of their loved ones. But we are under no illusions. New York State legislators take plenty of campaign money from the same hospital and nursing facility lobbyists that fund Cuomo. Those Democratic committee chairs could have subpoenaed Zucker to provide the numbers they so stridently demanded on camera—but they didn't. They knew when they went into the room Zucker wasn't going to provide them, and the Democrats don't really want them. If they did, they'd subpoena them. These are the same people who voted for the lawsuit immunity back in March. They subsequently passed a bill, which Cuomo signed, that removed immunity for non-COVID patients, but that's of course not the big issue here, is it?

The Republicans pointed all this out at their grandstanding little hearing later in the month (which included a few token Democrats, none in leadership positions), and they demanded that the Democrats subpoena Zucker. But we are absolutely certain that if NY had a Republican governor and that party controlled both houses of the legislature, they would not subpoena Zucker either, nor would they cancel the COVID-19 lawsuit immunity, or pass any other laws that might seriously inconvenience the nursing facilities and hospitals that pay for their campaigns. In terms of losses in campaign contributions, talk is cheap. Very very cheap.

Part 2: A Sad Sideshow

In June NPR reported a startling statistic. Nationwide, only about 6% of people age 65 or

older live in congregate settings, even though most people seem to think that's where old people should go. According to 2019 US Census data, about 17% of New Yorkers are 65 or older. That's about 3.3 million people. 6% of that is almost 200,000, so in NY only about 3% of seniors are in those places.

But the same NPR story reported that between 13% and 20% of people with developmental disabilities live in congregate settings, mostly group "homes" and some larger institutions. NPR might be the only mainstream national news outlet where you'd even hear about that. That's because they have Joseph Shapiro, the journalist who wrote *No Pity*, the acclaimed history of the independent living and disability rights movement, back in 1994, and who has been specializing in disability news ever since. It's hard to find comparable numbers for NY, but the last time we checked, a couple years ago, OPWDD was reporting that about 21% of the people it serves were in congregate residential settings. There are, of course, people with developmental disabilities who don't get OPWDD services, including seniors living in nursing or adult care facilities, and probably a pretty big number in OMH facilities since about 40% of people with developmental disabilities have co-occurring mental health conditions.

The take-away from those numbers is that, while NY may be fairly good about enabling seniors with disabilities to live at home, it's worse than most other states about doing the same for people with developmental disabilities.

And that's bad, not just on philosophical integration vs "protection" grounds; it's a life-or-death issue. Shapiro reported that New Yorkers with developmental disabilities die at about "2.5 times the rate of others that contract the virus." In fact, they're about 4 times more likely to get COVID-19 than other Americans. It's true that lots of developmental disabilities come with "co-morbidities," especially respiratory conditions, that make death more likely for people who get the disease. But the reason they're much more likely to get it in the first place is because so many of them live in group homes. Shapiro spoke to Scott Landes, a Syracuse University professor who's been researching the issue. As NPR reported, "You reside with multiple roommates, with staff coming in and out," says Landes, "your chances of actually contracting COVID are high. And then if someone in your home gets it, it's like there's nowhere you can go."

Part 3: Why?

Why is it that with a growing number of New Yorkers up in arms about the nursing home fiasco, we are hearing almost nothing about

group home deaths? It's been said that western society is a "throw-away" culture that discards its elders along with its trash, hauling them away to nursing homes to waste away alone. There is truth to that; America devalues caregiving in general, refusing to spend enough money to provide a living wage to homecare workers which, according to *The Nation*, leads two-thirds of them to quit their jobs every year. But people don't usually throw themselves away; they get tossed by others. That article also reported that a 2018 AARP survey found that about 75% of people over the age of 50 do not want to live in nursing homes. It looks like the older they get, the more of them become sure about that, since by age 65 only 6% of them are in those places. The key, perhaps, is that most of them make their own decisions and choose where to live. That's largely not true for people with developmental disabilities, even though at least 90% of them can learn to make sound choices with a little help. Most of those who live in group homes are put there by their families. We're sure many of those same families are among those upset by the deaths of loved ones in nursing facilities. But it's much easier to rage in the media at politicians because choices others made went bad; it's a lot harder to accept personal responsibility for making choices that harm or kill your loved ones.

The Nation raised the question: if 75% of older Americans don't want to end up in nursing homes, why do those places get 75% of the money we spend on long-term care for senior citizens? The answers are, of course, predictable: Nursing homes have powerful lobbies, as do unions that don't like homecare because they don't have much of a presence in that industry.

Most of that money comes from taxpayers, who foot the bill for Medicare and Medicaid. For decades disability advocates have been trying to deliver the message that taxpayers will get more bang for their buck if the funds are diverted from segregated to integrated services. That won't be enough, of course. The wealthiest taxpayers will have to pay more, not just in the short term to combat the most serious public health and economic crisis we've faced since the early 20th century, but far into the future if we are to meet our moral obligations to our rapidly growing elderly population. No one likes to be seen publicly benefitting from a crisis, but that old saying, "Tis an ill wind that blows nobody good" may never have been more apt than now. This moment may mark a turning point in the public consciousness, where we finally realize that nobody really wants these places, and it's time to shut them down.

Black Lives Matter — and Many of Them are Disabled Lives

By Ken Dibble

We at STIC fully support the aims of people of color across the nation to bring sustained attention to systemic racism and its effects on the lives of our citizens. "Black Lives Matter" does not mean that other lives do not matter. Maybe this would be clearer if the movement was called "Black Lives Matter, Too", but maybe not. The fact is that black lives have not mattered to most Americans enough to bring change, not only to the imperious behavior of the police, but to all of the other systems and circumstances that continue to keep people of color down. "Black Lives Matter" means not only that "attention must be paid," but that definitive action must be taken, and things must not "get back to normal" until some very big and permanent changes are in place. Until then a lot of us may be fairly uncomfortable, and that's just fine with us.

As a white Anglo-Saxon male who grew up in a privileged middle-class household, I'm aware of the pitfalls of asserting myself much here. But I would like to point out some important facts. They may not be new to some of our most thoughtful and perceptive disability rights or black leaders, but I don't think many of those leaders think explicitly about the role disability has played in all of this. And STIC happens to sit in a very white part of upstate NY. Most of the people around here never have a personal reason to think about these issues, but their tax dollars are needed as much as anybody else's if we are going to make real, permanent change.

Here's the thing: Whether we're talking about people with disabilities or people of color, we are, to a great extent, talking about the same people.

In 2018 the Brookings Institution published a study about this. You can read it here: <https://www.brookings.edu/blog/the-avenue/2018/05/15/disability-rates-among-working-age-adults-are-shaped-by-race-place-and-education/>. I'll just highlight some points.

They use the Centers for Disease Control (CDC) definition of "disability": "Disability is any condition of the body or mind that makes it more difficult for the person with the condi-

tion to do certain activities and interact with the world around them. The onset of disability can also take many forms: it may present itself at birth, stem from an accident or injury, or result from a long-standing condition or disease, among other causes."

The study focused on people of working age, which, while somewhat limiting, removes the skew toward elderly people from the equation. Brookings found that "At the national level, Native Americans have the highest disability rate among working-age adults (16 percent), followed by blacks (11 percent), whites (9 percent), Hispanics (7 percent), and Asians (4 percent)."

I don't want to needlessly perpetuate stereotypes. People of color at all income and education levels, no matter how important or influential their work is, constantly experience racism. A black Congressperson may be less likely than a guy who works in a convenience store to be pulled over and hassled by the police for nothing more than "driving while black," but s/he is still much more likely to experience that outrage than any of his or her white colleagues. Many of you may know who Henry Louis Gates is—he's the PBS "Finding Your Roots" guy. He is also a distinguished Harvard professor, historian, and producer of TV films. At the outset of the Obama Administration, Gates arrived in a cab at his home in Cambridge, MA after a trip to China and found that his door lock was jammed. The cab driver was helping him try to pry the door open when a passerby called the police. Gates got inside and called the Harvard housing people to have them fix the door. Then a cop showed up and demanded that Gates prove it was his house. Gates let him inside and showed him his Harvard ID and his driver's license with the address. The cop was persistently rude and Gates repeatedly asked him for his name and badge number, which the cop refused to provide. Gates followed him out to the porch, demanding his name and badge number, and the cop arrested him, handcuffed him, and hauled him to the police station where he was held for four hours. Gates went public with the story, which eventually resulted in President Obama inviting both Gates and the

cop to the White House to have a beer and talk it over. Obama did say he thought the cop had behaved “stupidly.” But then and now, many people of color have felt that merely “talking it over” for better “understanding” is a pretty poor substitute for actually moving the money to ensure that things really change.

That’s what “defund the police” really means. And I agree with those who think that’s a bad slogan. Nobody believes we can get along entirely without police. But much of the trouble the police are asked to deal with does not actually involve violent crime, and often it doesn’t involve crime at all. That means we don’t need people with guns showing up most of the time when people are having a problem. The police are the “first responders,” but they really should be the “last responders,” when everything else has failed. To make that work we need to take away a lot of the money the police get, and especially the funds they get for paramilitary assault vehicles, machine guns, and riot gear, so we can direct it toward people who actually know how to help people in crisis without hurting them. We need to take even more of the money and put it into programs we know can keep people from reaching the crisis stage. When we do that, we put the police in their proper place, which is to deal with a limited number of the most dangerous situations and to investigate real crimes. And we also take away the money from their unions and lobbyists—the money that makes them powerful and influential enough to control public policy on this issue. That absolutely has to happen if we really want police violence and abuse to end.

But it’s not just about the police. The COVID-19 pandemic has brought to light the effects of systemic racism on the health of people of color. Through August 18, 2020, according to APM Research Lab, 88.4 black people per 100,000 have died of this disease in the United States. For native Americans, the number is 73.2; for Pacific islanders it’s 63.9; for Hispanics, 54.4; and for white people, it’s 40.4 deaths per 100,000 population.

So while people of color don’t have to be poor, uneducated, or living in the inner city to experience frequent racist abuse, we do have to point out that disability and poverty correlate closely, as do disability and lack of education, and both of those disadvantages also correlate to race. According to the US Census, the median household income for all races in the United States in 2017 was just over \$61,000. In that year the number was just over \$68,000 for non-Hispanic white people, while for Hispanics it was about \$50,400 and for black Americans, about \$40,250. Just two years earlier

the Census reported that the median income for Americans with disabilities was \$20,250. National Center for Education Statistics data for 2016 showed Hispanics with the lowest high school completion rate at 67%. Native Americans came next, at 83%. 85% of blacks completed high school in 2016, while 92% of whites did so. In 2015 the Census Bureau reported that almost 33% of white non-Hispanic Americans had at least a bachelor’s degree; the figure for black Americans was 22.5%, and for Hispanics of any race, 15.5%. 16.7% of Americans with disabilities of any race had bachelor’s degrees in that year. According to the CDC, about 20% of white Americans of all ages have a disability, while that figure is 25% for blacks, 30% for native Americans, and about 17% for Hispanics.

The interaction between disability, poverty and low educational achievement is not one way, and that is also true for other minority groups. Poor people are more likely to live in environments where extensive air, water and ground pollution cause health problems, and/or in so-called “food deserts” where good nutrition is not readily available, and they are more likely to be victims of violent crimes. These conditions can cause permanent disabilities acquired either congenitally or later in life. Once you have a disability, the likelihood of getting a job that pays enough to get you out of poverty is very low; the actual unemployment rate for working adults with disabilities is 60%. Many people with disabilities don’t believe they can work and are not trying to. But many others have experienced employment discrimination, and/or lack access to reliable transportation or an adequate education—the same roadblocks to employment that racial and ethnic minorities experience. People of color with disabilities, of course, get a double whammy from job discrimination. But even when disabled people get a lot of extra help to find and keep jobs, the jobs typically are part-time, minimum wage positions that don’t lift them out of poverty.

The current round of highly public activism against racism began with the murder of George Floyd, a black man, by a Minneapolis police officer. His autopsy indicated he had been using fentanyl and methamphetamine. If that’s true (it wouldn’t be the first time a coroner lied to protect the police), there’s no evidence those were legal prescriptions, but also no evidence that using those substances permanently affected his ability to do important life things, or that they impaired his judgment at the time of his death. Nobody deserves to die because they illegally use drugs. But substance “abuse”—that is, use of any drug, legal or not, in a manner

that reduces a person’s ability to function in important ways, is a disability. Even some disability activists don’t want to recognize that. Most people who abuse substances are self-medicating due to psychological trauma or mental illness, which are also disabilities. Trauma is more likely among people who are impoverished, and black Americans experience post-traumatic stress syndrome at a somewhat higher rate than white Americans (8.7% vs 7%). The *Journal of the American Psychiatric Association* reported in 2019 that racism can itself be traumatizing.

In America, more white people are killed by police than any other racial/ethnic group, only because most Americans are white. As reported by *US News & World Report*, “More than 1,000 unarmed people died as a result of police harm between 2013 and 2019 ... About a third of them were black. About 17% of the black people who died as a result of police harm were unarmed, a larger share than any other racial group and about 1.3 times more than the average of 13%.” Of course, many more people harmed by police violence survive. Police violence is itself a significant cause of disability, especially among black people.

As we reported a few years ago (*AccessAbility* Summer 2016), good data is hard to find, but various sources estimate that between one third and one half of people killed by police have disabilities. That includes many of the black victims we’ve heard about over the years, such as Eric Garner, Sandra Bland and Freddie Gray. The media rarely reports that aspect of these killings, and when it does it’s often not until much later, after public attention has gone away.

Then there’s our jails and prisons. Although the racial disparities in those places have actually been shrinking over the last decade (perhaps due to efforts to legalize marijuana and end incarceration or shorten sentences for minor drug crimes), still a far larger percentage of jail and prison populations is people of color than their percentage of the population as a whole. In 2017, the Pew Research Center reported about 13% of Americans overall were black, but they were 33% of the sentenced prison population. Hispanics were 16% of Americans but 23% of prison inmates. Whites, who make up 64% of US adults, were 30% of prisoners. It’s harder to get good data on the percentage of people with disabilities in jails and prisons, because different sources don’t agree on the definition of “disability.” But according to the Bureau of Justice Statistics, in a survey conducted in 2011-2012, about 40% of prison and jail inmates had disabilities. For decades,

the United States has been using jails and prisons as a substitute for support services for people with mental health, cognitive, intellectual, and substance use disabilities.

We should emphasize here that Americans of color are far more likely to be wrongfully convicted of crimes than white people, and far more likely to be jailed while awaiting trial because bail amounts are set higher for them, making them less likely to be able to afford bail. As a result, a very large percentage of innocent black people accept a plea bargain to get a shorter sentence, since without bail they may spend months or years locked up awaiting trial. You can get details from this University of Michigan report: http://www.law.umich.edu/special/exoneration/Documents/Race_and_Wrongful_Convictions.pdf. So, a lot of people of color sitting in jails and prisons have not actually committed a crime.

A significant amount of “crime” in the United States is actually the nonviolent, usually self-destructive, behavior of impoverished people of color whose disabilities, which resulted largely from the social and public health effects of pernicious racism, impair their ability to make good decisions. Imagine what would happen if tens of billions of dollars were taken away from the police and used to support low-income housing for homeless people (in mixed-income developments, not poverty ghettos), follow-along support for people with mental illness, and drug rehab for those with substance issues.

As we reported recently (*AccessAbility* Fall 2019), that very thing has happened in Los Angeles, where activists succeeded in getting a multi-billion-dollar plan to build a new jail cancelled and the funds diverted to various social services. It could be happening everywhere.

That is, it could be as long as people of color keep the pressure on, in the media and in the

streets. STIC applauds and supports these efforts and their leadership, on behalf of all of us.

ADA is Thirty!

On July 26, 1990, President George H.W. Bush signed the Americans with Disabilities Act (ADA) into law.

The law itself is similar to other federal civil rights legislation enacted earlier in our history. As the activists of ADAPT have pointed out, it enables people with disabilities “to boldly go where everyone else has gone before.” And yet it is fundamentally different from other civil rights legislation because it requires people to submit proof that they “qualify” for protection, and because it sorta-kinda requires organizations to spend money to improve their physical or program accessibility to people with disabilities in ways that can be hard to clearly define.

Nevertheless, it’s those required changes in accessibility that have been the ADA’s greatest legacy. Although it was a struggle, early on, to get the word out and convince organizations to make those changes, all around us now we can see the results: curb cuts, elevators, wider doorways, stepless entrances, accessible restrooms and buses, braille signage, sign language interpreters, and more.

Many of the unfinished tasks that remain are fundamentally the same as those that have not been resolved by those earlier laws: Bigotry employed in sneaky ways to deny jobs and homes, and unfair distribution of school funding to ensure unequal educational results. Add in another form of prejudice exclusive to people with disabilities: Taking advantage of isolation to keep people from finding out about their rights to be fully integrated into society and no longer denied autonomy and

freedom of choice in the name of “safety,” or merely because the operators of segregated facilities have lots of money to shower on political campaigns.

Then too, there has been backlash. We’ve had to beat back attempts to hollow out the enforcement provisions of the ADA, and more recently the nursing home lobby seems intent on clawing bodies back from the community and into their institutions, with the help of their well-paid political servants in Albany and elsewhere.

All around the country, and despite the pandemic, celebrations of this anniversary were held. We at STIC created a commemorative video, which you can see on our website at www.stic-cil.org.

To see more celebrations and learn more about the ADA, visit: www.adaanniversary.org.

Happy Birthday!



courts watch

New York vs Homeland Security: Viruses Don't Obey Court Orders

This case relates directly to one we’ve covered here before, *Washington v US Dept. of Homeland Security* (see *AccessAbility* Winter 2019-20). It may in some sense be the same case, as many of the myriad cases filed to stop the Trump Administration’s new anti-immigration “Public Charge” rule were combined and considered as one by the courts.

Various plaintiffs, including state governments and immigrants’ and disability rights organi-

zations, sued the US Department of Homeland Security in the federal District Court for Southern NY to block the rule which, among other things, deems people with disabilities as potentially undesirable immigrants and can, under some circumstances, prevent them from coming into the country. It specifically cites dependence on Medicaid as a bad thing, and many people with disabilities have a lifelong dependence on Medicaid because it is the only insurance that pays for permanent long-term services and supports. The suit wasn’t just

about disabled immigrants, but it did argue that Section 504 of the federal Rehabilitation Act bars federal agencies from discriminating against people solely on the basis of disability.

In October 2019 the New York judge ruled for the plaintiffs and issued a preliminary injunction blocking the rule from taking effect nationwide. The defendants appealed to the Second Circuit Court of Appeals, which also approved the injunction. Homeland Security then took it to the US Supreme Court, which lifted the injunction on January 27, 2020

without ruling on the merits of the case. Reporting on the case has been confusing, and we can't find the Supremes' majority opinion; we've only seen Justice Gorsuch's concurring opinion which mostly emphasizes his opposition to the widespread practice of district judges issuing nationwide injunctions. The NY district judge, in his decision on July 29, 2020, says the majority did not explain very much at all; it just stayed the injunction. The case is not settled; the arguing thus far has mostly only been about whether an injunction prior to actually trying the case is justified.

Then came the pandemic. The plaintiffs went back to the district court for a new injunction citing new circumstances. Among various harms the rule is causing in relation to the pandemic, perhaps the most potentially disastrous one is this: Immigrants make up a very large percentage of essential workers, including not only personal care assistants and nursing facility aides, but also restaurant and food service workers, and cleaners in hospitals and elsewhere. The rule has had a chilling effect on immigrants who could apply for Medicaid, or even without Medicaid obtain free COVID-19 testing. They are refusing to do those things for fear of being identified and deported. It's quite true that documented immigrants of all types—not just those with green cards—cannot legally be deported summarily, but the federal Immigrations and Customs Enforcement bureau (ICE) is well known to detain (and abuse or neglect), and even try to deport people without legal justification at times. So Trump's Public Charge rule is having the very real and dangerous effect of increasing the chances that the people who provide the most intimate and vital personal services may transmit the disease to the people they serve.

The feds responded that they've released "guidance" stating that the rule will temporarily not apply to people who need medical

services due to COVID-19. But the guidance actually says that only people who apply for Medicaid solely for that purpose, and who disenroll from Medicaid as soon as they no longer need those services, will be exempted. There is no way, in a Medicaid application, to indicate that you're only asking for COVID-19 stuff; no way to prevent a person, once s/he has Medicaid, from using it for other services equally important to public health, such as treatment for the flu and other infectious diseases or for chronic conditions, such as diabetes, that make serious symptoms or death from COVID-19 more likely; and "no longer need" is a very vague judgment call; after all, this disease is likely to be present among humans for decades if not centuries, and ongoing services may very well be required to stay healthy.

Homeland Security said it's too bad that those fearful immigrants are mistaken, but the federal government can't be held responsible for that. The Public Charge rule only applies to people who have requested permanent residency status but have not yet been approved. Hold your horses, said the judge. In 2019 the Supreme Court "recognized injury where the plaintiff's harms are based on the 'predictable effect of Government action in the decisions of third parties,' even if such decisions are 'motivated by unfounded fears.' Here, such decisions are more than predictable, they are already occurring."

The judge, in his decision granting the new nationwide injunction, also took care to insulate himself against attacks from Gorsuch and his supporters. He pointed out that the damage caused by the rule cannot possibly be limited to the region his court covers, because no one can control where documented immigrants go once they enter the country, and no one can keep the virus from leaving his jurisdiction once an immigrant transmits it there. The only injunction that could truly address the problem is a national one.

So now another round of appeals will begin. Stay tuned.

Watch Out for For-Profit COVID Testing

The federal government has provided a lot of money for free COVID-19 testing. It's covered by Medicare and Medicaid, and various state and federal emergency regulations require most private medical insurance plans to pay for it. Just about everybody who needs testing should be able to get it, eventually, without paying for it.

"Eventually" is a key word. It may no longer be necessary to get a doctor to order it for you, but you will have to make an appointment to get a free test, even for the drive-up services. Even with an appointment you can wait in long lines for your test. This may be why some people have been going to for-profit walk-in centers for tests. **BEWARE!**

The feds have provided billions in federal grants to for-profit medical providers to address the pandemic. But those companies are **NOT** required to provide tests for free; they are just "encouraged" to do so. We know what that kind of encouragement is worth, don't we?

So if you go to one of these places and you don't have medical insurance, they will demand an up-front cash payment of anywhere from \$75 to \$200 before they will test you. You don't have to do this! Go to a free test site instead; it's worth the wait. We know that at least one of these "urgent care" companies is operating in our area: WellNow has offices in Ithaca and Oneonta and they're working on setting one up in Johnson City.

How Bad is New York's Budget Deficit, Really?

Governor Cuomo has periodically said that the state is facing massive budget deficits, in the \$15 billion to \$20 billion range, due to the pandemic, in large part due to loss of tax revenue. He has repeatedly threatened to cut state-funded programs by 20% "across the board" as a result, and now those deep cuts have begun to happen—though only to programs deemed "non-essential."

He can't cut Medicaid rates without federal approval, and even if he got that, it would mean forfeiting most of the extra money he got from the feds for medical services due to the "maintenance of effort" requirement in the CARES Act—some of which he's already spent. That covers most of our CDPA and OPWDD services. And some of our state-funded programs, such as the TBI and NHTD Waiver Centers, have been deemed essential. But recently we've learned that there are 20% "holds" on some of our other funding, including various contracts with ACCES-VR, and our OPWDD ISS (rent subsidies for consumers) and FSS (behavioral support) services, which are 100% state dollars. These holds are on reimbursements for money we've already spent. We can't operate like this for very long, if at all.

So it's important to understand what's really going on in the state's coffers.



Tax revenue is affected by two things: The economy and the feds' delay of the federal income tax filing deadline to July 15 of this year. The first is a permanent problem; the second is not, although the delay in receipt of those taxes also caused a delay in the ability to project revenue accurately.

That deadline has passed, and whatever income tax the state is going to get this year has been gotten, or is at least known.

The economy, of course, has taken a huge hit with large numbers of small businesses closing and unemployment at near-Great Depression levels. That means that income tax payments are going to decline—but that will happen next year, not now. Sales tax, on the other hand, comes from the money people spend now. Lots of people have been eligible for the very generous federal \$600 per week unemployment supplement, on top of the unemployment payments they would normally get. But state unemployment offices have been totally jammed up by the number of applicants, and lots of people still haven't collected that money. They will eventually get it—all of it—but that affects what they can spend right now, and so sales tax revenues have been down

sharply this summer. They may well pick up and even exceed normal levels for a time when people get those checks and start buying things they've deferred. Only some of that tax goes to state coffers though; a lot of it stays at the county level.

All of this deficit talk has been based on financial projections, which may or not be accurate. Cuomo thinks it helps to threaten worst-case scenarios to get Congress to enact a bailout for state governments. That's bogus. Most of NY's congressional delegation is already firmly behind such a bill, which has already passed the House of Representatives. The holdup is in the Senate, whose Republican majority cares not a whit about what happens in NY. It includes some senators from other states who are also pro-bailout, but those Republicans are not moved by anything Cuomo says. A bailout, if it passes, will pass without NY's, or Cuomo's, help.

In July New York's Comptroller issued a report on the state's finances that suggests Cuomo has been exaggerating. The report said "the State's General Fund balance was \$6.9 billion as of June 30, \$3 billion higher than the Division of the Budget (DOB) projected in

February, primarily due to extraordinary measures. Resources available for State purposes in the State's Short Term Investment Pool, which includes the General Fund as well as certain other funds, totaled \$19.7 billion as of June 30." In other words, as of the end of June there was no actual deficit at all.

The state legislature has granted Cuomo authority to borrow to address temporary cash flow problems, and he has done so. That report suggests he could keep doing that instead of refusing to reimburse agencies for money they've already spent. Also, despite the stubbornness of both political parties causing a delay in another bailout bill, most policy analysts, including conservative ones, believe there will be a relief bill enacted along with the next round of federal appropriations, which must be done before September 30th to avoid a government shutdown. So it's very likely that Cuomo would be able to quickly pay back whatever he borrows.

At the start of the Civil War, Abe Lincoln remarked, "the bottom is out of the bucket." Well, we aren't there yet, no matter what our governor says. We'll let you know if and when we actually lose any water.



STIC NEWS



STIC COVID Update August 2020

By Maria Dibble

Here I am on August 19, 2020, writing another update on the COVID-19 pandemic and its ongoing impacts on STIC, our staff, and the people we serve. Sadly, I hadn't expected when this all began that it would last so long. None of us did I'm sure, but here we are again.

First, STIC opening: We are not opening for the foreseeable future, that is, we aren't moving staff back into their offices, and we are not allowing consumers into the building. However, our staff are working from home, except for DSPs and personal assistants who are delivering services in person for the most part. Personal assistants in the CDPA program have been working all along, and many DSPs have been seeing consumers face-to-face throughout the pandemic (if the consumer wished it) for which they all deserve our thanks. We are still considered an essential agency so these services have been provided and will continue to be.

Telehealth services are being provided as well, so we can communicate with consum-

ers and families via phone, Zoom or similar methods as consumers prefer. Some still fear having people come into their homes, which is understandable, so we are using these other approaches to keep in contact.

At this point, our employees are functioning well at home, and IT and other supports are available to them as needed. Our front desk is now staffed, so people can call for information or to leave messages on people's voice mails. Calls are returned daily (unless someone is on vacation, or only works part-time).

Our Loan Closet is partially functioning. We are loaning equipment that is washable and that we can sanitize easily. We are not loaning cushions or other cloth-covered items. To borrow an item, people must make an appointment by calling (607) 724-2111 and asking for Sam. Arrangements will be made for people to pick up the equipment. All items are cleaned and sanitized before they are loaned out. Please wear a mask when picking up an item.

We don't know how long these circumstances are going to last, but at this point I expect that employees will be working from home at least until the end of the year, unless things change significantly (such as a safe vaccine becoming available). We put a lot of thought into the decision to leave everything as is, and we decided that both employees and consumers would be the safest this way, especially with flu season on the horizon. We still have a skeletal crew in the office, continue to hire and train new staff as needed, and we do as much as we can using telephone, Zoom, or other remote means.

This has been a difficult time for everyone. We want to make sure that we continue to meet the needs of people with disabilities despite the pandemic. Feel free to call STIC for information and/or support.

Until my next update, I wish everyone good health and peace of mind.

Statement on Racism

By Maria Dibble

The board of Directors and employees of Southern Tier Independence Center (STIC) condemn the acts of violence perpetrated by some police officers against African Americans and other people of color across this country. No human being should ever have to feel that they are without value, nor should they be treated as such. Our constitution promises equal rights and opportunities to all Americans, sadly a promise that has not been kept for people of color. It is time for all human beings, no matter what race, ethnicity, gender, religion, etc., to express our outrage at and intolerance for the unequal treatment of African Americans, and to do what we can to end the racism that is poisoning our society. We can all fight back in our own way. We can join the peaceful protesters, or write letters to our government representatives demanding substantive action, and we can all exercise our right to vote!

Black lives most certainly do matter, and we need to ensure that the law and our society never forget that. All too many times the scenes such as the one pictured in the video of Mr. Floyd's death have occurred. No one can any longer deny the reality that our neighbors of color face every day, a terrible, unjust, reality where they have to fear going for a jog, or even driving to the store.

There is no room for racism in a truly democratic and free society, and STIC stands in solidarity with all who fight discrimination, racism and hate. Sadly, systemic institutional racism won't end overnight, but it will never end if each one of us doesn't do his or her part to bring about the necessary changes to our attitudes, beliefs, laws, and public policies. We are all responsible!

Helen Keller said it best when she wrote in 1916, *"Let all lovers of justice unite, let us stand together and fight every custom, every law, every institution that breeds, or masks violence and prejudice, and permits one class to prosper at the cost of the well-being and happiness of another class."*

Reflections on the New Abnormal Times

By Sue Ruff

As I waited in my work office for a rare meeting with other staff to start, I looked around the room. It had been a quiet, masked walk to my room through empty STIC hallways as I followed the direction arrows for new traffic patterns.

My office wall calendar was stuck on the March page. I took it down and looked through the ensuing months. It's a calendar with photographs of isolated buildings in very remote but scenic locations (mountaintops, islands, etc.) When I ordered it last fall, I didn't anticipate the irony of isolated hermitage locations it portrays month after month of 2020.

The desk is mostly empty because my work computer and equipment occupy a space on my home desk. I dusted the office desk and fingered some small toys I keep. Can unplayed with toys feel lonely? Or is that only in animated feature films?

The plants were OK, thanks to my supervisor's watering regimen on Fridays. I removed a few dead leaves but that's just general upkeep.

As I stared at my children's pictures on various bookcases, I recalled where and when those pictures had been taken. And remembered the trips to the beaches where we had collected the shells that sit near those pictures. No trip this year.

A stack of voter registration forms sits on top of a filing cabinet. Voter registration support will have to be done mostly online this year. The filing cabinets still need to be cleaned off but that can wait.

The snacks on my bookcase are stale and heading home for the compost pile.

My favorite souvenir tea mug from Key West sits empty.

I look at the pictures on the walls. *June Jumpers*, a woodcut of three children jumping, rolling, and leaping in a sprinkler, makes me long to play with my grandchildren, thousands of miles away in Arizona. Edward Hick's *The Peaceable Kingdom* sits above the bookcase, reminding me that our times and politicians don't match Hick's vision. My brother's oil painting of fall trees graces another wall. A Martha Perske charcoal print of children with disabilities tugs at my heart as I think about the children who have been quarantining and unable to spend time with their friends and teachers. *Early Morning Sunflower for Ron*, Bruce Lieberman's memorial tribute to art historian Ron Pisano, looks like a scene from my son's garden this year. But we can only face-time.

My attention is drawn to some buttons on the bookcase. They are reminders of the advocacy demonstrations many months or years ago: "SAVE CDPA," "VOTE-It's Not Just Your Privilege...It's Your Duty!," and my favorite, "Work for a Community Where Each

Individual Is Cherished." A saved bottle cap catches my eye: "Real Fact #921 -If you had 1 billion dollars and spent 1 thousand dollars a day, it would take you 2,749 years to spend it all." But we have been told it is unfair to tax billionaires in order to save community based services?

Oops—time is flying and I lock the door as I head to the meeting. I miss you, office. But mostly I miss the people with whom I work and think about them as I pass their locked doors. The times unfold daily with new and old needs. Staying safe is lonely.

Disengagement

Southern Tier Independence Center, Inc. is no longer an owner of Prime Care Coordination (PCC).

PCC is a Care Coordination Organization (CCO) for people with developmental disabilities who receive services from the Office of People with Developmental Disabilities (OPWDD). It was formed in 2017 when OPWDD required organizations that provided service coordination to transfer those services to CCOs to address federal conflict-of-interest requirements. PCC, like other CCOs in New York, was formed by former service coordination agencies, including STIC, and is a for-profit corporation. As such, STIC and the other organizations each owned shares of PCC and held seats on its board of directors.

In early 2020 PCC bought out the shares of the other organizations. Although it is legally a free-standing corporation, it is now effectively solely owned by CDS Life Transitions, Inc., a not-for-profit service agency in Rochester that operates sheltered workshops and group homes along with some integrated programs. CDS has always been PCC's largest shareholder; now it is the only one.

Therefore, STIC no longer holds a seat on the PCC board or has any governing relationships with the company. STIC does still have a contract to provide some administrative and IT support services to PCC. And, of course, many of the people STIC serves continue to receive care coordination from PCC.

As of August 20, 2020, PCC's website has not been fully updated to reflect this change, but STIC is no longer a "Partner Organization" of PCC.

We thought you'd like to know.

Voting Information

By Sue Ruff

Election Day is November 3, 2020. Want to register? Apply for an absentee ballot? Find your polling location? Become a poll worker? Need help? I am happy to help you.

Call (607) 724-2111 and ask for Sue Ruff.

Email: advocate@stic-cil.org

What's on the Ballot?

What will your ballot look like? Vote411 will have ballot information as Election Day gets closer, but not all counties have Vote411 links at their websites:

<https://www.vote411.org/>

Dates and Deadlines

General Election Day—November 3, 2020

Early Voting—October 24—November 1 (locations and times vary by county)

October 9—last day to postmark your voter registration form

October 10—last day to register to vote in person at your county Board of Elections (BOE) office (but it's a Saturday and not all BOE offices are open across the state *—don't wait—register early*).

October 27—last day to postmark applications for absentee ballot by mail

November 2—last day to apply in person for an absentee ballot

November 3—last day to to postmark an absentee ballot or to deliver an absentee ballot in person at your county Board of Elections

Who Can Vote?

You have to be a citizen and age 18 on or before Election Day, November 3, 2020, in order to vote. 16 and 17 year olds can pre-register but can't vote until they are 18.

Registering to Vote

Do you need to join a political party when you register?

No, you do not have to join a party. On the registration form there is a box to check if you do not want to enroll in a party.

Not sure if you are registered because you haven't voted in a while? You can check to see if you are registered here (though when we

tested it in mid-August the site kept "timing out" with a message that the site was experiencing "higher than expected usage"):

<https://voterlookup.elections.ny.gov/>

Here's a PDF version of the NYS Voter Registration Form with instructions. You can fill it out, print it, and mail it to your county's Board of Elections (you can't save your changes).

https://1a0628bc-14f5-4dd7-8b9a-cf91d0c809e5.filesusr.com/ugd/be9a23_5a167c417b5d484bb59d3aed076d92a0.pdf

One can also register to vote online through the DMV if you have a NYS driver's license or non-driver ID:

<https://dmv.ny.gov/more-info/electronic-voter-registration-application>

Early Voting

Voting during early voting is the same as voting on Election Day. (Info on how to find the early voting sites in Broome, Chenango and Tioga Counties is below.) When you get to the Early Voting Center, you will check in to vote, receive your paper ballot, and vote as you would at any other election. Early Voting Centers will have voting instructions and a notice of the voters bill of rights. Plus at any time you may ask an election inspector to explain the how's of voting, or for any assistance, if needed.

Remember, if you vote early, you are not eligible to vote again on Election Day.

Absentee Voting

If you are out of your home county or if you are permanently or temporarily disabled, ill or are the primary care giver for one or more people who are ill or physically disabled, or a resident of a veterans hospital, or detained in jail awaiting grand jury action or incarcerated for an offense other than a felony, you may apply for an absentee ballot. Due to the pandemic, you can also request an absentee ballot if you can't vote in person due to the risk of contracting a disease and spreading it to other members of the public (on the application, check the box for "temporary illness or physical disability"). Also for the pandemic, you can request an absentee ballot any time between now and Tuesday, October 27. **Apply for absentee ballots as early as possible!**

Accessible absentee ballot applications were available during the primary season. We expect they will be available for the fall election but suggest you call your county Board of Elections if you have questions.

Local County Information

Each county has a Board of Elections website with information about registering, where and when to vote, and more. Here's information for Broome, Chenango and Tioga Counties:

Broome County

<https://www.broomevotes.com/>

607-778-2172

Registration: <https://www.broomevotes.com/registrationform>

Finding your polling location:

<https://www.broomevotes.com/pollingplace-lookup>

<https://www.broomevotes.com/nyaccessible>

Absentee voting:

<https://www.broomevotes.com/absapplication>

Military/overseas/absentee request and time lines:

<https://www.broomevotes.com/military-overseas-absentee>

Early Voting:

As of mid-August locations for early voting were not yet posted on the Broome BOE site.

General Election: Fall 2020

Saturday, October 24, 9 am—5 pm

Sunday, October 25, Noon—5 pm

Monday, October 26, Noon—8 pm

Tuesday, October 27, Noon—8 pm

Wednesday, October 28, 10 am—6 pm

Thursday, October 29, 10 am—6 pm

Friday, October 30, 10 am—6 pm

Saturday, October 31, 9 am—5 pm

Sunday, November 1, Noon—5 pm

Want to be a poll worker?

<https://www.broomevotes.com/inspector-application>

Poll worker classes run through September:

<https://www.broomevotes.com/inspector-class>

Chenango County

<https://www.co.chenango.ny.us/elections/>

Poll worker info:

<https://www.co.chenango.ny.us/elections/in-spector.php>

<https://www.co.chenango.ny.us/elections/poll-worker-training.php>

General Election Early Voting Location:

Chenango County Board of Elections Office
5 Court Street, Basement Level
Norwich, NY 13815

Dates and Hours:

October 24, 25, 31 and November 1, 9 am to 2 pm

October 26, 28, 30, 9 am to 5 pm

October 27 and 29, 9 am to 8 pm

Please note, 2020 in-person Voter Registration Applications must be received by 5 pm, October 9, 2020 at the Chenango County Board of Elections office.

Registration form:

https://www.co.chenango.ny.us/elections/documents/508_FINAL%20English%20VR%20Form%20Fillable.pdf

Pre-registration for 16 and 17 year olds:

https://www.co.chenango.ny.us/elections/documents/508_FINAL%20VR%20Form%2016%2017%20year%20old.pdf

Tioga County

<https://www.tiogacountyny.com/departments/board-of-elections/>

(607) 687-8261

Registration:

<https://www.tiogacountyny.com/media/5896/2020-vr-form-fillable.pdf>

Absentee ballot, Tioga County:

<https://www.tiogacountyny.com/media/3084/absenteeballot-english-2016.pdf>

Early Voting Location:

Tioga County Board of Elections

1062 State Route 38, Owego NY 13827 (It is accessible)

Saturday, October 24, 9 am—2 pm

Sunday, October 25, Noon—5 pm

Monday, October 26, Noon—8 pm

Tuesday, October 27, 10 am—6 pm

Wednesday, October 28, Noon—8 pm

Thursday, October 29, 10 am—6 pm

Friday, October 30, 10 am—6 pm

Saturday, October 31, 9 am—2 pm

Sunday, November 1, 9 am—2 pm

Poll worker information:

<https://www.tiogacountyny.com/departments/board-of-elections/news/call-for-election-inspectors/>

Tioga County posts this link for information about ballot marking devices used in their county:

<https://www.elections.ny.gov/machine-sequoia.html>

Polling locations:

<https://www.tiogacountyny.com/how-do-i/elections-voting/polling-locations/>

Link to registration form:

<https://www.tiogacountyny.com/media/5896/2020-vr-form-fillable.pdf>

More Information

The League of Women Voters in NYS is an excellent resource.

Locally:

<http://www.lwv-broometioga.org/>

<https://www.facebook.com/lwvbroometioga/>

Statewide:

<https://my.lwv.org/new-york-state/voting-2020-faqs#thr>



The Voting Outlook



Back in the autumn of 2018, our Executive Director, Maria Dibble, wrote “In our lifetimes, there has never been a more important opportunity for you to make a difference than you will have on” that year’s Election Day. This year’s opportunity is even more important. Each of you absolutely needs to vote, *whatever it takes*. Unfortunately, the COVID-19 pandemic is making it harder to do what you need to do. Please don’t let the difficulties stop you.

In this issue of *AccessAbility*, we’ve devoted an unprecedented amount of space to making sure you have all the information you need about how to cast your vote on or before November 3 (see page 13). But we would be remiss if we didn’t also talk about the elephant in the room: Will your votes be counted?

Several states are requiring, or at least allowing, people to vote by mail instead of in per-

son, to avoid the risk of COVID-19 infection. Five states—WA, OR, UT, CO, HI—have had “all mail” voting for several years, although some amount of in-person voting has continued to be available in those states as well.)

There is absolutely no evidence that voting by mail is especially subject to fraud, and no evidence that election fraud is anything but extremely rare. But it is true that in states like New York, which don’t do automatic vote-by-mail every election, the county election boards aren’t used to handling large numbers of mail ballots and will likely have problems, the least of which will be very late final tallies. This will probably be true even though Governor Cuomo has issued an executive order requiring county boards to begin immediate planning for this and send information on their staffing needs to Albany, presumably to get extra money to process ballots.

It’s certainly true that some public officials are deliberately trying to keep people from voting. This is nothing new in the US. But as we went to press there was a major controversy over the effects that cuts at the US Postal Service (USPS) could have on by-mail voting, and President Trump said that he didn’t want to give extra funds to USPS that could be used to improve delivery of mail ballots, because he thinks voting by mail helps Democrats (which it may, or may not, depending on various equally respectable sources).

On the other hand, the pandemic is making it harder to keep in-person polling places open. Most poll workers are elderly volunteers—people who are at very high risk for severe COVID-19 infections. A lot of them decided to stay home during this year’s primary season and we can expect more of the same in November. Organizers are encouraging younger

people to volunteer, and since many of them have been laid off from their jobs, they could take up the slack (you can't just show up, you have to be trained—but you will get paid), but it's not clear if they will do so. Also, many of the locations used as polling places, including schools, churches, service-clubhouses, and other venues were simply closed down, with not even minimal caretakers working, during the height of the pandemic, which was also prime primary season. In late August it wasn't very clear how many of these sites might be open by November.

Some people believe that absentee ballots aren't even counted unless an election is close. That's definitely not true; all valid, authenticated ballots are counted, eventually. But in many pre-pandemic elections the number of absentee ballots cast was too small to affect the results one way or the other. That's not going to be the case this November.

The "valid" part is very important. In the June primary, over 20% of mail-in ballots—over 80,000—were rejected by election authorities in New York City. Some of this happened because post offices, overwhelmed by the volume, neglected to postmark some ballots or did it sloppily. Ballots were also rejected because they arrived unsealed or late, their inner "affirmation" envelopes were missing or not signed, or signatures weren't properly witnessed or were judged not to match those the Board of Elections had on file for the voters.

A lawsuit was filed and the state legislature passed (and Governor Cuomo signed) bills to address some of this. One bill requires the Board of Elections to notify voters of problems with their ballots within one business day of the discovery of the problem, by email or phone if possible, as well as by mail, and the voter will have five business days to file a correction (presumably in-person or by mail), even if by doing so the correction arrives after the deadline for mail-in ballots. Notably, there is no remedy for late delivery of an original ballot or corrected ballot by the Postal Service, and if a ballot arrives unsealed the only option is to submit a new ballot before the deadline. Another bill allows ballots without legible postmarks to be counted if they have been date-stamped by the Board of Elections receiving office no later than the day after the election.

In order to vote by mail in NY you must first request an absentee ballot, and you must give

a reason why you need one (see page 13). You can fill out and print a PDF request form from a state or county website and mail it in (or submit it electronically if you have a valid NYS driver or non-driver ID card). Due to the pandemic you can make those requests right now. The BOE must receive it no later than seven days before the election.

Even with all this legislation there's a lot of room for things to go sideways here. At STIC we have three recommendations:

1. Take advantage of early voting and vote in-person if you can. Go as early as you can on the first day you can.
2. If you absolutely positively can't do that, request an absentee ballot right now. Don't even finish reading this article. Go do it. We'll wait. Then, as soon as you receive the ballot, fill it out and mail it in. Immediately. Preferably while you're still standing at the mailbox. **DO NOT PROCRASTINATE.** But double-check everything about the ballot: Is the "affirmation" envelope signed? (When you sign, bear in mind that they will compare it to the signature they have on file for you, and sign it the same way.) If you make a mark that must be witnessed, make sure you get that done—and Postal Service employees are not allowed to be your witness. Make sure you seal both the inner and outer envelopes. **Be careful** with the envelopes; if either of them gets torn your ballot will be rejected.
3. Really, it's better to vote in person if you can. Did we say that?

We realize that many of you have good reason to be very concerned about getting this disease. But there is also considerable serious risk of what will happen if people don't vote, or their votes are not counted. Even if all of the things that the NY legislature can control are addressed, the Postal Service cannot be controlled and they are very likely to run late with these deliveries. The problems with the Postal Service didn't start with the controversy over funding cuts; it started in April when people stopped buying things in stores and began relying on delivery service for almost everything. Those problems will continue even if the USPS gets some extra money between now and Election Day. **PLEASE.** Wear a mask. Wear gloves. Stand six feet apart. Go early. **But if at all possible, please vote in person.**

Our future depends on what you choose to do.



PLEASE DO THE CENSUS!!

Use the code the Census Bureau sent you to fill it out online. It's very short and very easy.

If you can't do that, fill out the paper form the Census Bureau sent you and mail it in.

If you can't do that, be kind to the Census worker who knocks on your door and answer his or her questions so you can be counted.

**WE ALL NEED AN ACCURATE
COUNT OF ALL PERSONS IN
THE UNITED STATES!**

It controls apportionment of legislative districts, and it controls the federal funds NY receives.

If you are an undocumented immigrant, please don't fear that you will be reported to ICE. The Constitution says "all persons" must be counted, not just citizens or immigrants with papers. You matter just as much as anyone else.

DO IT BEFORE SEPTEMBER 30!



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

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If you would like to support STIC, please use this form.

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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!

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