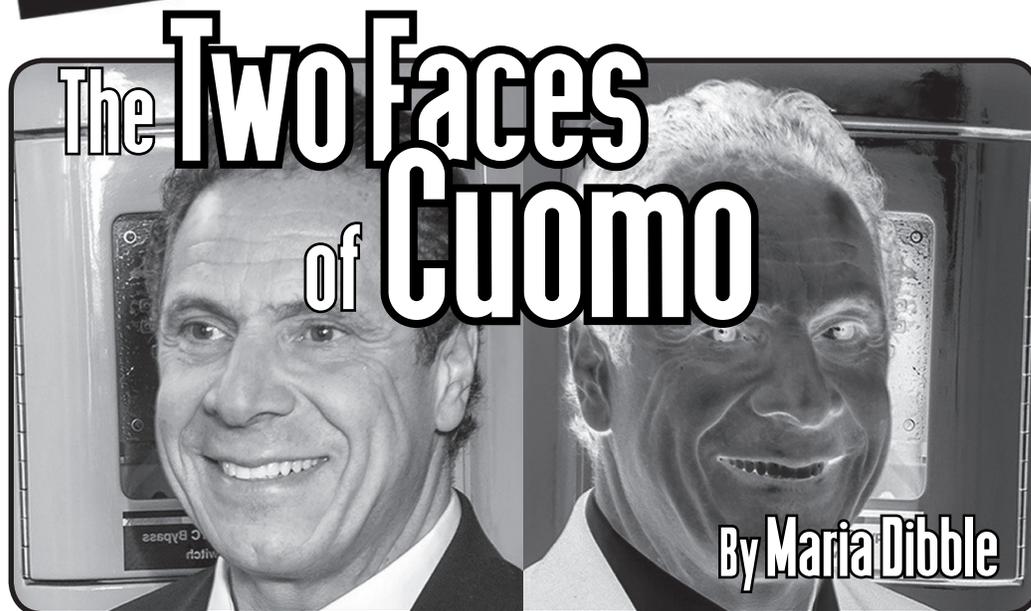


# AccessAbility

Summer 2020  
Number 139



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It has been fascinating, though frustrating, to watch Governor Cuomo's performances throughout the COVID-19 pandemic crisis in his daily press conferences and in other venues. He is the image of a good leader, concerned about healthcare providers and other essential workers, even to the point of advocating with the federal government for "hazard pay." (Not offering to have NY provide such pay, mind you, just suggesting the feds do.)

A personality cult has grown up around him in NY and even nationwide. He seems to have become a hero, a knight in shining armor, one who can do no wrong, virtually overnight.

He thanks essential workers profusely for their contributions, for being out on the front line, putting their families and themselves at risk on a daily basis. And who can argue with that? I certainly won't because I agree with him totally, as I am quite sure all of you do.

Yet he has slashed some of the same essential agencies and workers in his budget, going so far as to demand that Congress remove the "maintenance of effort" clause, which would keep him

from cutting Medicaid if he accepted funds under the CARES Act. He threatened to reject billions of dollars to help offset revenues resulting from the economic shutdown, just so he could make massive cuts to integrated long-term care services and the hospitals that were then being overwhelmed. Does this sound like a hero to you?

In NY's recently passed budget, he proposed cuts across-the-board to hospitals and community-based long-term care (including CDPA). These cuts would cause CDPA workers to be cut back to minimum wage, and would likely force them to quit their jobs, leaving people with no workers and no options except placement in nursing facilities, whose rates are not subject to the across-the-board cut. Under these circumstances, these workers could make more money working at Burger King than in the CDPA program

So let's talk about nursing "homes", since Governor Cuomo seems to favor policies that will force people into them. Nursing facilities account for about 25% of the deaths in NY due to COVID-19. When they first asked Cuomo for help securing

personal protective equipment (PPE), he told them that it wasn't government's job to supply PPE. At the same time, he was telling Trump that the federal government should do just that. Then he issued an Executive Order telling nursing facilities that they couldn't refuse to admit people who were confirmed to have COVID-19. When asked about it at a press conference, he claimed he knew nothing about it, and it took weeks for him to reverse the policy, while refusing to take responsibility for it (see page 2). I'm an Executive Director, and my parents taught me, "the buck stops here." He's the state's Chief Executive, he should accept responsibility, but if he did, the armor would be tarnished and people would see that he isn't a hero or a knight, but just a human being like the rest of us.

Now that the public knows of the high death rate, he can't help nursing homes

# AccessAbility

June 2020

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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

## Our address is:

*AccessAbility*

Southern Tier Independence Center

135 E. Frederick Street

Binghamton, NY 13904

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enough with PPE and other supports. Yet those facilities are overwhelmed, and he refuses to support programs that keep people out of them, such as Personal Care and CDPA. He still wants to slash them, causing a much bigger shortage in personal assistants than we had before the pandemic, leaving institutional placement the only option for elderly and disabled individuals who just want to stay in their own homes. As bad as that was before, it is almost assuredly a death sentence now.

He doesn't deserve the full blame; the leaders in the NYS legislature were complicit. They approved most of his cuts, and the icing on the cake? They gave him even more power to make cuts throughout the year. Though many rank-and-file members voted against the budget, both chamber leaders and nearly all of the committee chairs voted for it. They've been sucked into his cult as well, afraid to challenge such a popular governor, just hoping he'll take the blame for the bad cuts in the budget that they claimed they didn't really support. (See page 4 for more on this.)

I admire the public face of Cuomo. He is sensitive, considerate, concerned, and strong in his leadership, but when he takes off the mask, what's behind it is not a pretty picture. He appears to have a vendetta against people with disabilities and the programs that serve them in the com-

munity. He claimed, and in fact promised, that no people with disabilities would be harmed by his budget. WRONG! Cutting agencies like STIC will result in fewer supports in the CDPA program, a program that has saved countless lives in this pandemic by enabling them to stay at home, where every non-essential non-disabled person has been told to stay. Another sign that he is targeting people with disabilities was his unwillingness to provide a live sign language interpreter for his daily briefings, the only Governor in the country that did not, forcing a lawsuit to resolve the issue (which we won; see page 6).

More evidence of his vendetta is that current law requires that all people receiving homecare services be told about CDPA. The Governor proposed, and the legislature approved, removing this requirement. There is no rational reason not to share information about the least expensive program that gives people with disabilities the most autonomy, independence and freedom to control their own services. Don't we have a budget crisis? Don't we need to save money?

Those who see Governor Cuomo as a knight in shining armor, rising to meet the challenge and rescuing New York, should take a second look, and notice the tarnish that is beginning to spread and dull the shine.

## Cuomo's Pro-Nursing "Home" Bias Blows Up in His Face

As we've reported elsewhere (see page 6), nursing facilities and other congregate residential settings have been hit especially hard by COVID-19 all over the US. Gruesome stories of truckloads full of decaying dead bodies in nursing "home" parking lots and frantic relatives, not allowed to visit their loved ones due to social distancing rules, and unable to get information about them because of a mixture of staff shortages and administrative cover-ups, have been reported from several cities.

There are many reasons for this. Most of the people in nursing facilities are elder-

ly, and elderly people are the most likely to die from this disease. Various chronic health conditions, such as diabetes or heart disease, also common in these places, are another risk factor for COVID-19 death. The facilities have notoriously lax infection control practices. Over the past four years, 63% of all nursing "homes" in the US, including 40% of those with five-star quality ratings, were cited for infection control deficiencies, according to *Kaiser Health News*. Many of the citations were for things that are extremely dangerous now, such as failure to wash hands or wear masks. They also face chronic staff

shortages for the same reason the home-care industry does—low wages. Of course, nursing facilities have had the same difficulties getting masks and other “personal protective equipment” (PPE) as have hospitals during the crisis, and many of their own employees have come down with the disease, exacerbating shortages among staff who might otherwise be working to constantly clean and sanitize those places.

Finally, they are not well-monitored. The federal government has ultimate responsibility for nursing facilities, which are funded by Medicare and Medicaid, but the feds hand off inspection and enforcement to states whose health departments are typically run by former nursing facility executives and lobbyists. The feds have refused to mandate minimum staffing ratios in these places, and have also reneged on effective enforcement of their own regulations.

Given these sad facts we might conclude that New York, where about 25% of COVID-19 deaths have occurred in nursing and other “adult care” facilities, isn’t much different from other states.

Except that’s not the full story.

Early on in the crisis, on March 25, Governor Cuomo issued an executive order stating that no nursing facility could refuse to admit anyone because they test positive for COVID-19. Presumably this was because hospital beds had to be reserved for the sickest patients. However, even at that time everyone knew that the biggest spikes in deaths were happening in nursing facilities, and that they were not going to be safe places for anyone. And this order remained in effect even after hospitals ceased to be over-filled. In fact, the emergency hospital set up in the Javits Convention Center in New York City never came close to using its maximum 2500-bed capacity (at its peak it had 450 patients), and the thousand-bed US Navy hospital ship *Comfort* only served 182 New Yorkers. Instead, hospitals, the places with the best infection control, continued to move or return people with the disease into nursing facilities—the places with the worst infection control imaginable—as soon as they were deemed not to need intensive care.

The NY and nationwide media remained hypnotized by the governor’s strong

and stern, yet fatherly, performances at daily press briefings for a few weeks while this went on. But finally, as stories of these charnel houses began to emerge from other states, spurred on in large part by disability rights advocates, some reporters began asking questions of Cuomo at his briefings.

At first he claimed not to know anything about his own executive order; he blamed it on NY Department of Health (DOH) Commissioner Howard Zucker. Zucker was reluctant to provide data on the deaths. He grudgingly listed nursing facility deaths by county but refused to name the facilities where the people had died, citing non-existent “privacy” issues under the federal Health Insurance Portability and Accountability Act (HIPAA), even though other states were reporting facility names. Only after continued pressure did he produce those names, but only of facilities in which five or more people have died, until very recently.

Zucker also claimed that nursing facilities were strictly following policies to prevent disease transmission. But the *NY Post* reported on April 20, “Assemblyman Ron Kim (D-Queens) said Zucker’s assertion that necessary precautions were being taken to prevent the spread of infections in nursing homes was clearly not the case. ‘It’s either he’s lying or they have absolutely no idea what’s going on on the ground,’ Kim said. ‘The staff, the families, everyone is telling me there’s completely a lack of support and they don’t have the necessary PPE to be safe.’”

Also in mid-April the *Post* reported that DOH approved a request from a Hornell nursing facility to allow COVID-positive nurses to continue to work there, while refusing a request from a Brooklyn facility to move COVID patients to the nearly-empty Javits Center or hospital ship.

Then it was revealed that the daily deaths reported on a DOH website had been undercounted, and on May 5 another 1,700 people were added to the rolls.

As the questions persisted, Cuomo said he would investigate and get to the bottom of the situation. He eventually issued an order reversing the original one, mandating that hospitals may not release any patient to a nursing “home” who

does not test negative for COVID-19. He also ordered that all nursing facilities must test their employees for the disease twice weekly and bar anyone who is positive from working. He ordered that all employees must wear appropriate PPE. And, according to the *New York Times*, he threatened to yank the license of any facility that “failed to provide appropriate care for each of its residents, whether because of a shortage of personal protective equipment, staff or inability to appropriately isolate patients.”

Many observers around the nation pointed out that this crisis was predictable and resulted from an ongoing failure to effectively regulate and monitor nursing facilities. According to *Lohud*, a news website covering Westchester and Rockland Counties, “Brian Lee, executive director of the advocacy group Families for Better Care, asserted many states withheld details about COVID-19 in nursing homes because officials were trying to protect providers from potential litigation in a post-pandemic world.” But Charles C. Camosy, a professor of Ethics at Fordham University, called it a moral failure and the result of a “throw-away culture,” in which we toss aside people who are perceived as having outlived their usefulness (the elderly) or who were never believed to be useful to begin with (people with disabilities).

The most charitable interpretation of Cuomo’s performance is that he didn’t get involved in the details and delegated things to Zucker, so he wasn’t really aware of what was in the orders that Zucker wrote and he signed. But Cuomo has hung his hat on his prized “Medicaid Redesign” project for nearly 10 years now, and he heavily promoted the MRT’s alleged objective, science-based planning not to cut care, but to provide better care. It is not believable that he was not aware that his MRT was controlled by, among other big-money healthcare people, nursing home operators, that his health commissioner was in their pocket, and that the people who fund his campaigns want regulatory hands off, and more people living in, their facilities.

Cuomo’s most recent response to criticism is to claim that there was nothing really

wrong with the nursing “homes” at all, they were doing a great job and they were just “unlucky” to be in New York City, the world-wide epicenter of the pandemic. He’s also claimed, falsely, that even under his order the facilities had discretion to reject anyone they couldn’t properly care for. And he’s been accusing all crit-

ics of engaging in partisan politics at the expense of people’s health, even though Democratic Assemblyman Kim was an early objector and Democratic Assembly Health Committee chair Richard Gottfried joined Republicans in calling for an independent investigation of the debacle. He cut one recent briefing short as soon

as the questions turned to nursing facility deaths. Although observers have contrasted Cuomo’s focused, rational briefings with Trump’s embarrassing, rambling, invective-filled daily circuses, in the thinness of his skin and his unwillingness to accept responsibility, Cuomo has proved Trump’s equal at last.

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# Budget Betrayal will Boost Nursing “Home” Profits—and Deaths

Last time around we gave you a lot of gritty details about the attack on CDPA (see [www.stic-cil.org/newsletter/AccessAbility\\_Spring\\_2020.html#CDPA](http://www.stic-cil.org/newsletter/AccessAbility_Spring_2020.html#CDPA)), the second coming of the Medicaid Redesign Team (MRT) ([www.stic-cil.org/newsletter/AccessAbility\\_Spring\\_2020.html#MRT](http://www.stic-cil.org/newsletter/AccessAbility_Spring_2020.html#MRT)), and Cuomo’s budget proposals ([www.stic-cil.org/newsletter/AccessAbility\\_Spring\\_2020.html#Budget](http://www.stic-cil.org/newsletter/AccessAbility_Spring_2020.html#Budget)). We don’t have space to summarize all of that here.

What was already an especially contentious budget season was completely derailed by the COVID-19 pandemic. Panicking legislators in a rush to quarantine themselves gave Cuomo nearly everything he asked for initially, and power to make more changes later in the year.

As expected, no Republicans voted for the budget bill. A surprising number of Democrats in the Assembly (25) voted against it as well, where it passed by only one vote. Notably, Assembly Health Committee chair Richard Gottfried, and our very own Donna Lupardo, among several other Democrats who had promised to defend the CDPA program and other essential services, caved in completely. If those two had voted the other way the budget would not have passed. They’d like you to believe that they’re really sorry but there was just no time to do better in a public

health emergency, but that’s a lie. We have plenty of ears behind the scenes. The truth is that Cuomo, with his daily news briefings, was building up such a head of steam as the Great and Glorious Leader Who Will Save Us All that they were terrified to oppose him. Some in the media have expressed similar fears, making it hard to get the truth out—until recently (see page 2).

So what’s in this budget?

Most destructive is a wholesale reworking of homecare services. Homecare includes several programs, including “traditional” Personal Care, Certified Home Health Aides (CHHA), Private Duty Nursing, and Consumer Directed Personal Assistance (CDPA) services. Personal Care includes Level I and Level II services. CDPA personal assistants, hired, trained, scheduled and supervised by people who need them, can do anything that Personal Care attendants and CHHAs can do, and most things that Private Duty Nurses can do.



Level I Personal Care provides attendants to assist with “instrumental activities of daily living” (IADLs)—things like cooking meals, doing laundry, balancing a checkbook, grocery shopping, “light housekeeping”—and, strangely, walking. Level II covers “activities

of daily living” (ADL) tasks involving a person’s body, like bathing, dress-

ing, using the toilet, and getting in and out of bed. If you need Level II services, Level I comes along with them automatically. Before this budget passed, a person with a disability only had to qualify for Medicaid and get a physician’s order and nursing assessment stating that s/he needs help with IADLs to qualify for Level 1.

Almost since STIC first opened in 1983, NY governors have been trying to eliminate Level I services. The older folks among you may recall the Pataki effort, in which state legislators were induced to call Level I “free maid service.” But Mario Cuomo tried it first, until he was stopped dead in his tracks in the halls of the Capitol, in front of the press corps, by a courageous young advocate named David Veatch, who offered him the keys to his home and car and told him he might as well take them, because Mario’s cuts were going to put him in a nursing home. (Cuomo knew Veatch was waiting for him; he could have gone a different way but he chose to come out and meet him. Many have since commented that his son lacks the fundamental heart and humanity of his father.) Andrew Cuomo initially managed to put a cap of 8 hours a week on Level I, but it was, in theory, blown away by his later adoption of the Community First Choice program, which requires that no arbitrary caps can be placed on any services funded through that program, and all medically necessary services justified by a functional needs assessment must be provided. However, Community First Choice has faced delay after delay in getting off the ground, and Cuomo’s Department of Health (DOH) still operates personal care, includ-

ing CDPA, under regulations that are now technically obsolete.

Under the new regime, no one can qualify for Level I services alone, whether through CDPA or “traditional” Personal Care. Instead, people with physical disabilities must have at least three needs for Level II-type ADL services (people with various forms of dementia need two), and “walking” doesn’t appear to qualify since it’s an IADL. All such people will get Level I as well. Also, you can no longer have your own doctor, who is familiar with you, authorize your services. Instead, an independent physician approved by DOH must issue the order (and this probably will end up being a doctor employed by Maximus, the state’s managed care plan broker).

There are two obvious groups that will be harmed by this. People with certain disabilities, such as blindness, who can care for themselves physically but can’t do important things like money management and shopping, will not be able to get services. Also people who can do almost everything for themselves but are unsteady on their feet and can’t walk safely alone. You might expect them to just use wheelchairs, but a surprisingly large number of them live in tiny, inaccessible apartments where, for example, a wheelchair can’t get into the bathroom or kitchen.

But it’s not all bad news. First, everybody already getting homecare services is “grandfathered” in under the old rules, for as long as they retain their current Medicaid eligibility status. Second, responsibility for the needs assessments that determine what, and how much, service people can get will be taken away from counties and managed care companies and given to an “independent” third party—again, Maximus. Needs assessments will now only have to be done once a year in most cases, not every six months. Personal assistants will be able to transport people to medical appointments instead of them having to arrange rides through the central scheduling service. And the usual red-herring efforts to eliminate spousal refusal and spousal impoverishment were defeated.

All of this is supposed to save money, but nearly everyone who qualifies for any form of homecare also qualifies for a nursing facility. Under federal Medicaid law,

states don’t have to provide personal care but they do have to provide nursing facilities. People who can’t get homecare will end up in nursing facilities, surrounded by COVID-19. Before the pandemic the average lifespan of a nursing “home” resident was 18 months. It will be much less than that now. In almost all cases, a facility placement will cost more than serving the same person with homecare. Still, there are some people who may actually be cheaper to serve in a nursing facility than at home. For those there is the *Olmstead* Supreme Court decision, which says states must offer people services in the most integrated settings that meet their needs. Although it doesn’t say, “regardless of cost,” the fact is that integrated services in the aggregate across all people served by a state will cost less than nursing facility services for the same number of people, and a strong argument can be made that this is the only valid cost comparison.

In other Medicaid news:

The 1% so-called “across the board” cut in payments to Medicaid service providers, which covers long-term care services, including CDPA, was increased to 1.5%. One source estimated this to be a \$45 million cut for providers, many of which already operate very close to the bone.

An MRT proposal to impose a 5-year look-back period for applicants for “community” Medicaid (like the one for “institutional” Medicaid that pays for nursing “homes”) was reduced to 2.5 years. These look-backs are intended to prevent well-off people from dodging income eligibility rules by transferring their assets to friends or relatives; if you’ve made such a transfer, you can’t get Medicaid until the look-back period ends. These policies mostly achieve what they are intended to do without harming poor people, except that when you apply for Medicaid, there may be as much as a six-month delay while the state investigates your bank records before you are approved. The legislature also added in a provision allowing you to get reimbursed for three months of services paid for out-of-pocket during the waiting period.



A looming question is what will become of CDPA Fiscal Intermediaries like STIC, whose funding will be cut off at the knees if DOH’s proposed per-member-per-month rate system is allowed to take effect unchanged. As we reported last time, DOH’s request for public comment on the plan elicited several comments that were eloquent in their disapproval of both the plan and of DOH’s clearly dishonest statements about it. Nothing further has been heard, probably in part because a lot of DOH employees have been sitting at home for the last few months.

As of this writing, most of the changes resulting in homecare service availability reductions will not take effect until at least October 1, 2020. These are changes to NY’s Medicaid State Plan and can’t take effect until they are approved by the feds—though there’s little doubt that the Trump Administration will approve them. However, the first round of federal COVID-19 emergency assistance increased the federal share of Medicaid spending by almost 7 percentage points for the duration of the emergency, as long as states don’t cut services or eligibility (the “maintenance of effort,” or MOE clause). Cuomo, in an astonishing display of anti-disability perversity, railed against the MOE because it wouldn’t let him cut services even though the feds were giving him the extra money needed to pay for them. He ranted publicly about it, and behind the scenes pressured the NY congressional delegation to repeal the MOE clause. In May an exception to the MOE specifically for NY was inserted into the fourth round of assistance passed by the House of Representatives. This \$3 billion bill, which would have included assistance for state and local governments that are in serious trouble with lost tax revenue from the economic shutdown, was pronounced “dead on arrival” in the US Senate. At press time there were backroom negotiations on producing a bill to aid state and local governments, which has fairly strong bipartisan support, and we also heard that there was little interest in preserving Cuomo’s MOE exception.

But we’re not done yet. The budget gave Cuomo the option to consider revenues vs expenses on a quarterly basis and propose

more cuts or additions. The legislature has ten days to respond with their own ideas to achieve the same amount of cuts or increases. If they fail to do so, Cuomo gets what he wants. At press time, the bill was coming due at the end of June, and Cuomo was threatening an \$8-billion-plus round of cuts unless Congress comes through with a bail-out. The legislature returned to Albany in the latter part of May. Stay tuned.

## Deaf and Hard-of-Hearing Accessibility during the Pandemic

By Heather Shaffer

Since the COVID-19 pandemic began in March, Governor Andrew Cuomo placed himself on television daily. Many people applauded him as the great leader of our beautiful State of New York, a leader who should run for the President of the United States. His daily press briefings have different platforms: televised news, Facebook, Twitter, Instagram, and they reached not only the people of NY but people all across the US. However, a large group of people in our progressive state were left out of his briefings: people who are Deaf or Hard of Hearing (HOH). There are over 300,000 Deaf/HOH people in New York State. While we are fortunate to have access to technology that provides different approaches to spreading information, we still need access to our language for an effective understanding of what is happening, the daily changes being announced, the implementation of regulations in regard to mask wearing and social distancing, and crucial information that is important for everybody to have and understand.

Yes, closed captioning of the Governor's press conferences is provided. Yes, people can read closed captioning. Unfortunately, closed captioning is not entirely reliable or equally accessible. The captioning goes fast and not everyone is a speed reader. Even hearing people would have difficulty following the captions if they were to use it alone. Sometimes the closed captioning just stops working. When that happens, information is lost. There are people who struggle with reading. Not that we Deaf/HOH people can't read, but as with the general population, there are those who struggle with reading but can hear and process that information. Deaf and HOH rely on their eyes. Sign language is visual and easily accessible.

ASL is the first language for many Deaf/HOH people. For some it is the only language they understand clearly. So without access to the daily briefings, some people were not fully aware of what was happening around them.

Advocates, including our very own Deaf and HOH community, and others all over NY made calls to Governor Cuomo's office stating that they need an interpreter. After very many requests his office began to provide a link on his Facebook page that goes to a separate link which shows a CDI (Certified Deaf Interpreter) in a box next to the governor. These briefings with the CDI are then uploaded to YouTube after the event. This worked great for people who have Facebook and are tech savvy, but not everyone is, and often information was not easily accessible. Deaf/HOH people who don't have Facebook, a computer, smartphone, tablet, access to the internet, or tech news were left out, as were Deaf/HOH people who rely on TV news stations for information. Some people said, "but Cuomo provides PowerPoint—read that!" But the PowerPoint made no sense without interpretation of what Cuomo was explaining.

Enough was enough. Lives are at stake here. All we were asking for was an interpreter to be on the screen with Cuomo, not be in person with him. Today's technology allows an interpreter to be in a separate room, yet have their image appear next to Cuomo's, which is exactly what Cuomo was doing with his ASL link on Facebook. He could have easily used that method from the start. Every other Governor in the United States and many local leaders have an ASL interpreter, six feet away or in a box on screen with them.

Disability Rights New York filed an ADA Title II complaint with the Department of Justice. The complaint was not moving fast enough to help the Deaf/HOH community, so DRNY sued in federal court. On May 11, US District Judge Valerie Caproni ordered Governor Cuomo to provide in-frame ASL interpreters during his daily briefings immediately. A great win for DRNY and the Deaf/HOH community of New York State! To quote Timothy A. Clune, DRNY Executive Director, "our clients can no longer be an afterthought when it comes to daily life matters and especially emergency planning. We should not have been forced to go to court to ensure the safety of thousands of deaf New Yorkers."

## Response to Panic: Lock 'em Up? Or Let 'em Die?

The Washington *Post* reported on a study in May that found that approximately 50% of COVID-19 deaths in the United States up to that time occurred in nursing "homes" and other so-called "adult care" facilities. In some states it's much worse than that; in Pennsylvania about three-quarters of the deaths occurred in those places, and Connecticut reported that during one terrible week in April over 90% of deaths in that state were in nursing facilities. As of April 6, New York State reported that about 1,100 of the approximately 140,000 people with developmental disabilities served by OP-WDD had tested positive for the virus—a rate much higher than for the general population. The *NY Times* reported, on April 9, "a study by a large consortium of private service providers found that residents of group homes and similar facilities in New York City and surrounding areas were 5.34 times more likely than the general population to develop Covid-19 and 4.86 times more likely to die from it. What's more, nearly 10 percent of the homes' residents were displaying Covid-like symptoms but had not yet been tested." Deaths for all types of congregate residential facilities may be under-reported. When I worked at Broome Developmental Center in the early 1980s, we were told, "nobody dies here," because even though the place had doctors on call, any dead bodies were to be quietly moved to hospitals to be pronounced dead so as not to create the wrong impression. This practice continues today in residential facilities, large and small, operated or funded by OP-WDD and OMH.

Why this happens is easy to understand (and we've explained it on page 2). What people don't seem to understand is that the *last* place any elderly or disabled person should be right now, and for the next year or so at least, is a congregate residential facility. All over the world, including the US, authorities saw this problem as being so serious that they released non-violent people from prisons and jails to prevent spreading infection. Yet these same authorities are trying to reduce releases from nursing facilities and increase the numbers of people living in them.

On the federal level, allegedly only to combat the pandemic, the Centers for Medicare and Medicaid Services (CMS):

- waived requirements that hospitals discharging patients must tell them they have a right to choose among all available homecare and residential services, and must give them a list of all available providers of those services.
- waived the requirement that persons seeking admission to nursing facilities be screened before admission for developmental and mental health disabilities that would ordinarily result in them being referred to more appropriate services.
- allowed nursing facilities to stack extra people up in dining rooms, activity rooms, and conference rooms.

In NY, an executive order permits OPWDD residential facilities to exceed certified capacity limits.

A charitable view would be that when people are panicking, they fall back reflexively on stereotypical beliefs. They think of prison as a form of punishment and they don't want blood on their hands for allowing punishment to degenerate into murder. But they think nursing facilities are benign and bend over backwards to make sure that people with disabilities get all the help they need from them. They can't see that prisons and nursing homes are exactly alike in their potential to infect and kill their inmates. There are lots of people with disabilities in prisons and jails; they may actually be luckier right now than those who are kept in "adult care facilities."

A more cynical view would be to point out that over the last couple of decades the disability rights movement has made real progress in getting people out of nursing "homes" and into their own, real homes with appropriate supports. Now the nursing facility operators, whose lobbyists stalk the halls of Congress and state legislatures, and whose former employees lurk in state and federal government health bureaucracies, have seen a chance to regain some ground here.

Sadly, it's no surprise that the first impulse of our leaders was to pit people with and

without disabilities against each other and take actions to make it easier for people with disabilities to be killed by this pandemic. In March, a rash of complaints emerged from around the country that public health authorities were planning to ration care in ways that excluded disabled people.

*The Atlantic* and other sources reported that Washington, Tennessee, Alabama, Kansas, Pennsylvania, Oklahoma, North Carolina, Oregon and NY all had emergency medical rationing plans that would exclude ventilator and other types of life-saving care for people with disabilities. These were considered to be "best practice protocols." The Alabama plan explicitly excluded people with severe intellectual disabilities. Kansas and Tennessee would leave people with "advanced neuromuscular disease" (like ALS, multiple sclerosis and muscular dystrophy) at the bottom of the list for rationed care. In Washington, anybody with a low-enough "baseline status" for physical ability or cognition might be left to die.

Some people have personal portable ventilators that go with them everywhere, including, occasionally, to the hospital. In NY, a plan drawn up in 2015 to allocate scarce ventilators in the event of a pandemic states that hospital triage committees would be expected to take these ventilators away from people if a "sicker" but allegedly more likely-to-survive (or easier to treat) person needs one. The authors felt it necessary to state that medical authorities would not go into people's homes and take their ventilators, but that once they arrive in the hospital, people with personal ventilators would be treated like anyone else. The plan's authors understood that this policy would "make victims" of people with disabilities but they simply did not care. They also acknowledged that the policy would scare disabled people away from hospitals in a pandemic, but they had an answer for that:

"While a policy to triage upon arrival may deter chronic care patients from going to an acute care facility for fear of losing access to their ventilator, it is unfair and in violation of the principles upon which this allocation scheme is based to allow them to remain on

a ventilator without assessing their eligibility. Distributive justice requires that all patients in need of a certain resource be treated equally; if chronic care patients were permitted to keep their ventilators rather than be triaged, the policy could be viewed as favoring this group over the general public."

As *The Atlantic* reported, the people making these decisions tend to believe that people with disabilities have a lower quality of life than nondisabled people do. But they also assume—often correctly—that it may cost more to keep people with significant disabilities alive than nondisabled people.

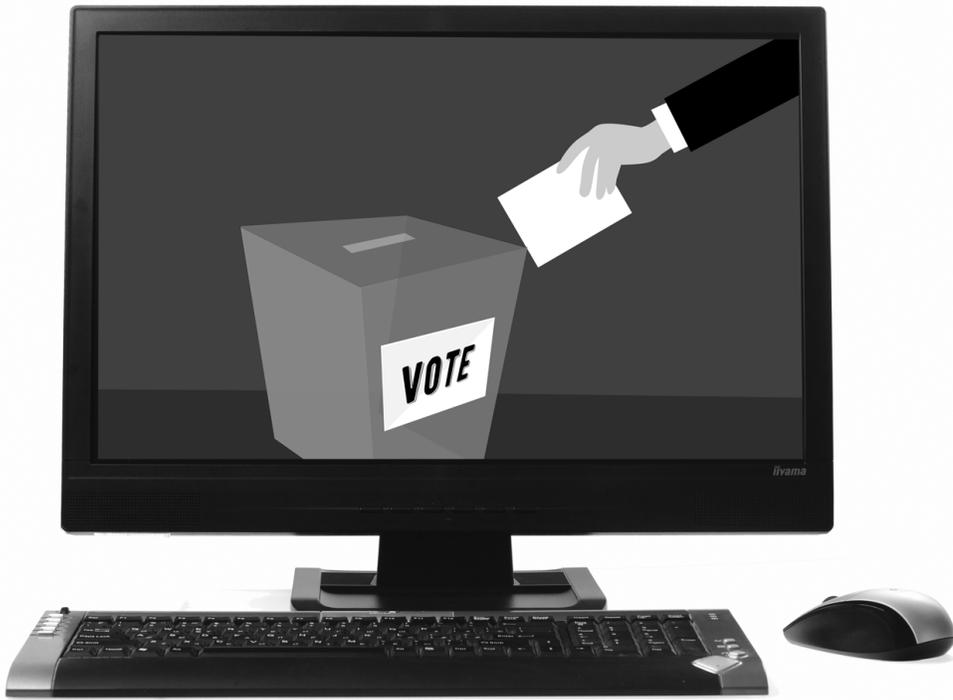
But is it *ever* right to let somebody die when spending more money could save them? Or more to the point, is it right to let poor people die because those who are well-off in this country refuse to pay a truly fair share of taxes? Most people with disabilities live in poverty due to employment discrimination, and disability occurs at a higher rate among disadvantaged minority groups. Who are we *really* proposing to let die, and *why*? Where does "distributive justice" come in here?

After complaints reached the federal government, on March 28, the federal Department of Health and Human Services Office of Civil Rights (OCR) issued a bulletin that told states that these kinds of rationing plans may be illegal; they violate the civil rights of people with disabilities under the Affordable Care Act and Section 504 of the Rehabilitation Act. The bulletin said, "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."

OCR followed up on some complaints and in April reached resolutions with Alabama and Pennsylvania. Complaints are pending in the other states, including one filed by Disability Rights New York on April 7 against the state's ventilator triage plan.

Disability advocates issued urgent advisories on this topic in an effort to prevent people from being cut off from needed services. You have rights! See page 14 for more information.





# Election Security vs Ballot Access

*By Ken Dibble*

On April 21, 2020, a group of advocates for blind people, including the American Council on the Blind, the National Council on Independent Living, and the New York Association on Independent Living (NYAIL), filed a civil rights complaint with the US Department of Justice's Office of Civil Rights (OCR) concerning NYS Governor Cuomo's COVID-19-related executive order on voting. The advocates say the order, which suspends in-person voting and requires elections to be conducted by absentee ballots, violates "federal law" because it does not provide a way for blind voters to vote privately and independently. A press release issued by the group's lawyer states, "On-line accessible options are available and are in use in other States. There is no reason New York cannot provide its residents with such an available accommodation."

As a disability rights advocate, I am sympathetic. As someone whose responsibilities include cyber-security, however, I am going to have to pass on some tough facts.

**There is NO SUCH THING as secure online voting.**

In late April NPR reported that, "When asked about security concerns with the technology, [Eric Bridges, Executive Director of the American Council of the

Blind] said that's not his job, that's the role of security firms and the government. 'We want access,' Bridges said. 'It's not really up to the American Council of the Blind to ensure that these systems are secure.'"

This borders on the irresponsible. In 2016, the Obama Administration discovered that Russian agents had penetrated the voter registration systems of several states and could have easily modified registration data. Obama was concerned that if his administration announced this discovery so close to that year's election, in the wake of candidate Trump's public request that the Russians hack his opponent's emails, that he could appear to be taking a partisan position. So he provided secret evidence of the hacks to Senate Majority Leader Mitch McConnell and asked him to issue a joint statement with him. McConnell refused. He told Obama that if he made a solo announcement he would lead the accusations of election interference in the media.

The United States, right now, is not a country in which our leaders can be counted on to protect the integrity of our elections.

Many of the most prominent and respected cyber security experts have

repeatedly warned against implementing voting systems that don't produce paper records or which allow for internet voting. Bruce Schneier is one of these people. If you visit his website and search on "voting" you will find a great deal of information that should clarify the issues: [https://www.schneier.com/news/archives/2019/10/bruce\\_schneier\\_on\\_ho.html](https://www.schneier.com/news/archives/2019/10/bruce_schneier_on_ho.html)

These experts agree that a paper ballot is an essential aspect of secure voting. It is far more difficult to alter a paper ballot than it is to alter electronic voting data without getting caught.

As to the "other states" that "have" online accessible voting, there are just two, only one of which has actually used the system in an election, West Virginia in 2018, and only with a small number of overseas voters. (The other, Delaware, has a system in place that it plans to use this year.) The press release issued by the lawyer who filed the complaint also says that WV's effort was successful and secure, a claim for which there is no evidence.

The system used in WV is called "Democracy Live," and its creators are so skittish about this issue that they refuse to admit that it is, in fact, internet voting. They claim it's really

a paper-based system because it just allows a person to fill in a ballot using an online website; an election official has to print out the ballot before it can be counted. But the ballot is generated and transmitted electronically before it is printed, and so is subject to a broad array of vulnerabilities.

*Lest you assume that an electronic voting record would be kept safe or counted accurately once it reaches a state-operated database, here's a story that should give you pause.*

There are various problems with online voting, beginning with determining the identity of the voter who is using the website with 100% accuracy, and ending with what happens to the votes once they reach the election authority. But let's consider just one aspect.

There are several points during the transmission process where a person's ballot choices could be intercepted by a hostile entity and edited before sending them along to their final destination. Although there are theoretical ways to protect the process, they all rely on having all of the relevant devices and software fully patched with all of the latest security fixes. This is something that almost NEVER happens. In reality, almost everyone casting a vote in this way will be sending that vote through a series of processes that are highly vulnerable to attack.

Lest you assume that an electronic voting record would be kept safe or counted accurately once it reaches a state-operated database, here's a story that should give you pause. In January 2020 NYS officials announced that several databases used by state agencies had been hacked by criminals from outside the US. The criminals exploited a known vulnerability in NY's computer network for which a patch had been issued more than a month earlier. If the state had a competent cyber security team, it would have patched the problem before the hack occurred. The lesson here is that the best way to be safe when using computers is not to rely on government or "experts" to protect us, but to use common sense and avoid doing risky things when there's no compelling reason to do them.

The danger of enabling criminals and hostile governments to hack our election

systems doesn't require such hacking to change an election outcome. The danger is that the American people will come to believe that all of their elections are rigged, and that it doesn't matter who they vote for. That will create a situation in which every election is fought in the courts, and, perhaps, the streets. It's clear that our

current president was gearing up for just such a scenario with his frequent claims that the election process was rigged, up to the point when he began to win. It is very likely that we will hear those claims again if he doesn't do well this November. And it is quite likely that his loyal base will believe him. Think about what could happen then.

There currently exists a product that enables a state to issue ballots to people at home in the form of an HTML document that can be displayed and filled out in a web browser without being connected to the internet. The person's screen-reading software would speak the ballot to the person as they filled it out, and when they finished they could print it. Before mailing it to the election authorities they could, and should, scan it and read it to make sure it printed properly.

I think this could address any security concerns, with the important caveat that the system must enforce a **requirement** that there be no internet connection while the HTML ballot is being filled out and printed. It's not sufficient merely that it **can** work offline; if it doesn't **have to** work offline, many people will decide it's too inconvenient to shut down their internet while voting. But I am not a top expert in this field. I would urge any election authority looking at this to have it vetted by such renowned people as Bruce Schneier and Brian Krebs before adopting it.

NY is persistent (and may be alone at this point) among states in insisting on a "full-face" ballot that displays all voting options in table format on one page. Tables can be difficult for some screen readers and some blind people to read. Full accessibility might require the state to enact a law to

end the full-face ballot requirement, a political football that delayed adoption of accessible voting machines early this century before a machine was found that could handle it.

In-person voting, with accessible, though "quirky" voting machines may resume in NY before this issue is resolved. We support accessible voting as an option for those who do not have, or wish to use, someone to help them fill out any by-mail or absentee ballot, and this is not currently available in NY, even in normal times. We don't support taking hasty actions that can compromise election security and the public's faith in our democracy merely because these are not normal times.

At press time we learned there was a settlement in the case. We haven't been able to review its details, but it may rely on fillable PDF forms, which is a potentially hackable technology, depending on how the forms are distributed to the voters. Stay tuned.

## **Rotenberg Shocker: There IS Gain WITHOUT Pain**

On March 6, 2020, after years of advocacy and protests by people with disabilities, and four years of pondering, the United States Food and Drug Administration (FDA) finally banned the use of electric shock devices as punishment for undesirable behavior in people with disabilities.

This was a tremendous victory for long-suffering advocates, and the celebrations were just getting underway when, on March 27, the FDA placed an indefinite stay on its own ban.

Why? Because the Judge Rotenberg Center, the only program in the US that shocks people for punishment, and their rabid little group of deluded—but well-funded—parents, told them they plan to oppose the ban in the Federal Circuit Court of Appeals for the District of Columbia.

The ban has two parts. The first part bans the use of the shock devices for anyone not already being so tortured effective April 6. But the second part allows a 180-day "transition period" during which the 50 or

so people being shocked by Rotenberg would work with physicians to develop a plan to be weaned off the devices, which hopefully would be replaced with positive behavioral supports. That's the part that's been stayed.

The FDA could have told Rotenberg and the parents to pound sand and they'd see them in court, but they didn't. Why? Because COVID-19.

What? You ask. Here's what they said:

"FDA plays a critical role in protecting the United States from threats, including emerging infectious diseases like the COVID-19 pandemic, and we advise limiting individual contact with health-care providers to reduce the potential for exposure to COVID-19 as well as to conserve healthcare delivery resources. Creation or implementation of a physician-directed transition plan has the potential to increase the risk of transmission or exposure to COVID-19, and it may divert healthcare delivery resources from other uses during the pandemic."

The stay thus applies only to the only actual people that this issue affects—the people being shocked today. The prohibition on new victims remains in effect—as if there were ever going to be any new victims. The stay is in effect for the duration of the emergency, plus whatever time it takes for the FDA and/or the court to respond to the appeal petition.

Let's look at this more closely. Who are these "physicians" who will be "directing" these transition plans? They will be psychiatrists, since they are the only physicians that work with behavioral issues. COVID-19 isn't going to keep psychiatrists busy intubating people or administering experimental anti-viral drugs; that isn't the sort of thing they do. And the people who would have to carry out these plans would be the same ones who already work with these people in the Rotenberg facilities, with whom they've been exchanging germs for years. None of those workers is suddenly going to run off

and start working in a hospital with COVID patients. So there is no actual "public health" basis for this stay.

Before the panic infected the FDA, they issued a response to public comment along with the ban order, which contained a rather remarkable statement: It said that pain, in and of itself, is harm. And over the last 30 years or so, the behavioral science profession has concluded that pain is no longer an acceptable price to pay for behavioral improvement. This is no surprise to most of the conscientious and caring professionals we work with, but it comes as a ... er ... well ... shock to the Rotenbergs and their hangers-on. When there is no objective evidence that pain brings long-term results, and plenty of evidence that other methods that don't involve pain at all do work, then no amount of pain is acceptable. It's the first time, we believe, that a US government body has taken that position. That is, indeed, a victory that has potential to benefit everybody.

## courts watch

### ***DRNY v NYS Department of Corrections: Paperwork is real work***

This case concerns efforts by Disability Rights New York (DRNY), the state's designated watchdog organization for various providers of services to people with a broad range of disabilities, to obtain records concerning inmates of state prisons under the control of the NY State Department of Corrections and Community Supervision (DOCCS). DOCCS delayed responding, or failed to respond, to DRNY's requests for records pertaining to over 35 inmates. Federal laws and regulations give DRNY the authority to obtain just about any records about people with disabilities that it requests for the purpose of determining whether abuse or neglect took place. That makes this a federal case and it was filed in federal district court for the Northern District of New York in August, 2018.

The case illustrates the limits to which the "letter" of ambiguous laws and

regulations can be enforced, as well as the importance of government agencies behaving in a way that inspires trust in their intentions.

At least four different federal laws govern "protection & advocacy" (P&A) agencies like DRNY. Some of them require organizations to fulfill requests for records within a specified, small, number of days. Others only say such requests should be met "promptly."

Similar previous cases have resulted in the conclusion that the meaning of "prompt," and whether any specific deadline must be taken seriously, depends on how many records are requested and the difficulty in producing them.

In these cases the question of whether the organization that holds the records is acting in good faith and having difficulty meeting the requests, or has been doing something that it doesn't want to see the light of day, becomes important. If an organization like DOCCS wants to

demonstrate good faith, it might want to respond, quickly and politely, to complaints about delays by saying, "Hey, we're reviewing the records carefully so we aren't giving you something you aren't entitled to have. Please bear with us." Instead, DOCCS typically responded with silence to repeated requests until it was good and ready to provide records, and sometimes flat out refused to provide them for obviously bogus reasons. They claimed, for example, that HIPAA prevents them from releasing records, but the inmates in almost all of these cases signed a release allowing DRNY to see the records, as HIPAA requires. Or they claimed DRNY had to provide evidence that abuse or neglect had occurred in order to get the records, but that is absurd. The laws governing DRNY state clearly that if it has reason to suspect fraud or abuse, it has the right to any relevant records, period. In most of these cases, DRNY had complaints from the inmates. In one case, the inmate had died in pris-

on. DOCCS also claimed they'd complied with requirements for promptness and fixed deadlines by telling DRNY they could come in and physically inspect the records and make their own copies whenever they wanted. But when one DRNY representative showed up to do just that, they were told the records weren't available.

In a different world, one in which, over the eight years of DRNY's existence as the state's first truly independent P&A agency, all of the various NY state agencies serving people with disabilities, which were used to dealing with an "oversight" body that was itself a state agency with a reputation for sweeping scandals under the rug, had not repeatedly stonewalled DRNY's requests for records, DRNY might be moved to give DOCCS the benefit of the doubt. But these agencies seem to think this is some kind of "catch me if you can" game. They don't behave like neutral institutions upholding the public trust, but like people with something to hide. Most folks would be suspicious and

unwilling to take any more guff after a few years of such behavior. And so was DRNY. They said that the time it takes to procure records isn't their problem, and it wasn't their job to send people to physically look at records that DOCCS was absolutely required to hand over by mail, courier, or electronic transmission, and they wanted those records NOW.

And that is where they stumbled. Judges aren't allowed to be suspicious and distrustful of state agencies, unless and until those agencies jerk *them* around. In his initial decision on September 24, 2019, this judge pointed out that federal regulations allowed P&A agencies to "inspect" records and request the specific documents they need; they could even make their own copies. Therefore, in many of the individual inmates' cases, DOCCS had offered DRNY a reasonable alternative to waiting weeks or months for records and DRNY should have taken them up on it.

At that point, the US Department of Justice (DOJ) entered the fray. They is-

sued a "friend of the court" brief in support of DRNY, stating that federal law does not require P&A agencies to physically inspect records before they can expect to receive copies, and organizations like DOCCS must simply respond to all appropriate requests by providing the records in either paper or electronic format, within the time frames given by the regulations, period.



## STIC NEWS



### STIC COVID-19 Update

By Maria Dibble

It seems like a year since the Governor closed all non-essential businesses and ordered New Yorkers to "shelter in place," but it has just been a little over two months as of this writing.

STIC is designated as an "essential business" due to the services we provide to people with disabilities in our area, including Community Habilitation, Consumer Directed Personal Assistance, and Supported Employment. Our workers have been serving people face-to-face, via telephone or the internet since the beginning of the shut-down, putting themselves and their families at risk to assist people to safely weather this pandemic, and they deserve our thanks for their selflessness and dedication.

At first, we had to furlough about 90 employees, but with some federal support

from the Payroll Protection Program, we've been fortunate enough to bring most of them back.

Our employees who aren't working in the community are working at home, and are keeping in contact by phone with consumers, attending virtual meetings, and performing as much of their work as possible under the circumstances. As many have said of late, thank goodness for Zoom.

I won't say it has been easy for many, trying to manage work while children are home and the like, but I think we are quite fortunate that none of our employees have contracted the virus, unlike my colleagues in NYC, where illness among staff and consumers is rampant.

It was quite the scramble for our IT Department to gather information about the types of internet service our employees have at home, and set up computers with the appropriate software so

that workers could access their work email and other information available on STIC's servers. It was a challenge, but we met it and things have gone very smoothly since then.

Many have asked when we will officially open, and I sadly don't have an answer. But whenever that time arrives, we will do it in a measured and careful manner, to ensure the safety of our workers and consumers. Staff will return to the office gradually, complying with social distancing and using masks and gloves as appropriate. We have added new protocols for cleaning and sanitizing the building, including commonly touched surfaces such as door knobs and light switches. It would be foolish on our part to rush things and waste the good fortune we've had to date. The final step will be to open our doors to consumers and visitors. Much depends on how the reopening goes all over the community. If the

rate of infection continues to decline, or at least remains steady, we'll consider the risks vs the benefits and make our decisions accordingly. The health and safety of employees and consumers is paramount and will govern our overall process for reopening.

We currently have some employees in the office, including myself, and the phones are being answered and calls forwarded to the appropriate staff, so feel free to contact us.

Lastly, as per the Department of Health, as well as STIC, our loan closet is closed for the duration of the emergency. This is due to the real danger of transmitting the virus on equipment, or bringing it into STIC inadvertently from outside borrowers. We deeply regret any difficulties or inconvenience this has or will cause, but it is necessary in the current environment. I mention this service because we are getting calls for loan equipment that we, regrettably, can't fulfill.

I hope all of you are managing under our newly restricted lifestyles, staying both physically and emotionally well. We are a phone call away if you need us. We will keep you informed of any future developments.

## **Coronavirus 2020— Working at Home**

By Kim Kappler

*A new experience or a new norm or both?  
To be determined...*

I have learned many things as we live and make new experiences professionally and personally.

The word came and isolation and distancing began; what does that mean—what do we do—how do we do it?! Frustration sets in, uncertainty starts, fear in place, children at home all day, home schooling begins, job diminishing, retirement funds disappearing. Layoffs begin, unemployment unreachable, life turned upside down and bills to pay and food to buy. What do we do?

New policies and procedures developed and implemented, direction provided. Laptops, printers and scanner too, put in place for me and you. We march forward

with fury and commitment as we always have; are our consumers ok? What do they have? Do they, do we have all that we need? We have the tools; we always have, what more do I need?

I rearrange my living room to set up office space, only to realize every day it is in my face. I need a break and change the space. I move things in a different place. It is in a room with a door. I can close it when it is 4 (or 10, 1, 3, 6, 8 etc.)

I keep my daily routine, up at 5 and get ready for work. Open the door and turn the laptop on. Check my email and ready to work. Maintaining a schedule is key for me; although I do like the option of flexibility. I thought the time would go slow, but as usual I don't know where it goes. Phone calls, emails too keep me connected with my consumers and you people too.

I miss the team and the chit chats in between; but the technology gives us what we need. Conference calls at 1 & 3; keeps us connected in a new way for you and me.

Our work is important whether we are near or far...in our office or in a car. I enjoy working at home and glad I can. I am happy to work for an agency that values me as much as they value the consumers and supports me and provides the tools to support the people I work with. Thank you for your continued support!

## **FI during the CRISIS!**

By Rhonda White

Hello everyone: These have been trying times for all of us. Do this! Do that! Never mind do this again! To say the least, it has been confusing, if not downright scary. But here at STIC we have strong leadership. Maria, Jen, and Ken have been right there to assist us all to keep serving you!

It starts with "working at home." WHAT?—How can we serve people without seeing them face-to-face? Well at first it was definitely a hard concept to wrap our heads around. But Ken and his IT team jumped into overdrive and set us up. I am proud to say that this "OLD LADY" is completing conference calls and videoconferences from home with ease. STIC

is here to help with all your Self Direction Fiscal Intermediary (FI) Service needs!

STIC is still accepting new Self Direction approvals. We are developing a system to continue processing start-up budgets and starting new staff with individuals, with independence and safety as our first priority. I am proud to state that it really has been a fairly smooth process that just takes a little longer, as our FI program is developed around a true person-centered process. It has been our intention to stay focused on the people and not the money!

So if you are approved with OPWDD services and would like to start Self Direction, just ask your Care Manager to put in a "Service Amendment Request Form" (SARF) for you or your family member. Once approved, you will be sent a list of Brokers and FI agencies to choose from. Please interview as many as possible so you are comfortable with your TEAM through the COVID-19 crisis and after. You are your own or your child's best advocate. In the Self Direction process, you are the team leader and we are here to assist in developing a strong program for health, safety and independence within OPWDD guidelines. Up until now, there has been limited choice for FI services in this area, but now YOU CAN CHANGE your FI provider. I am happy to say that STIC and several others are now choices for you. I would encourage you to interview a few, even if you do not choose STIC. Just make sure you choose who is right for you!

Now for those of you who are thinking—Geez she sounds like she has it all together. No, not really! The first few weeks were really hard here at our house. With two adults working from home and one teen trying to keep up with school work, it has often been an internet nightmare. First off, we established a work schedule so that we only had two on at a time. Strict organization has been a key lesson. However, if our schedule is messed up for some reason, we do fall apart.

Here's something I find funny now that it is over. Ken might not, but I am still laughing (*Ken is still laughing too—Ed.*) I had to

use the scanner and it just wouldn't work. Frustrated, I contacted the IT team, and we found that I never turned it on. So, I turned it on and it still wasn't responding. After a few emails back and forth, I started taking pictures of each command it was giving me. OOPS—I guess you have to put something in the scanner for it to scan. Not my finest moment, but that's the second thing we learned here. Be kind and patient with yourself!

The most important thing is to allow yourself to make mistakes! Oh Lord—COOKING and house cleaning. You

would think we would have a nice neat house during all our time at home, but think again. Some days it looks like a hurricane came through here. As for cooking—I need to remind myself that I am not going to be an awesome cook over night. My poor children taste everything slowly now. I've burned things; I've substituted items that I thought might work to find out that sometimes hamburgers on the grill are our best friend. And then it snows! So—peanut butter and jelly sandwiches for everyone! Or better known as—"Fend for yourself night!"

Finally, though we are all going through this together, we each have our different circumstances and reality. Be kind to others who might be going through different things than you. Assist others if you can, because it will make you feel better to be able to help. Sometimes a phone call from a friend can make our worst day better. And know that none of us have been through this before and we all are doing the best we can. So I end with this—Stay Safe! Stay Calm! Stay Kind!

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# Xscapes: *We'll be Baaaaack!*

By Bill Bartlow

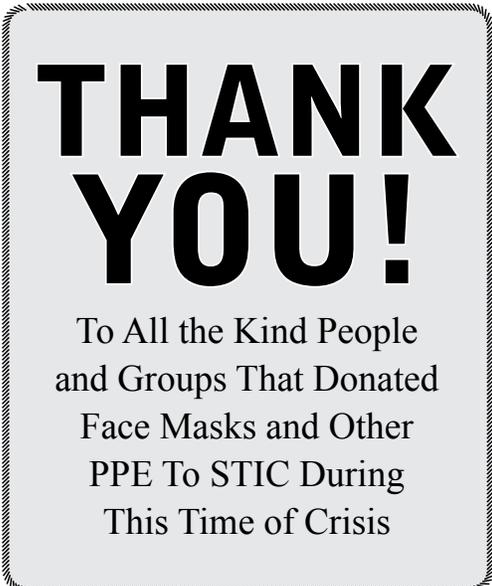
We are fortunate that STIC perseveres through this global pandemic, adapting to a unique set of challenges to serve our community. For safety reasons, though, Xscapes has been on a two-month hiatus. But beginning Monday, May 11, our team was back in action. We are retiring the hugely popular "Pulse" escape room and creating a new and even more exciting Xscape experience, "Exit Protocol." We hope to have it ready for you in a few months.

We are redesigning the physical space and creating a dazzling high-tech espionage experience. It goes like this: Your team has been read-in to the sensitive

and critical mission. Enter the "Chenango Insurance Associates" office, which is a front for clandestine operations of national security importance. But intelligence analysis reveals that the agency is compromised. A directive was sent to the station chief to retrieve all critical information and destroy the facility. Having seen no progress, we assume he has been terminated. Your team must complete the mission before enemy agents arrive in about an hour. No pressure!

A Critical Consideration: We have all become hyperaware of contagion issues, but you can rest assured that we will take all appropriate measures to

ensure your safety and minimize threat of exposure to potentially infectious agents by sanitizing our rooms between each group's use. I am fortunate to have over 40 years of experience and training in operating room sterility techniques. As a Navy corpsman and operating room technician, I know what sanitized means. You will enjoy care-free and long overdue relief from stress with much needed entertainment. We are responsible people here and take seriously the inherent trust you invest in us. So, when we reopen, come on in, and enjoy yourselves.



# Working from Home

by Charlie Kramer

Working from home is more difficult than it appears. I thought that FaceTime, Zoom, and phone calls would be more or less that same energy output as the normal work with face-to-face meetings. Well I am wrong. Personal contact with consumers or other staff actually gives

us more than we realize. We get endorphins from being with others. There is a feedback loop that gives us that energy even when we are the provider.

So if you're feeling low even when you have family around, it can be that the positive energy we get from the

outside contacts is missing. I know that some of our consumers have no one except us and a few other providers as resources. So we will keep this all in perspective. To quote Crosby, Stills and Nash, "Rejoice, Rejoice, we have no choice but to carry on!"

## STIC HELP

### COVID-19 Resources

Many people have contributed resources for those seeking information or assistance with a range of issues from preventing illness to helping sick friends and relatives, to getting your stimulus check. This is a selected set of items that we thought might be of most importance at the end of May. This is a rapidly changing situation and we apologize if any of this is out of date by the time you read this. Feel free to ask your favorite STIC-sters for updated information.

#### This is Real

We at STIC would like to emphasize that the dangers of transmission of the COVID-19 virus by unprotected people in relatively close contact are very real and very severe. An infectious disease expert has provided the following information (<https://www.erinbromage.com/post/the-risks-know-them-avoid-them>):

It matters how long you are exposed in unprotected settings. A single breath from an infected person in a closed room may infect everyone in that room within 50 minutes. A cough or a sneeze in that room can infect everyone there in just a few minutes. An infected person, merely by talking face-to-face to one person, can

release enough virus to infect that person in 5 minutes.

It doesn't matter if the people you encounter have any symptoms of the disease. About 44% of all COVID-19 infections were transmitted by people who had no symptoms, and people may not show symptoms for three to five days after they become contagious.

We know that everyone is hurting. ***But this is not a partisan political issue.*** Nobody wants people to lose their livelihoods or the economy to tank. This is not some left-wing conspiracy to keep you and your friends out of bars and restaurants, or from worshipping or celebrating life's most important events together. Until we have enough reliable tests and effective treatments for this disease, anybody who spends much time without a mask in an enclosed space with other people who are not known absolutely to be virus-free is **LIKELY TO GET INFECTED**. Even if you wear a mask, if you spend enough time in such a place, you may get infected.

#### Symptom Check Card for Deaf People

The New York State Department of Health developed a COVID-19 Symptom Check card to assist medical professionals and Deaf/Hard of Hearing (HOH) individuals to communicate regarding COVID-19 symptoms. Deaf/HOH people can use the icons on the card to convey their preferred method of communication, level of pain, symptoms, time frame of symptoms, and

if they've had close contact with someone who has COVID-19. It can be printed out via this link:

[https://coronavirus.health.ny.gov/system/files/documents/2020/05/13104\\_015773\\_covid19\\_hearingimpairedcard\\_version4.pdf](https://coronavirus.health.ny.gov/system/files/documents/2020/05/13104_015773_covid19_hearingimpairedcard_version4.pdf)

**Information on CARES Act provisions** (stimulus and unemployment money, SNAP, and more) can be found here:

<https://empirejustice.org/covid-19-resources/>

#### Testing Options and more in Broome County

<http://www.gobroomecounty.com/hd/coronavirus>

#### Medicaid Eligibility Automatically Extended for 12 Months

The NYS Department of Health has extended Medicaid for all cases active in March for 12 months automatically, and for active cases expiring in April, May, and June. This means that consumers and clients do not need to submit renewals for these months. The same waiver applies to the service reauthorizations, meaning no M11-qs required.

#### The Illegality of Medical Rationing on the Basis of Disability

From the Disability Rights Education and Defense Fund

<https://dredf.org/the-illegality-of-medical-rationing-on-the-basis-of-disability/>

# NY Hospitals Must Allow “Patient Support Persons” as Visitors

Here’s an abridged version of the NYS Department of Health policy:

Effective March 27, 2020, hospitals must suspend all visitation except for patient support persons, or family members and/or legal representatives of patients in imminent end-of-life situations.

Hospitals are required to permit a patient support person at the patient bedside for:

- Patients in labor and delivery;
- Pediatric patients;
- Patients for whom a support person is determined to be medically necessary, including patients with intellectual and/or developmental disabilities, or cognitive impairments including dementia.

Given the risk of COVID-19 in healthcare settings, healthcare providers should thoroughly discuss the potential risks and benefits of a support person’s presence at the bedside with both the patient (if 18 years of age or older) and the support person. For those patients and support persons who make informed decisions that a support person at the bedside is essential, hospitals should develop protocols for minimizing risk of potential COVID-19 transmission, including when the patient is confirmed or suspected to have COVID-19.

- For labor and delivery, the Department considers one support person essential to patient care throughout labor, delivery, and the immediate postpartum period, including recovery. This person can be the patient’s spouse, partner, sibling, doula, or another person they choose. This person can stay in all Article 28 settings with the patient and will be the only support person allowed to be present during the patient’s care.
- For pediatric patients, the Department considers one support person at a time as essential to patient care in the emergency room or during hospitalization. For hospitalized pediatric patients, especially with prolonged hospitalizations, the patient or

family/caregiver may designate two support people, but only one support person may be present at a time.

- For patients for whom a support person has been determined to be medically necessary, including patients with intellectual and/or developmental disabilities (I/DD), or with cognitive impairments including dementia, the Department considers one support person at a time as essential to patient care in the emergency room or during hospitalization. For these hospitalized patients, especially with prolonged hospitalizations, the patient or family/caregiver may designate two support people, but only one support person may be present at a time. This support person can be the patient’s family, caregiver, or another person they chose. In these settings, the person will be the only support person allowed to be present during the patient’s care.

- For patients in imminent end-of-life situations, the Department considers one family member and/or legal representative at a time as a support person who should be permitted at the patient bedside. Imminent end-of-life situations are defined as a patient whose death is anticipated within less than 24 hours. The patient and/or family/caregiver may designate up to two support people, but only one support person may be present at a time. In the event the patient is a parent of a minor child, one adult family member and one child may be permitted at the patient bedside.

These restrictions must be explained to the patient and/or support person in plain terms, upon arrival, or ideally, prior to arriving at the hospital. Hospital staff should ensure that the patient and/or support person fully understand the restrictions. Individuals age 70 years or older are not encouraged to be support persons at this time due to increased risk of COVID-19 infection.

With all patients—confirmed, suspected, and tested COVID-19-free—the support persons should:

- Wear a surgical or procedure mask throughout their time in the hospital;
- Practice scrupulous hand hygiene;
- Remain in the patient’s room except for entrance and exit from the hospital; and if the patient has confirmed or suspected COVID-19, the support person should, in addition to the measures listed above:
- While in the room, wear a gown and gloves to prevent the person’s hands or clothes from becoming contaminated. Eye protection should be worn while in the room if available.

Hospital staff must screen the support person for symptoms of COVID-19 (e.g., fever, sore throat, runny nose, cough, shortness of breath, muscle aches, or diarrhea) and conduct a temperature check prior to entering the clinical area and every 12 hours thereafter. When providing personal protective equipment to a support person, instructions on PPE conservation strategies should be provided (i.e. prolonged wearing). If a support person has confirmed or suspected COVID-19 or develops symptoms, they should be excluded from the facility.

In this situation, through informed decision making the patient and family may select a different support person. Hospitals should develop clear protocols for communicating with family members or caregivers of any patient who does not have a support person at the bedside. This should include considerations for assisting patient and family member communication through remote methods when possible, for example, via phone or video call. Hospitals must post signage notifying the public of the suspension of visitation in all hospital entrances and parking lots. In addition, these policies should be posted to the hospital’s website and social media pages.



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

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