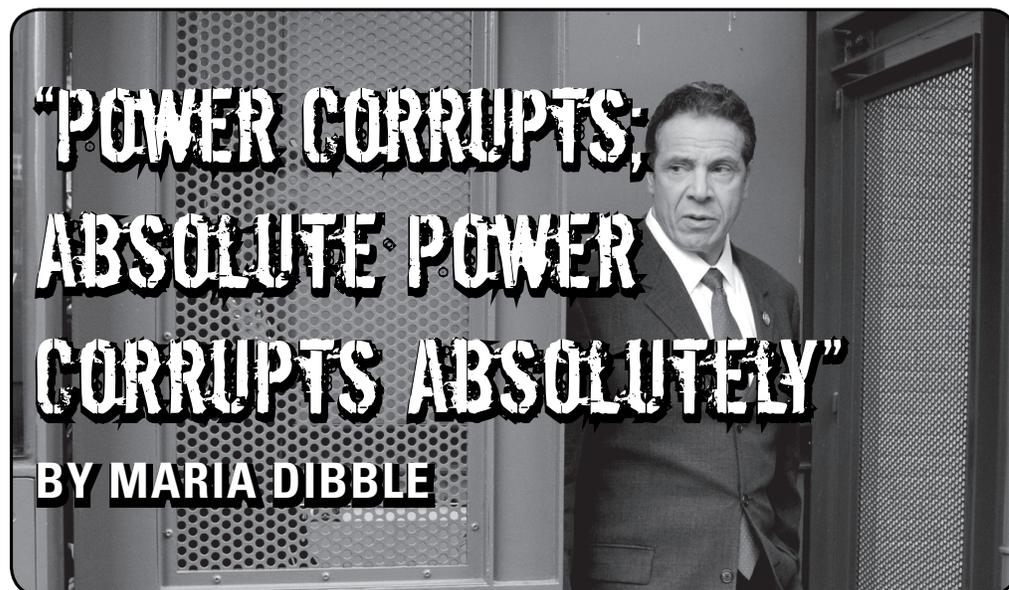


AccessAbility

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Former Governor Andrew Cuomo is the latest example of that famous saying, which has likely haunted humanity since the beginning of civilization.

We should have recognized the signs when he somehow strong-armed the legislature into giving him more budgetary power during his first term, which he has been ruthless in wielding for his own ends. Now that he has left office, people with disabilities can breathe a deep sigh of relief, with few if any tears being shed over his departure.

The media have spent a great deal of time on Cuomo's sexual harassment scandal, and rightfully so. Lost in the mix, however, is his legacy of neglect, disdain and outright hostility toward people who are elderly and/or have disabilities.

In his tenure, he decided to largely ignore, or blatantly work against, policies that would improve the lives of people with disabilities. He immediately targeted Medicaid, creating a global spending cap that was unrealistic and largely unsustainable, and resulted in cuts to essential

programs and services for people who are elderly and disabled.

He repeatedly said that Medicaid costs were too high, and implemented managed care to solve the problem. It has, in my opinion, been a massive failure. Prior to managed care STIC billed NY directly; now we bill the managed care organization (MCO), which then bills the state. How can you save money when you insert another layer of payment between the service and the final payer?

One thing I will say about the MCOs, they recognized that CDPA was the least expensive of the personal care options, and funneled as many people as they could to the CDPA program, dramatically increasing the numbers receiving the service. So what did the Governor do? He said CDPA was costing too much based on its high numbers and cut the program. He neglected to look at the other "traditional" homecare options whose numbers surely grew more slowly because of the MCOs' actions. He targeted CDPA specifically, even though it was the least expensive and most effi-

cient program, and was highly preferred by a large number of consumers.

He created the Medicaid Redesign Team (MRT), stacked mostly with his cronies and donors and a few token advocates, and charged them with proposing cuts to Medicaid that were laughingly called "efficiencies". The MRT recommended changes to Personal Care eligibility so that fewer people would qualify, a reduction of the number of Fiscal Intermediaries (like STIC) in the CDPA program, and other changes harmful to people with disabilities.

Among other actions, the Governor made cuts to Medicaid home and community based services but then provided additional funding to nursing homes, whose largest lobbying group was a major donor to his campaigns; failed to live up to several promises to provide employment

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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.

opportunities for people with disabilities; and repeatedly vetoed bills supported by the disability community, some of which included language provided by the Governor's office.

He is applauded for raising the minimum wage in NY to \$15 per hour, but often people forget that while this figure applies to everyone in New York City and some surrounding areas, it only applies to fast food workers upstate. I agree those workers deserved a raise, but what about the rest of the low-income upstate workers, for whom the minimum is only \$12.50/hour? Over and over again he has ignored the crisis caused by the significant shortage of homecare workers in NY, and by increasing the minimum wage for one group but not everyone, he has made that crisis even worse. He has, in essence, said that flipping a burger is more valuable than helping a disabled person live independently in the community. He has supported huge infrastructure projects but has refused to fund independent living centers adequately, or to reinstate the NYS Office of the Advocate for People with Disabilities, a very low-budget item.

We have protested his actions in letters, emails, newspaper articles, and eventually through rallies, where some people were arrested for their outspokenness, and he has ignored all of our efforts. If anything, the more we objected the more it seemed he targeted our community. As the lead representative of the people, he should be listening, not retaliating, but that's where the quote at the beginning of the article comes into play, because who could stand up to his bullying? When we approached

the legislature, they supported many of our issues, but at the end of the day, most of those issues never made it into the budget. When asked why, we were told that the Governor didn't agree. But it's "three people in a room"; two of them could have overruled him, but they didn't.

And let us not forget the COVID nursing home scandal. Covering up the deaths of elderly and disabled people must have seemed like a cake walk to him. After all, who cares about those "throw away people"? He thought he could lie with impunity, but he got called out on his egregious actions and tactics. He forgot that elderly and disabled individuals have families, friends and advocates who love and care about them and don't think they are like so much junk that can be tossed in the garbage and forgotten. That scandal began over a year ago, but what followed this spring brought him down to his self-serving, pompous resignation speech.

Eleven courageous women stood up to him, denounced him for the disrespectful bully he is, and with the Attorney General's assistance, dealt Cuomo a stunning blow. But in the end, it was his longstanding meanness, vindictiveness, and cruelty to those around him that left him without friends when he needed them, and brought about his final downfall.

He's a shameless bully who thought he was invincible. I hope he reaps the rewards he justly deserves and has most definitely earned.

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.

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American Rescue Plan Needs Rescuing

The American Rescue Plan (ARP) was the Biden Administration's first big COVID-response bill; it was signed into law on March 11, 2021. It included, among many other things, billions of dollars that states can use to supplement their Medicaid home and community-based services.

As explained by New York State Department of Health (DOH) officials, NY was required to submit its plan for how it wants to use this money to the federal Centers for Medicare and Medicaid Services (CMS) by around the middle of July. A guidance document released by CMS on May 13 indicates that the agency would approve the plan within 30 days if there were no problems with it.

The requirements that states must meet to get this money are devilishly complicated, and the timetable was extremely short. However, CMS required states to collect public comment on the plan, and DOH, and the state Offices for People with Developmental Disabilities (OPWDD), Mental Health (OMH), and Addiction Services and Supports (OASAS) did so, in a series of webinars ranging from mid-March into early June. (The OMH webinars asked for input on how to use COVID relief funding from the Trump December 2020 law as well as the Biden money.)

DOH issued written transcripts of its webinars as well as recordings; OMH and OASAS published recordings, and to date, OPWDD has not published anything. (You can read the plan and access the transcripts and recordings here: https://health.ny.gov/health_care/medicaid/redesign/hcbs/enhanced_funding/) We were able to read all of the DOH transcripts and listen to one OMH meeting, but we didn't have time to listen to all of the recorded events. Due to the short federal time frame there wasn't a lot of notice for these events and the critics are right: they weren't widely publicized, and they don't appear to have been well-attended. A representative of the New York Association on Independent Living, to which STIC belongs, did attend at least one of the DOH forums.

DOH submitted its "initial draft" plan to CMS on July 8. Since then it has been heavily criticized by a variety of disability advocates for failing to do enough for homecare and for using some of the money inappropriately. The planners were also criticized for failing to effectively publicize opportunities for public comment. As this is being written in late August, according to its own timeline CMS should have already approved the plan if it contained no errors. However, there has been no announcement. We have learned that the NYS Division of the Budget is "tweaking" it, and it will then be released as a "concept paper for discussion", and later resubmitted to CMS. This implies that CMS rejected the first draft. However, allegedly DOH officials do not plan to make any real changes as a result of such "discussion". Ignoring public comments has long been a standard DOH tactic.

Forcing Them to Work on the Workforce

All of the public commenters emphasized "Workforce. WorkForce. WORK-FORCE!" That is, addressing the state-wide shortage of direct service workers in all of NY's home and community based service (HCBS) programs should be the top priority for all agencies. And almost no one disagrees that the primary cause of these shortages is low wages and few or no benefits for the workers. This problem has been building throughout the western world for at least two decades, as we've reported many times (*AccessAbility* Spring 2018, for example), and has long been exacerbated in NY by the Cuomo Administration's austerity approach to Medicaid funding. But the pandemic has worsened this situation considerably. Early on it was because even though these folks are "essential workers," few of them felt safe outside their homes. As time went on and PPE and vaccines became widely available, many did go back to work, but many others did not. One reason for this is because most of the people who do this work are women, and the greatest burden of child

care falls on women (despite claims from many men to be "enlightened" or "feminist"), and childcare providers have been decimated by the pandemic, so many of these people cannot return to work. Most schools have been open in New York for a while, providing supervision for older children, but that doesn't help those with preschool-aged kids.

Despite this unanimous clamor to fix the workforce problem, the one obvious solution—use the ARP money to raise worker wages—is almost nowhere to be found in the state's plan (it does appear in one relatively small OPWDD proposal). Why not? State officials have a short answer that seems obvious but is misleading: This extra money is temporary, but states are required to show how they will sustain whatever they choose to do with it after it runs out. The reason that's misleading is because the plan is full of things like "retention bonuses" and "improved health benefits" for workers; they aren't wage increases but they are very much like them, and they also must continue long after the extra help from the feds is gone, if they are to have any effect.

The problems with New York's plan for this money actually start with the language of the ARP law. Despite the publicity surrounding it, it is not aimed exclusively at integrated community based services. Those problems have been greatly amplified by CMS. That agency's guidance, written in a rush, is confusing, contradictory, and, arguably, imposes restrictions that the actual law, which is quite brief and pretty easy to understand (it's here: <https://www.congress.gov/bill/117th-congress/house-bill/1319/text#toc-H04B309FD-B3FA4109B306C6622D55C4D8>), does not. Although we are never too quick to assign benign motives to DOH, in all fairness, most of the plan is focused on improving conditions for, and providing more money to, homecare and other direct-service workers. Although we believe that some of the motives of DOH's planners are wrong-headed, we also believe they were confused, and mistaken,

about some of the CMS requirements, and we also believe some of those requirements aren't justified by the law's actual language. In order to get a handle on this, we're going to have to journey into the weeds a bit.

It's All about the Match

The Biden bill provides the state an opportunity to draw down a higher federal matching share of New York dollars spent on a broad array of HCBS services and supports, which can then be "re-invested" in the state's Medicaid program. However, that extra money can't be applied to things the state was already doing; it must be used to "supplement, and not supplant, the level of State funds expended for home and community-based services ... through programs in effect as of April 1, 2021." The law also says that the increased matching share only applies to money spent on HCBS, and HCBS is clearly defined, in the law, as things that do not take place in large residential institutions such as hospitals and nursing facilities—sort of. Sadly, federal definitions of HCBS do not exclude all types of segregated settings, so the money *can* be used in assisted living facilities, group homes, and segregated adult day care programs. But even worse, the match can also apply to expenditures on "such other services specified by the Secretary of Health and Human Services." Now, one can argue that "such other services" limits the Secretary's discretion to additional services that basically resemble other HCBS, but we could lose that argument in a room full of lawyers, and even if we don't, that's still a pretty big loophole. The law also says that in order to be fully in compliance with this program, a state only has to "implement, or supplement the implementation of, one or more activities to enhance, expand, or strengthen home and community-based services under the State Medicaid program." Crucially, this language does not clearly and explicitly say that a state must use all of the new money directly for HCBS; it is possible to argue that "enhancing" or "strengthening" HCBS can be done by means of activities that fall outside the definition of HCBS.

So what advocates need to understand is

that despite its use of the term "HCBS," this law does not guarantee that all of the money can only be used for things that advocates consider to be integrated or truly community-based. We'd like that requirement to be there, we'd hoped it would be there, but in the end, it's just not.

Fuzzy Logic

The law itself, while brief, still manages to be fuzzy in important ways. It gets much worse when we look at the "guidance" that CMS wrote to help states apply for the money. The law takes about one page to lay out. The CMS guidance is 26 pages of stuff that is mostly not clearly authorized by the law (if you want to read it, it's here: <https://www.medicaid.gov/federal-policy-guidance/downloads/smd21003.pdf>).

Not everything in there is a problem; arguably the law itself doesn't provide enough detail to enable all of that money to be spent in an accountable way. For one thing, the match only applies to Medicaid expenditures that a state incurs during the "HCBS Program Improvement Period" of April 1, 2021 through March 31, 2022. CMS explained that money spent by a state on HCBS during that period will be used to calculate how much money the increased match (an additional 10 percentage points over what the state was already getting, up to a maximum of 95%) will bring in. The state actually has until March 31, 2024 to spend that extra money. DOH believes NY will receive well over \$2 billion dollars from this initial matching process. But CMS's interpretation of the spending and claiming process is that the state could get a "second" match on any of that new money that it spends before March 31, 2022, so if NY spends the full \$2 billion-plus by then it would actually get about \$5 billion from this program.

But the guidance contains many ambiguities and contradictions.

It's not very clear on some of the rules for spending the extra money. It takes very careful reading to determine that extra money only *comes from* state spending on "matchable" services, but once that extra money is received, some of it can be *spent*

on "unmatchable" activities. DOH wants to avoid doing that as much as possible and get that second match on as many dollars as it can. This desire seems to be driving most of the decisions DOH has made in its plan.

The guidance has a "maintenance of effort" (MOE) requirement that appears to replace the one that has been in place for state Medicaid programs, or at least their HCBS portions, since the Families First Coronavirus Response Act of March 2020. The new law only says that the money must be used to "supplement, and not supplant, the level of state funds expended for [HCBS] ... in effect as of April 1, 2021." The guidance says this means that "states must:

- Not impose stricter eligibility standards, methodologies, or procedures for HCBS programs and services than were in place on April 1, 2021;
- Preserve covered HCBS, including the services themselves and the amount, duration, and scope of those services, in effect as of April 1, 2021; and
- Maintain HCBS provider payments at a rate no less than those in place as of April 1, 2021."

The problem is that the earlier MOE applied to Medicaid programs as they were at an earlier point in time—as of March 18, 2020. CMS's bullet points weaken the law's statement that the amount of money being spent must not decrease, period. Those points would seem to let a state take actions that actually do reduce their Medicaid spending prior to April 1, 2021, such as New York's as-yet unimplemented plan to wipe out most of the state's CDPA providers (see page 7). Also, NY passed a law to impose stricter eligibility standards for Personal Care services (including CDPA) in April 2020 (the "ADL minimums"; see *AccessAbility* Summer 2020). Under the old MOE the state was prohibited from carrying out that change. Now we're not so sure. The state's position is that because the law was passed prior to April 1, 2021 it should be permitted to occur. However, our position is that the change was never actually implemented. A change like that requires CMS approval and as best we can

tell, DOH never submitted it to CMS on the record. Certainly, none of the rules in the change were actually being followed, and therefore it was not “in place” before that date. DOH claims that CMS did approve that change. However, if such a change was actually “in place” before that date, then it would have violated the older MOE, requiring the state to repay all of the extra COVID Medicaid relief it had received through March 31 of this year. Also, DOH is taking the position that it should try to spend all of this money as quickly as possible, because, they say, “the sooner we spend the money, [the sooner] the MOE requirements expire.” The section of the law that describes this program does not contain any limitation on when the funds must be spent, or a termination date for the MOE requirements. What a (court) room full of lawyers would say, we don’t know, but we should probably find out.

CMS says that any changes a state makes to its Medicaid program to use these funding opportunities must comply with all existing regulations for making such changes. For example, a change, such as rates of payment for providers, would require an amendment to the state’s managed care waiver, which currently pays for most CDPA services in NY. DOH would have to go through the usual public comment and CMS approval process for a waiver amendment, which could take at least six months and probably much longer. That would obstruct DOH from spending the money as quickly as possible, so they say they want to avoid taking that route.

DOH is also favoring, among its own programs, those that are largely run through managed care. Their argument for this is that money paid to Medicaid managed care organizations (MCOs) for HCBS is matchable, even if the activities that MCOs fund with that money are not. During the public comment period the DOH officials themselves didn’t seem too sure this would fly. It looks like an obvious attempt to dodge the rules that CMS should immediately block. DOH’s reasoning, as explained in one of the public comment transcripts, is half-baked at best. First, everything of real consequence that is paid for by managed care

plans, including increased wages paid to workers who provide HCBS, is already matchable under the letter of the new law. And a program that can actually provide more reliable hours of service because its workers are paid enough to keep them on the job would certainly be an “enhanced” or even “expanded” program compared to what we have now. Increasing homecare workers’ wages, which DOH is refusing to do, is an explicitly approved activity in the CMS guidance, as is paying recruitment and retention bonuses to them, which DOH wants to do, even though the guidance does not explicitly list either type of expenditure as matchable. DOH points out that rates paid to providers, which cover wages, are subject to CMS approval and changing them requires time-consuming amendments to the relevant waiver or the State Medicaid Plan. However, managed care premiums require the same amendment process. So they plan to issue the extra money to MCOs as “direct payments,” to be “passed through” to the service providers in the MCOs’ networks, rather than as part of the premium. This also will require a separate CMS approval process, but we don’t know if that includes a public comment period. In any event, “direct payments” to MCOs for HCBS activities are not premiums, and while they should be matchable under the law, the CMS guidance does not make that clear, which was the rationale for this whole bit of trickery in the first place.

The CMS guidance has an “Appendix B” that lists all of the various types of HCBS services on which a state can spend money that would be eligible for the increased matching funds. The list essentially repeats the one in the law, with a bit more detail. However, the appendix also lists “HCBS Authorities,” and within that section it says, “Only the ... services defined in this appendix that are provided through a managed care delivery system are eligible for the enhanced [match] referenced in this guidance.” Wha...?? “Direct payments” are provided through a managed care delivery system, but that sentence seems to say that only services paid for through managed care can generate ANY of the matching funds available from Biden’s program.

There is no such restriction in the law, and neither CMS nor DOH seem to be acting as though this is literally true, but it’s there in black and white, adding even more confusion.

The Best-Laid Plans ...

Advocates object to the managed care ruse for a different reason: The rules for MCOs are set by CMS, but monitoring and enforcement is largely a state responsibility in the Medicaid system. MCOs in New York are woefully under-monitored. DOH simply waits for the state Comptroller or federal auditors to issue reports every few years or so, which routinely show that MCOs were overpaid billions of dollars for things they didn’t do, or didn’t do right, and then the state pays those funds back to the feds. Allegedly they can recoup that money from the MCOs, but MCOs can go to court to keep it, and when they do, they can cite the lack of clear direction and real oversight on the part of DOH as a reason why they shouldn’t have to repay it. Although the federal managed care regulations are clear that direct payments must go directly to service providers and MCOs can’t hold on to them, it is quite possible that they will do that and not get caught for many years, and when caught, will not actually have to return the money to the state.

The plan is a list of several projects for how the state would like to spend the extra money once it receives it. DOH alone accounts for almost \$1.3 billion, and over a billion of that is directly aimed at putting more money, and better benefits, into the hands of homecare workers. However, one of their projects is to provide over \$55 million to nursing facilities to “expand and enhance advanced training programs incentives for direct care workers to recognize signs of patient clinical improvement and the potential for HCBS programs and services to allow for community discharge and reintegration.” This is not matchable because nursing facilities are not home or community-based services. It may be allowable under the law because there is no clear restriction on what the money can be spent on. In fact, the CMS guid-

ance explicitly endorses such programs under the rubric of “Institutional Diversion,” where it includes “Strengthening/improving Preadmission Screening and Resident Review (PASRR) processes to prevent unnecessary institutionalization.” PASRR is a thing done in nursing facilities. Critics point out that this money would be better spent on the state’s “Open Doors” program, which is run through Centers for Independent Living like STIC, and helps people get out of, or avoid going into, nursing facilities and is underfunded. Federal regulations already require nursing facilities to offer all of their residents an opportunity to leave every three months, and if a resident says they are interested, they are supposed to refer them to Open Doors. Nursing facilities don’t do this very well, and it’s as simple as distributing surveys to residents and reading them after they’re filled out. But they don’t want their residents to leave. DOH, then, needs to monitor nursing facilities more closely, and impose real penalties for noncompliance.

On August 5, several advocacy organizations sent a letter to CMS outlining objections to New York’s plan. The issues with using managed care to channel the money, and with funding for nursing facilities and not for Open Doors, were discussed. There really doesn’t seem to be anything in the law or CMS guidance stopping New York from simply raising wages for HCBS workers, and the letter suggested this could be done by establishing a separate mechanism for homecare providers, including CDPA Fiscal Intermediaries, to simply draw down the extra money as an explicit “enhancement.” Such a procedure might be viewed as being outside the rate-setting process and therefore not require any waiver or State Plan amendments. DOH might respond that it would still take too long to set up a new system to do that, while MCOs already have the mechanism in place. That’s not likely to be true in reality, because the plan requires the providers to meet specific service quality criteria and the MCOs would have to collect and evaluate information on those criteria before they could release the money, procedures they do not

ordinarily follow. However, DOH may be thinking that giving the money to the MCOs constitutes “spending” it for purposes of getting the second match and ending the MOE.

The letter also points out that this whole emphasis on speed in order to spend the money as quickly as possible to terminate the MOE is detrimental to people with disabilities, and DOH should not be focusing on implementing its delayed cuts to CDPA and Personal Care services.

While we generally agree with the letter, there is one point in it with which we do not agree.

DOH proposes to spend over \$400 million to accommodate “natural growth” in the state’s homecare programs—again, by providing cash and other incentives to hire more workers. “Natural growth” means the growing need for services due to the aging of the population, as well as ongoing increased use of Medicaid due to COVID-related job losses. The advocates’ letter opposed this idea, claiming that paying for natural growth is not an allowable “enhancement, expansion, or strengthening” of the state’s HCBS programs; it’s just using the money to pay for the existing system. That’s just not true. The state’s current budget allocations and funding mechanisms cannot possibly adequately address this growth, so using the ARP money to do that is clearly an “expansion.” Further, the advocates don’t object to the idea of using the funds to pay higher wages for existing homecare workers serving existing people, or to ensure that more people who are eligible right now can actually get workers to serve them right now.

There are some other good ideas in the plan. For example, a new “Adult Companion Service” would be added to the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) waiver programs. The rate paid by OPWDD for Intensive Behavioral Services would be greatly increased, explicitly to enable a wage increase for the people who provide this service. Finally, while some advocates say that recruitment and retention bonuses and benefits enhancements aren’t as effective in get-

ting, and keeping, workers on the job as wage increases are, they are not nothing, and they will help some.

Politics as Usual?

Yet overall the plan appears to have been designed to achieve two longstanding public goals of the Cuomo Administration: To put an end to the MOE so Medicaid services can be cut, and to structure temporary expenditure increases in a way that they won’t be counted toward Cuomo’s prized Global Medicaid Spending Cap. Over the years, Cuomo has shown that he considers his “Medicaid Redesign Team,” which has “bent the cost curve” of New York’s Medicaid program, one of his finest achievements, and a key aspect of his political appeal to right-wing corporate leaders. It may also be oriented toward a third longstanding Cuomo goal, one that he won’t admit to publicly, which is to increase the wealth of the managers and principle stockholders of MCOs in New York State, who have contributed to his campaigns.

Cuomo’s political concerns are no longer operative. The fact that CMS has not approved his plan by now suggests that it will have to be changed. Perhaps the new administration will take a more rational approach to the real needs and costs of New York’s Medicaid-funded long-term care system and its imperative to serve a growing number of people in the most integrated settings. The tax increases enacted this past April will be sufficient to pay for adequate wages and benefits for homecare workers after the Biden money goes away. Cuomo would likely have proposed cancelling them to further his re-election campaign in 2022. Although Cuomo’s successor, Kathy Hochul, says she plans to run for a term of her own then, we hope that she will apply a different calculus—one that expects the state’s wealthiest citizens to continue to pay a full fair share to support the needs of people with disabilities and senior citizens.



Here's the latest twist in the saga of the New York State Department of Health (DOH)'s efforts to decimate the CDPA program by wiping out most of that program's Fiscal Intermediaries (FIs).

We last reported that STIC and 304 other applicants, including most of the Centers for Independent Living, were not approved to continue providing that service, so the legislature intervened to require DOH to issue additional awards to at least one applicant that is located in a county with 200,000 or more residents, and to at least one applicant that serves people with developmental disabilities or other "special needs" groups, such as language or cultural groups.

DOH surveyed the applicants to find out how many of them met the criteria for those extra awards. Then, apparently, someone at the agency told someone that they intended to "double-count" applicants who met more than one criterion. For example, if one applicant in a large county also served people with developmental disabilities and Spanish-speakers, DOH would count it as satisfying both of those criteria, and if it was one of the already-approved applicants, so much the better. This plan does not seem to have been made public initially.

In mid-July, a group of about 30 "traditional" homecare agencies that had been

authorized to operate CDPA programs organized a coalition called "New York Advocates for Home Care" and issued a press release opposing DOH's original action in disapproving so many providers.

Crain's Health Plus quoted a lawyer from the group as saying, "There seemed to be no rational reason to deny many of the contract awards. The Health Department appeared to have followed a capricious evaluation process of the applications and in some cases did not follow some of its own guidelines." This echoes the formal protests that STIC and other rejected FIs submitted to the New York State Comptroller, who oversees state contracting procedures, in February.

A board member of the organization told *Crain's*, "The coalition is willing to work with the Health Department on a fix. 'Throw out the RFO [Request for Offers, the application process] and start over again,'" she said. 'If not, we will have to move through the courts.'"

Meanwhile, NYS Assemblyman Richard Gottfried (D-New York City), who chairs the Assembly's Health Committee and has at times been somewhat supportive of some disability issues, provided they don't involve voting against budget bills, wrote a letter to DOH Commissioner Howard Zucker criticizing DOH's ap-

proach to the FIs and its "double counting" plan.

He also tried to disavow responsibility for the state budget measure that led to DOH's RFO process, even though he voted for it. He said, "When the legislature proposed a system of authorizations for FIs in 2017, our intention was to have a simple system of quality oversight. However, DOH turned this into a mechanism for constricting and limiting CDPAP to a handful of FIs, undermining CDPAP's ability to adequately serve its consumers." He then characterized the legislature's requirement for additional awards as an effort "to reduce the damage" and urged Zucker to "rescind the current plan and issue a new document to accurately reflect the plain language of the law."

As it stands in mid-August, DOH has not publicly announced any winners of the second round of awards. As for New York Advocates for Home Care: STIC does not belong to that organization, and we have been clear in the past about our disapproval of the large number of "traditional" homecare agencies that DOH has previously approved as CDPA FIs even though they do not truly follow a consumer-directed approach. But at this point, anybody who says, "Throw out the RFO" and offers to back it up in court is a friend of ours.

Criminal Investigations Continue despite Politics as Usual

As ethical disability rights advocates, we frequently need to remind people, in these paranoid and tumultuous times, of a very important point:

The fact that some bad political actor is for or against something does not automatically mean that good people should take the opposite view. Even a broken clock is right twice a day.

Back under President Trump, when the needless, completely preventable COVID nursing-facility massacre came to light, his Department of Justice (DOJ) began investigating the states that ordered nursing facilities to accept COVID patients, "often without adequate testing," as DOJ's press release said.

The states targeted were California, New York, New Jersey, Pennsylvania, and

Michigan. All of those states had Democrat governors. Those governors pretty quickly began insisting that this was just a political hatchet job instigated by Trump.

But DOJ dropped CA from its list when its Governor Gavin Newsom revoked his order about ten days after he issued it. As the death toll mounted, in NY, Cuomo, one of the loudest complainers about partisan politics, instead of realizing his

mistake and revoking his order, focused on insisting that he had done nothing wrong, there was nothing wrong in the nursing facilities, and everybody was doing a bang-up job dealing with the pandemic. He didn't revoke his order until May 8, 2020, 44 days after it was issued.

We have not been able to get a definitive list of all of the states that issued such orders. Some of those that did actually required nursing facility operators to isolate COVID patients in separate wings or floors or buildings, and those states did not experience the level of carnage that was seen in New York (though some New York facilities did isolate those patients voluntarily). But it might be true that the only states that issued such orders had Democrat governors. So what?

Some people like to claim that “progressives” prefer centralized decision-making, whereas “conservatives” prefer local control, but that notion can be refuted by pointing out that only “conservative” governors have been forbidding localities from imposing their own mask mandates on businesses or schools. Regardless of where politicians fall on the political spectrum, they all try to make it hard for other politicians within their orbits to do things they don't like.

In late July Biden's DOJ announced that it would not continue to investigate any of these states' actions with regard to “public nursing facilities.” Republicans in Congress and in New York immediately began calling for Biden's head. NY Congresswoman Elise Stefanik called the decision a “gross miscarriage of justice” that makes “President Biden complicit in the criminal corruption scandal and cover up of deaths of thousands of vulnerable seniors.”

The thing is, only about 7% of nursing facilities in New York are “public”—that is, owned and operated by governmental units. The investigations of public facilities that DOJ terminated were civil investigations, not “criminal corruption” investigations. The US Attorney for Brooklyn, a DOJ employee, along with the FBI, a unit of DOJ, is continuing the

“criminal corruption” investigation of Cuomo's order, which applied to all 630 nursing facilities in the state.

Although Assembly Speaker Carl Heastie called off his chamber's impeachment investigation of Cuomo when the governor's resignation was announced, the state Attorney General is still investigating Cuomo's alleged illegal use of state employees and resources to help write his self-laudatory book last year, and investigations of Cuomo's preferential COVID testing for his family and friends, and of irregularities in the contracting and construction process for the “Mario Cuomo Bridge,” are also ongoing. After trying to bury the impeachment investigation's findings, and facing a huge public uproar, Heastie backpedaled and announced a report of those findings will be issued to the public.

Politicians and demagogues (is that redundant?) can't always get what they want, and if the rest of us will just stand down from the culture wars and pay attention to the facts, we just might find, we get what we need.

Undercounting Also Continues

On July 14 the Associated Press reported that New York State's count of COVID deaths was 11,000 lower than the number the federal Center for Disease Control (CDC) has for the state. A CDC spokesperson said he didn't understand why this was happening; the CDC numbers come from the death certificate data conveyed to them by the state.

The CDC death certificate form lists an “immediate” cause of death, the multiple conditions that led to the death, the “underlying cause” and “other significant conditions contributing to death.” We know that honest people can have differing opinions on how to count these numbers.

But the AP also reported that “The Cuomo administration's count includes only laboratory-confirmed COVID-19 deaths at hospitals, nursing homes and adult-care facilities. That means its tally ex-

cludes people who died at home, hospice, in state prisons or at state-run homes for people living with disabilities.” Shortly after taking office, new Governor Kathy Hochul ordered DOH to publish the death certificate data. But questions remain.

What possible reasonable basis could there be for excluding all of those categories? A spokesperson indicated the state considered death certificate data to be “preliminary,” while the data it publicly reported is “confirmed.” Why would it be so hard to “confirm” deaths in those other places? And why is it so hard in “state-run homes for people living with disabilities?”

Does that mean that such data is confirmed when people die in group homes run by not-for-profit agencies? Not necessarily; reporters often get details like this wrong, such as assuming that not-for-profit residences, which are only funded by the state, are “run by” it. (A report by the New York State Bar Association in June found that as of February 10, 2021, there had been 6,698 COVID cases among residents of OPWDD-operated or –funded facilities, and 618 deaths.)

Is this another case of people being “thrown away” because they aren't considered useful? Maybe not. Typically we include residents of nursing facilities and adult “homes” in that category, but New York is reporting those deaths as confirmed. Yet the Bar Association reports that “OPWDD-licensed and operated community residences were not afforded the same priority as skilled nursing facilities and other congregate care settings for allocations of PPE.”

When people die at home, the first thing on their families' minds is not getting a laboratory to confirm a cause of death. But if it's important to do so when someone dies in a nursing facility, why is it not equally important when someone dies in other state-run or –funded places?

Perhaps this is tacit acknowledgement that the systems that operate those places just aren't very well-run?

Insupportable Supported Decision Making Bill

The New York State Senate passed a Supported Decision Making bill, S.7107, sponsored by Senator John Mannion (D-Syracuse), in June.

We've reported on Supported Decision Making previously (see *AccessAbility* Winter 2015-16 and Spring 2016, for example).

The idea behind Supported Decision Making is that just about everyone gets help from others, whether family, friends, or experts, when they make important decisions. Almost nobody makes big decisions completely alone.

Everyone accepts this—except when it comes to people whose disabilities are believed to interfere with making good decisions. Then the typical response is to demand that somebody else make the decisions for them, whether through formal legal guardianship arrangements, so-called “capacity assessments” as mandated by OPWDD (which are the personal opinion of some, not always very well-trained, paid employee), or designating family members “legal representatives” and letting them overrule their relatives’ wishes even when there is no formal guardianship.

As our previous articles showed, there is very good evidence that people with intellectual, mental or cognitive disabilities can make very good decisions when aided by ethical adults whom they know and trust. “Ethical” means those helpers do not attempt to coerce, manipulate or unduly influence the decision-maker, and accept her right to make the final decision, whatever it is.

Some of the people who believe in Supported Decision Making are of the opinion that the process needs to be formalized, with specific detailed written agreements between decision-makers and their helpers or “supporters.” They believe that when those agreements exist, they can be used to persuade others of the legitimacy and finality of the decisions that are made.

We are of two minds about this. On the one hand, as we've said, everybody gets

help to make important decisions, and everybody else accepts those decisions—unless the decision-maker is disabled. That's an injustice that should be corrected, but it should not fall to the decision-maker to have to jump through hoops and deal with a lot of paperwork to do it. On the other hand, there are lots of people—typically family members and employees of OPWDD-operated or –funded agencies—who, without formal guardianship authority, manipulate and coerce disabled people into doing what they want, instead of what the disabled person wants. Some of them may not be aware they are doing it, and others will swear that they absolutely do not do that, even when any observer can see that the disabled person is being played. It might be that if forced to sign a legal agreement stating that they won't do that—an agreement that the decision-maker can terminate all by herself whenever she wants—some of these people might back off. And if they don't, it might create a legal right of action for the decision-maker to force them to back off.

Senator Mannion's bill contains a presumption that anyone, regardless of the extent of their disabilities, can effectively use Supported Decision Making, and protects their ultimate rights to control the process, limit its scope, and make the final decisions. And it conveys the professional do-gooder intent of formalized Supported Decision-Making processes: that decisions made pursuant to a formal agreement entered into by decision-makers and supporters must be accepted by everyone in the same way that decisions made by nondisabled people are ... **EXCEPT:**

Decisions made by people who receive, or are eligible for, OPWDD services can be overridden by *anyone* as long as they “believe” that the decision “will cause the decision-maker substantial and imminent physical or financial harm” (section 82.11(D)). There is no requirement in the bill to submit evidence supporting such “beliefs,” and no method to appeal those “beliefs.”

Sigh.

The whole story of the endless dreary reign of paternalistic oppression of people with intellectual or developmental disabilities can be summed up by the common *belief* of most people who work for OPWDD, and of many of the family members served by that agency, that decisions made by people with those disabilities that contradict what their overseers want will cause them “imminent physical or financial harm.”

The bill envisions that its provisions may benefit people with other types of disabilities, but notably, Supported Decision Making is only mandated for people served by OPWDD, which is charged with issuing regulations to implement the law. So if this bill passes the Assembly and is signed by the governor, it will not only mean that its protections will be thwarted by a loophole big enough to drive the entire population of New Yorkers with developmental disabilities through, it will also establish, as a legal principle, that nobody has to accept any decisions made by anybody with those disabilities, regardless of their intellectual capacity, and even if they have a signed formal Supported Decision Making agreement, as long as they harbor bigoted views about their abilities. Autistic people ought to be especially alarmed about this.

We applaud the good intentions of Senator Mannion, but as we said almost three years ago (*AccessAbility* Winter 2017-18), formalizing Supported Decision Making is likely going to harm more people than it helps.

Yes, “there oughta be a law,” but that law should do only two things: 1) make it illegal for anyone, including OPWDD employees and family members, to ignore or reject any decision made by any adult who has not been adjudicated by a court to have limited decision-making capacity, regardless of their disabilities; and 2) repeal New York's Article 17A guardianship process (see *AccessAbility* Winter 2016-17), which allows a court to grant unrestricted guardianship on the say-so of a family member of a person who has a developmental disability.

Student Loan Forgiveness

On August 19, the US Department of Education (DOE) announced that it would begin automatically forgiving student loans for some people with disabilities, beginning in September.

The forgiveness applies to people who are on record with the Social Security Administration (SSA) as “totally and permanently disabled.” DOE matches its data against that from SSA every quarter, according to a DOE press release, and the next match is coming in September. When DOE finds a disabled person on the SSA rolls who has outstanding student loans, it will automatically discharge those loans without requiring the person to apply for forgiveness.

If your loan is discharged you’ll receive notice from DOE a few weeks later. DOE expects that it will be able to discharge all of the eligible loans by the end of the year.

There is a 3-year monitoring period after these loan discharges, during which a discharge can be revoked if the person’s income increases above a certain threshold. But in March DOE announced it would stop requesting income information from discharge beneficiaries during the pandemic, and in August they said they will stop making those requests permanently. DOE will also issue a new proposed rule that will eliminate the monitoring period.

DOE expects that over 323,000 disabled borrowers will have their loans discharged, representing more than \$5.8 billion.

OPWDD Housing Inequities Explained

In July 2021, The New York State Developmental Disabilities Planning Council released a report called *Reclaiming Innovation in Housing: Overcoming Institutionalized Models of Service Delivery in New York*. The report is the result of a grant received by another Center

for Independent Living like STIC, AIM Services, Inc. in Corning and Elmira. The report was written by John Maltby, a co-director of the New York Housing Resource Center for People with Intellectual/Developmental Disabilities. He is a well-known, much respected long-time advocate for people with developmental disabilities and their families.

The report contains a pretty technical discussion of the differences in how housing is funded and governed between “certified” and “uncertified” options. You can read it here:

https://mcusercontent.com/b5ba8e60a1cc093a382200353/files/ea4646b0-b096-989e-de83-401369fd08e8/reclaiming_innovation_in_housing_final.pdf.

“Certified” housing is operated and provided by OPWDD, or by not-for-profit agencies that contract with OPWDD. The most common forms are Supervised IRAs, which have 24/7 support, and Supported IRAs, which have considerably less support. “Uncertified” or independent housing is “just housing.” OPWDD service recipients can often qualify for subsidies to help pay for independent housing, but as the report notes, most of them can only succeed with additional support from families that can afford it. People from middle- or upper-class families are much more likely to be able to live in truly integrated homes than working-class people, and this is an issue because white people are more likely to have such families than people of color.

The report notes that certified housing is much more expensive for the taxpayers than adequately supported independent housing, and a system as reliant upon it as OPWDD is can never afford to meet the needs of all of the people eligible for its services. Thus, the situation is unsustainable.

We’ve long said that the way housing is funded creates incentives for providers to prefer large Supervised IRAs instead of provision of individualized supports in people’s own homes. This report explains precisely how those incentives work, and what could be done to change them.

We hope this report is taken very seriously by OPWDD management and our elected officials, who will need to act on some of its recommendations. Below are some important points from it.

“Certified housing receives direct and indirect funding for acquisition and maintenance. If the housing is owned, it is exempt from local taxes, and, if rented, it is reimbursed at a market-based rate. By contrast, independent housing receives no support for acquisition or maintenance costs, pays local taxes, and the rental subsidy is currently set at between 16% and 40% of the area rents. Certified housing is subsidized for vacancies, staff costs for administration, transportation, including vehicles, and home maintenance, and it requires limited verification of service provision daily. Independent housing does not receive these subsidies, and services are required to be reported on at 15-minute intervals.”

“The approved budget for [service-provider agencies that will be] creating the property, whether it be new construction or acquisition and modification, is based ... on the actual cost. [Rates are set by] DOH and OPWDD jointly. Rates vary around the state, and ... are no longer publicly disclosed by OPWDD. Reportedly, [they] range between \$90,000 and \$190,000 per bed, depending on location.”

“Recommendation 1. Unbundle property and support costs, and provide transparency to identify property costs. This will help agencies to actively separate the provision of property from the provision of services while allowing for personalized support and individualized budgets.”

“Recommendation 2. OPWDD should identify the number of unrelated people sharing bedrooms in certified housing and attempt to identify whether the people chose to share. Incentivize agencies financially to reduce the number of shared bedrooms where people do not wish to share by providing bridge financing and gradually phasing out extra-bed payments.”

“Recommendation 8. Rethink and revise the CCS [Congregate Care Supplement] to be distributed more equitably based on a person’s need rather than their residen-

tial setting. ... It should be attached to the individual rather than to the certified housing. It should follow the individual into the community if they move to non-certified housing, bridging the gap between the current housing subsidy and the real world.”

“The OPWDD housing subsidy used to be adjusted annually to match the HUD FMR [Fair Market Rate], but since 2012 that has not been the case. From 2012 to 2021, HUD FMRs have risen by an average of 26% statewide. The OPWDD housing subsidy is now inadequate, and most people receiving the subsidy have no savings or means of increasing their income to make up the shortfall. [This leaves people who’d relied on the subsidy to seek Least Restrictive Environments (LREs)] unable to maintain their homes safely and...in danger of losing them.”

“Recommendation 18. Clarify whether the 15-minute increment [for Community Habilitation service recording and billing] is a CMS requirement or OPWDD’s..., then seek to eliminate it. ... [That] every worker receives an electronic tap on the shoulder every 15 minutes betrays the state’s deep distrust of the people it supports and the means by which they are supported. Given that this only applies to people who are outside of the certified system, it is a clear institutional bias and directly counter to the principles of [the] *Olmstead* [Supreme Court decision].”

“Recommendation 21. (i) Establish pilot programs to develop ways to support people who self-direct to continue to live in their non-certified homes in their communities after families are gone. One option ... is the ‘enhanced broker,’ a person who can assume many of the necessary tasks. This would not require a change in the waiver.”

“(ii) Increase options such as Agency with Choice [for services such as Paid Neighbor, Individual Directed Goods and Services, and Live-In Caregiver] to make Self-Direction more accessible. Agency with Choice reduces the administrative and compliance role of the person and their family members while allowing for professionally supported services.”

“Recommendation 25. OPWDD should seek to obtain the same exemption [to allow people who are not nurses or clinically-trained paraprofessionals to distribute medication] in the 1915(c) waiver that applies to people providing Consumer Directed Personal Assistance Services (CDPAS) under the 1915(k) [Community First Choice, CFC] waiver.” (It actually applies to CDPA period, whether authorized and funded under the state’s fee-for-service Medicaid program, the 1115 managed care waiver, or CFC.)

Provide telemedicine “to people living in non-certified housing as the ‘Origination site.’ Given that members of the general public have access to telehealth from their own homes, this restriction might be considered a Civil Rights issue.”

“Recommendation 26. (i) The state should extend the Covid-19 relaxation of restrictions on Telehealth indefinitely—including for purposes such as Lifeplan meetings and some CommHab work meetings with CCOs [Care Coordination Organizations] and providers—and expand it to support people living in the family home. (ii) The State should permit the use of Telemedicine with a person’s home being the ‘Origination site.’”

To all of which, we shout, “AMEN!”

Long COVID: A New Disability?

As the pandemic passes the 18-month mark, a troubling development has begun to emerge: so-called “long COVID,” a varying constellation of health problems and symptoms of greater or lesser severity that lasts for a long time after the first signs of infection.

Although long COVID is long, it has not been going on long enough for us to have a clear handle on how many people have it and how long it will last.

There is not a standard definition for long COVID; some set the minimum duration of symptoms at three weeks, some three months, and some four months.

Prevalence, of course, depends on how long “long” is. A study from Geneva, Switzerland, reported in May in the *Annals of Internal Medicine* that 32% still had symptoms between 30 and 45 days after onset. Overall, men are more likely than women to be hospitalized and die from this disease, but women are more likely to experience long COVID. Incidence of long COVID seems to increase with age and level of obesity. Researchers seem to be settling around 13% of adults turning up with the syndrome overall. Children can also have it, and for them the data is all over the map, ranging from 9% to over 50%, depending on how the condition is defined.

The condition is worse among those who were hospitalized; a Chinese study indicated that 76% of hospitalized COVID patients still had symptoms after six months. But spending a lot of time in a hospital can alone cause enduring health problems, as can invasive treatments, such as use of ventilators, a fact that muddies the waters as to why some people stay sick so long.

How long does it last? It depends. A more recent Chinese study found that 50% of those who were hospitalized still had some symptoms after a year.

Why does it happen? Some of it comes from the serious lung damage that severe COVID-19 causes. But the effects that don’t involve breathing and blood oxygen are not well understood.

The symptoms vary in kind and severity as well. Here’s a list of possible issues from the Centers for Disease Control (CDC):

Tiredness or fatigue; difficulty thinking or concentrating (“brain fog”); headache; changes in smell or taste; dizziness on standing; heart palpitations; chest or stomach pain; difficulty breathing or shortness of breath; cough; joint or muscle pain; mood changes; fever; “pins-and-needles” feeling; diarrhea; sleep problems; changes in menstrual cycles; multi-organ effects or autoimmune conditions; rash.

“Anxiety” has also been reported, but there isn’t evidence that this is directly caused by the disease itself. Anxiety isn’t always a “problem” or an “illness”; it’s often a normal response to stress. If you’d been through a bad case of COVID, you might be anxious about your health and safety for quite a while too. Plenty of people who haven’t even been infected (that they know of) are anxious these days because of the uncertainty that the pandemic has brought us.

So COVID-19 is a disease, and as best we can tell so far, it’s not a permanent one. What’s this got to do with disabilities then?

There are various definitions of “disability” used by different programs and authorities. It can be temporary, but some definitions don’t recognize those that last less than six months. A diagnosis, by itself, is not a disability; the meaningful definitions require that the condition must limit a person’s ability to do important and/or common life activities to a significant extent.

Many of the listed symptoms may qualify if they are severe enough. Certainly some people have experienced such intense fatigue that they were unable to do very much at all for several weeks. Pain and lack of sleep can also sharply limit one’s abilities. Brain fog is a real thing and can make important or common thought-intensive activities impossible. The list goes on.

The federal Departments of Justice (DOJ) and of Education (DOE) have taken the position that long COVID can be a protected disability under the ADA, Section 504 of the federal Rehabilitation Act, and the Individuals with Disabilities Education Act (IDEA).

We are much closer to the beginning of this journey than the end, but COVID is likely to remain endemic among human beings for a very long time, and politicized anti-vaccination sentiments may endure almost as long. Although most cases of long COVID seem to be temporary and fade away eventually, we may yet find some who have permanent disabilities. Stay tuned.

Rotenberg Center v FDA: Back to the Drawing Board

After the Food and Drug Administration announced that it would ban the use of electric shock devices for “aversive conditioning” of people with developmental disabilities (see *AccessAbility* Summer 2020), the Judge Rotenberg Center in Massachusetts, the only organization that uses such devices that way, sued the FDA. They argued that the FDA lacks the authority to ban such devices for a particular use. They may be right, but there may also be a different solution.

Rotenberg bases its reasoning on a claim that the devices are the only thing that has ever worked for certain people with severe self-injurious or aggressive behavior, and that they are only used as a last resort on such people. This is demonstrably false; there are publicly-available videos and victim testimony of people who were continuously shocked for refusing to take off a jacket or simply being “sassy” to a facility employee, among other minor misbehaviors. But the FDA did not base its ban on the indisputable fact that the devices have been misused; it based it on overwhelmingly solid evidence that the devices, when used “properly,” are not very effective but are very dangerous. So to understand what happened with this court decision, we have to set aside the duplicitous and arguably criminal behavior of Rotenberg employees and just consider what the FDA can and cannot do, and should do instead.

Unfortunately, electric shock devices are used for aversive conditioning in other circumstances, such as to help people quit smoking, break alcohol or drug addictions, and, allegedly, to control their sexual behavior after they’ve experienced a brain injury. Although the devices used for those other purposes are different from those used by Rotenberg—which builds its own devices that are only used by them—federal law explicitly forbids the FDA to prohibit so-called “off label” uses

for treatments (including drugs, appliances and devices). Medical professionals are granted broad authority to follow their own judgment in deciding how and when to use them.

There is clear language in the federal law governing this issue that states that nothing in that law allows the FDA to regulate the practice of medicine—that is, how to use legally marketed products. The FDA contends that when it bans a device for a particular use, it can no longer be marketed for that use, and therefore would not be a legally marketed product.

The fundamental problem here is that the FDA tried to ban use of an entire class of devices, so-called “electrical stimulation devices” for aversive conditioning, for one particular use. After all, only Rotenberg uses such devices to “treat” self-injurious or aggressive behavior, and it only uses its own devices. But if the FDA only banned Rotenberg’s specific device, they would just make a different one, give it a different name, and continue to use it in the same way.

We might also consider whether the FDA should simply have banned all uses of these devices.

The FDA distinguishes between what Rotenberg does and devices used to treat addictions. In the latter cases, the person controls the device him or herself; s/he can set the strength of the shock, turn it off, or even simply not wear it. At the Rotenberg Center, the devices are locked onto people’s bodies and they have no control over them. But let’s look further at the alleged varying effectiveness of these devices for different uses. The psychiatric community has had a growing consensus for nearly two decades that “aversive conditioning” is less effective for permanently changing behavior than so-called “positive behavioral support,” which focuses on giving people something meaningful and socially acceptable to do instead, and rewarding them for do-

ing it. Therefore, the use of these devices is not a best practice in any situation, but that may not be enough to justify banning them. The court's opinion claims, without attribution, that shock devices have been used to control inappropriate sexual behavior among people with traumatic brain injuries. We've been unable to find an example of such use, so we can't verify this claim, but let's assume the devices are used this way for argument's sake. Such behavior is known to occur, and is considered to be a symptom of damage to the "impulse control" center of the brain. One can argue that this is different from what happens when people with developmental disabilities bang their own heads on the wall or hit other people. They are said to be expressing a feeling or need that they can't express any other way. Yet all of these activities are similar in that they involve natural impulses which the person is unable to control voluntarily, and whose expression in some ways is condoned by society but when expressed differently is condemned. Brain injuries can heal over time, though very slowly, whereas developmental disabilities are, by definition, permanent. If such devices actually appear to be permanently effective in brain injury cases, it may be only because the brain's impulse control center has gotten itself back online through the natural healing process and the devices had nothing to do with it.

We would probably be on solid ground if the FDA proposed to ban the use of such devices in all cases where the person subjected to shock cannot control the device. Nobody disputes that the FDA has the authority to ban all uses of a particular device. The dissenting opinion in the case took the position that the FDA also has authority to ban devices for specific uses in the exact manner that it chose to do so in this case, but its reasoning is shaky. Fortunately, that opinion cited an item from a congressional report that was produced when the

current law was being debated, that may give us an out: "Indeed, when Congress first granted the FDA authority to regulate medical devices, a House Committee Report expressly recognized that 'there may be instances in which a particular device is intended to be used for more than one purpose,' and anticipated that 'each use may . . . be treated as constituting a different device for purposes of classification or other regulation.'" The dissenting judge did not say the FDA should have taken this approach, but we certainly can: Just redefine the single "electrical stimulation device" into two different devices, one that is under the voluntary control of the person being "stimulated," and another that is not, and ban the second device for all uses.

The ruling came down from the federal District of Columbia Circuit Court of Appeals on July 6, 2021. The decision was written by a three-judge panel. The FDA had 45 days to decide whether to ask the full court to reconsider the case, or just issue a revised rule that attempts to address the decision. We won't know the next steps for a while.

Some advocates are taking the position that congressional action is needed. It is doubtful that the closely-divided Congress could pass something to change this situation; it fundamentally comes down to the "sacred" parental rights of a handful of families who have fought for decades to continue to allow the Rotenberg Center to carry out what the United Nations considers to be torture on their children. When the issue is portrayed as mistreatment of disabled people, a lot of sympathy is generated for our side. But

when it's presented as interfering in family decisions, then a lot of right-wingers get their backs up and refuse to act. We would probably be more successful in urging the FDA to rewrite the ban along the lines described here.

But if you want to get involved in helping the advocates pursue their strate-

gies, you can read a guide on what to say to members of Congress here:

<https://www.auteach.com/help-ban>

Or sign a petition to get the state of Massachusetts to pass a law to ban aversive treatments here:

<https://actionnetwork.org/letters/stop-theshock-support-ma-bill-h225>

Park-ing Breaks

(from the NYS Department of Health)

As part of our CDC Cooperative Agreement, the NYS Disability and Health Program partnered with the NYS Office of Parks, Recreation and Historic Preservation (OPRHP) and the NYS Department of Environmental Conservation (DEC) to purchase outdoor adaptive equipment at parks across the state. This equipment will increase the accessibility of outdoor recreation activities and programs offered at these parks.

Both the OPRHP and DEC have prioritized connecting people to parks and removing barriers to access so people of all ages and abilities are able to enjoy the natural and recreational resources.

Below are descriptions of the equipment purchased and the parks nearest to Binghamton that have them.

Beach wheelchairs: For people with mobility issues, the beach can be difficult to navigate. Beach wheelchairs make the sand and water accessible to everyone and can be scaled to fit any size person while keeping the body properly supported at an adjustable angle.

Allegany State Park, Salamanca

Mobility Mats: Non-slip roll out mats that allow beach access for people who use wheelchairs, crutches, walkers, or people pushing strollers. The mobility mats allow for universal access and allow families of all abilities to enjoy the beach together.

Chenango Valley State Park, Chenango Forks

Glimmerglass State Park, Cooperstown



Power Wheelchair Charging Stations:
These charging stations allow a user to boost-charge a mobility device battery so as not to be stranded. This increases accessibility for power wheelchair users and allows more time to be spent at NYS parks.

Green Lakes State Park, Fayetteville

For more information on DEC campgrounds and day use areas, please visit:

<https://www.dec.ny.gov/outdoor/7825.html>

For more information on NYS OPRHP parks, please visit:

<https://parks.ny.gov/parks/>



I CAN'T FIND HOMECARE!

The NY Caring Majority is asking you to share your stories of trouble getting enough personal assistance services.

Your story will be used exclusively for advocacy purposes. No personal information will be shared with the Department of Health or any other State actor.

Go here to fill out a very simple form with your story. It's easy!

<https://www.nycaringmajority.org/incident-report>



Disability Community Meets with New FEMA Administrator

(from a press release)

On Tuesday, August 17, The Partnership for Inclusive Disaster Strategies hosted a Disability Community Stakeholders virtual meeting with FEMA Administrator Deanne Criswell, who was appointed by President Biden earlier this year. Seven disabled panelists, joined by over 100 stakeholders, spoke to systemic barriers disabled people have faced during disasters including the COVID-19 pandemic. Administrator Criswell followed with brief comments on FEMA's commitment to disabled people.

Ebony Payne, a current resident of a nursing facility, shared, "I am stuck in a dangerous nursing facility in Illinois because there are no emergency relocation options available to help me get out of this scary and deadly place. I am scared for my life in this petri dish. There are FEMA funds to pay for my funeral, but there are no FEMA funds for emergency protective measures for me to relocate to safety." Misty Dion, CEO of Center for Independent Living of North Central PA (CILNCP), responded, "There are Centers for Independent Living (CILs) across the nation that provide Nursing Home Transition and could easily implement emergency relocation programs if we had access to additional resources like FEMA's Public Assistance Category B reimbursement funds, but we keep getting told we aren't eligible for reimbursement. CILs like ours across the country could help people like Ebony if we were funded."

The stakeholders also described problems with FEMA's Individual Assis-

tance Application, specifically an entry to report disability-related losses, and the lack of a mechanism to request accessibility accommodations. Tom Olin, a disabled resident of Texas, shared his experience of barriers in completing the form after the Texas Winter Storm. Marcie Roth, FEMA Office of Disability Integration and Coordination's (ODIC) original director, reminded the Administrator that these issues and civil rights violations have been raised since at least as far back as 2010 and that little progress has been made.

Administrator Criswell responded to stakeholders by saying, "I just want to say FEMA does remain committed to helping people with disabilities before, during, and after disasters. One of my priorities as I came into this role was to advance equity across all of our programs. It's people first, and ... if we put people first, then we deliver our programs equitably just by default. We take care of people when they are our primary focus, [and] ... we're trying to do everything we can to reduce the barriers to access of the programs that we have. To that end, I'd just like to say that we're really focused on trying to integrate the needs of people with disabilities across all our programs and services, and expanding this capacity across the agency ... I may not get it right right from the beginning, but I commit to you that we'll continue to work on this ..."



STIC NEWS



Welcome to the Delta Quadrant

By Maria Dibble

Who would ever have thought that the quiet gentle fourth letter of the Greek alphabet could wreak as much havoc on our lives as Delta has?

STIC had finally brought all of our supervisors back into the building and allowed vaccinated employees to go without masks if they wished. Sadly, the Delta variant of COVID-19 reared its ugly head in Broome County, and after only three weeks of what felt like freedom, we had to revisit our policy.

Currently, due to the high level of the Delta variant in Broome and surrounding counties, we are again requiring employees, people with disabilities and other visitors to our building to wear masks, unless med-

ically unable to do so. Please be aware that services are still by appointment only. This is necessary to protect the health and safety of everyone at STIC, as well as their family members and acquaintances. As you've likely seen from the rapid up-tick in cases locally, this virus is highly contagious and spreads like wildfire through the unvaccinated population.

Speaking of vaccinations, I urge unvaccinated people to reconsider their decisions, speak to their doctors and seek out the scientific facts about the vaccine. If your reason is political, please ask yourself if it is worth dying for.

My older brother was on the fence about the vaccine, and never got around to get-

ting it, but COVID-19 had no problem finding and infecting him and his wife. He told me he was "sicker than he could ever remember in his life, and sorely regretted not getting vaccinated." He was on day 14, and still feeling exhausted, queasy and lethargic when I last spoke to him. His wife was even sicker, at one point passing out. I'm grateful that neither of them died, but they easily could have, especially since they are both elderly and at a higher risk. Is it worth it to tempt fate like they did?

For the most up-to-date information on STIC's rules and requirements during this ongoing crisis, please monitor our website at www.stic-cil.org.



XScapes' Newest Game

By Todd Fedyshyn

A high-tech espionage experience awaits your team of C-Ops special agents.

Clock's ticking — how much time do we have left? Can we complete the mission?

The elaborate series of clues leads you towards your objectives. Challenge our newest escape room, "Exit Protocol", at Xscapes. Your team has been briefed on the sensitive and critical mission. Enter the "Chenango Insurance Associates" office. It

is of course, a front for clandestine operations of national security importance. Our intelligence analyses have concluded the agency has been compromised. A directive has been released to the station chief agent to retrieve all critical information and destroy the facility. Having seen no progress or status update, we assume that he has been terminated. Your team must complete the mission before enemy agents arrive in about an hour. No pressure, agents, you got this.

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

THANK YOU!

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