

AccessAbility

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IS EXTREMISM IN DEFENSE OF ACCESSIBILITY A VICE?

By Ken Dibble



In the 1964 presidential election, Republican Barry Goldwater ran against Democrat Lyndon Baines Johnson. Those were different political times, though just as polluted with dishonest efforts to “spin” the facts as today’s world. The main difference was that 1964 was still a time when “freedom of the press” was really only available to those who actually owned a printing press. Today any crack-brained idiot with a cell phone can spread toxic, politically influential insanity across the nation with a few taps on a touch screen.

Today Goldwater would be seen as a mainstream center-right politician—partly because he moderated his views as he got older, admitting, for example, that his opposition to racial integration had been wrong—but mostly because the political “center” is perceived to have shifted sharply to the right over the last decade or so. This is definitely spin. Survey after survey has shown that most Americans, when asked their opinions on various specific issues, such as availability of health care, fairness for people of color or of varying sexual orientations and gender identities, pollution and climate change, and immigration, have pretty compassionate and progressive views. Right-wingers have held on to power in recent decades because the Electoral College gives states with tiny, mostly conservative populations as much power in the Senate as those with tens of millions of citizens, and because they’ve gerrymandered election districts to give them an unfair advantage out of pro-

portion to their actual numbers. But spin could not be spun without the corporate news media. The popularity of Fox News and people like Rush Limbaugh (both of which have said they sell “entertainment”, not truth, to people whose difficulty in coping with rapid, unsettling social change makes them vulnerable to manipulation) has pushed other news and public affairs outlets to adopt a similar snarky tone and favor hyperbole over fact in order to compete.

But back in 1964 Barry Goldwater was accused of being an “extremist”, a label he wore proudly. “Extremism in defense of liberty is no vice ... moderation in the pursuit of justice is no virtue,” he said in his acceptance speech for the Republican nomination. He lost that election in a landslide, bested by voters who still had plenty of access to truthful news reporting and facts.

Today right-wingers are increasingly desperate to hold onto power, and there does not seem to be any limit to what they are willing to do. In the debacle of the 2020 election and its aftermath, we saw hundreds of well-educated lawyers who knew better but, as partisan politicians, tried to violate the US Constitution to overturn the decision of the voters. And we’ve seen some of these people embrace the wingnut Q-Anon conspiracy narrative in an effort to increase their support. Q-Anon started as an internet-based role-playing game. Granted, its creators had a right-wing libertarian bent,

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but they were just fooling around, and some of them quit when it became a motivator for fanatical political behavior and real-life violence. This allowed experienced “psy-ops” professionals to take over the “Q feed”. “Psy-ops” is short for “psychological operations”: organized military intelligence programs to manipulate public opinion by spreading lies and engaging in political theater, preying on people’s deepest emotions to destroy opposition movements or overthrow governments in foreign countries. These people saw they could use Q-Anon to spread distrust of our election systems and build support for overturning the election results, and their work helped lead to the January 6 insurrection at the US Capitol.

All of us have been living in this high-tension, polarized political scene, subjected to frequent flashy events that trigger strong emotional responses, for several years now. During the 2016 election, Russian agents manufactured fake left-wing and right-wing “activist groups” that used social media to stage simultaneous

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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.

rallies; they manipulated hundreds of people into showing up and protesting against each other, carrying ridiculous signs and shouting mindless slogans, while the rest of the public watched, and grew more cynical about elections—especially after the fakeness of it all was revealed—which was the intent. There were multiple mass shootings, many carried out by obviously mentally deranged people who happened to repeat some of the racist and anti-immigration rhetoric that has been bombarding them along with the rest of us. After one such event, our notoriously racist president accidentally, and clumsily, but nevertheless correctly, responded by pointing out that we have a serious problem with how we handle mental illness in this country. The knees of disability advocates jerked all over the nation as they responded to Trump's loathsome personality instead of using the opportunity to try to get more funding for community-based mental health services.

Then came the pandemic, in an election year when it was obvious that voting in person would be a health hazard. Ways had to be found to ramp up early by-mail voting for tens of millions of people. The problem was compounded by a Postal Service that had already begun downsizing its operations before the health crisis began because it had been losing money at an unsustainable rate. This became another political controversy when a new CEO, Louis DeJoy, a major Republican fundraiser, took over as Postal Service CEO in June, as Trump and his supporters turned up the volume on false claims that by-mail voting is riddled with fraud. Suddenly we heard about mail sorting machines and street-corner mailboxes disappearing; although this had been ongoing for months before DeJoy came in, it was now claimed that he was conspiring with Trump to suppress voting. There is bipartisan support for by-mail voting, and bi-partisan opposition to cutting postal services; Republican Senator Marco Rubio called DeJoy's actions "sabotage". Biden may appoint his own Democratic members to the currently-Republican Board of Governors and gain a chance to get rid of DeJoy, but the Board just elected its only Democrat, Ron Bloom, to be its chairman in February, suggesting there is less political bias there than some have assumed. DeJoy, Bloom and Biden notwithstanding, the Postal Service has a huge problem; it is losing money hand over fist. Congress may revise the law to let it fund its pensions more gradually, but that likely won't be enough. No government program that must provide services to everyone without adjusting pricing to cover highly variable costs can fully pay for itself; we can either cut those services, charge customers what

the services really cost, or subsidize those services with tax dollars. As always, truth is more complicated and nuanced than political spin.

Amidst the swirl of these panics and controversies, some disability rights activists stepped up demands to vote over the internet. We covered this last summer (*AccessAbility* Summer 2020). I won't rehash that case, which involved a human rights complaint against NY state, here. Since then, however, the National Council on Independent Living (NCIL) issued a formal position statement calling for "electronic voting" with no paper ballots, and several other disability rights groups took positions against any attempt to require paper ballots, on the grounds that people who can't see, and/or can't write, can't fill them out without assistance, so they can't vote privately. They argue that fully electronic voting is the "wave of the future" and requiring voting systems to produce paper ballots will result in systems that don't work easily or reliably, long after the technical security problems have been solved.

Sorry, but that's just wrong. I'm not just the newsletter editor, I'm STIC's Chief Information Officer, in charge of our computer systems. I know what I'm talking about when it comes to information security.

The security problems with electronic, internet-based voting will **NEVER** be solved. That's because the fundamental designs of the computers we use, and the internet, were developed without considering those problems. The dominant operating system, Microsoft Windows, has always been designed for ease of use; security was not built in from the beginning, and because it was not, there is always a way to get under or around the security features that have been grafted on after the fact. Although other computer operating systems are harder to crack than Windows, they were designed primarily for use by scientists who were assumed to be ethical and who worked in closed systems not accessible to the public. These operating systems can also be successfully attacked, and the more popular they become, the more we see their weaknesses exploited, as has been the case with Apple and Android computers and phones. The internet is descended from ARPANET, a defense department project to design a computer network that would still function even if large parts of it were destroyed by an enemy attack. That's one kind of security. But it never occurred to the designers that people would use that very resilience for evil purposes. And the public internet that evolved from that earlier system was developed and promoted by people who were, not to put too fine a point on it, naïve idealists who saw it as a great new way for people with common interests to get together with like-minded people to share new ideas and

foster greater human understanding and togetherness. It never dawned on them that it would become mostly a vehicle for commerce, a way to move money around, and therefore a natural target for criminals. Some of its early promoters were fuzzy-thinking libertarians who actually thought it would be a great idea for people to be able to communicate only with people they agreed with, and hear only news that they liked, while never having to face how the rest of the world thought and lived. Hence the aforementioned crack-brained idiots, who nearly managed to overthrow the government this past January.

Our computer systems, being designed for open-ness and multiple points of entry, are in a constant, losing battle with criminals and nation-states that have strong financial and political incentives to keep finding and exploiting weaknesses. The keepers of the systems do keep patching these vulnerabilities, but often only after they have been exploited. Yes, your computer and its connection to the internet can be kept pretty darn secure—but only if you constantly patch the software and replace the hardware, including the devices between your computers and phones and the internet—your routers and modems. Most people don't do that. And even if you do it, you will still be far enough behind the bad guys that you will occasionally be harmed.

The more valuable the online target, the more money, time, and effort those guys will expend to attack it. Precisely for the reasons we have just seen in the last few months, our election systems are at the top of the heap of valuable targets for the governments of Russia, China, and Iran, and for terrorist groups such as ISIS and al-Qaida. They will spare no expense to degrade our trust in the integrity of our elections, because when we stop trusting elections, then in our fear and panic, we look for other things to trust, such as right-wing authoritarians who will rule by decree and put an end to our efforts as a nation to uphold democracy and human rights.

It's too late to rethink the entire system from the bottom up and redesign everything to maximize security. Such a project would cost far too much money, and disrupt far too many businesses, to ever be taken on in earnest. Sure, we sometimes hear that something is being done about this: "Internet 2.0" and so forth. But that's all marketing froth, intended to get you to buy new stuff; there's nothing close to a complete overhaul on the horizon. Not in our lifetimes.

The thing about paper ballots is simply this: They aren't subject to any of these threats. It is much, much harder to alter a paper ballot without being detected than it is to alter a ballot that only exists as a file in a computer.

But our adversaries don't even have to go that far to win; they only need to demonstrate that they *could* alter those votes if they wished, to demoralize the electorate. Fear, uncertainty, and doubt: FUD. That's all it takes.

There are already electronic voting machines that can be used by people with a variety of disabilities to mark paper ballots. Some of them scan those ballots to produce data that will be transferred (physically, not over the internet) to election boards that will count them, but the paper ballot is preserved to validate the counts. They don't always work very quickly or easily; they aren't always kept in good repair; there aren't always knowledgeable poll workers who can show people how to use them, but they exist. And paper-ballot marking machines can be improved, and eventually perfected. Paperless voting cannot.

I know that everyone has been under tremendous stress, has experienced a lot of anxiety for this past year or so—longer for people who are especially interested in public policy and/or politics. I certainly have been anxious, angry, and depressed at times. And I have begun to recognize that I may have been getting just a leeeetle bit too jumpy, too jealously protective of my interests, too eager to leap up and start fighting. I think all of us need to slow down, step back, start paying attention to what all this chaos has done to our thinking and our behavior.

There is nothing sacred about unassisted private voting. People with disabilities—though often mistreated, misjudged, oppressed, and impoverished; subjected to a myriad of indignities, including, just lately, deliberate ridicule by our President and threatened with being denied medical treatment during a pandemic—have been living highly productive and successful lives with lots of assistance from other people. Disability activists have made a huge deal about personal assistants and are currently raising heaven and earth to try to boost their wages so they can continue to receive those services. These workers help with the most intimate personal tasks, both physical—bathing, using the toilet—and financial—shopping and banking. Sometimes the ballot-marking machines don't work, it's true. And voting is absolutely essential. The only way to counter the Electoral College and right-wing gerrymandering is to ensure that as many of the majority of Americans who support progressive ideas as possible vote, in elections that everyone considers fair and trustworthy. But do we really want to claim that the attendants, friends, and family members whom we trust with our very lives, can't be trusted to help us fill out a paper ballot? Really? Is this truly worth destroying the integrity of our election system, the only thing that stands between us and tyranny? No, it is not.

It's an extremist response to a minor problem.

And it is counter to the scientific facts about computers and the internet. We've all had enough of people so obsessed by ideology that they try to suppress science in order to have their way.

Trump and his minions promoted all kinds of fact-less claims about how fraud had stolen the election, from saying that video of the routine movement of boxes of ballots actually showed "smuggling" of fake ballots from China into counting centers, to promoting the theory that a major manufacturer of voting machines was controlled by the Venezuelan government and was "flipping" Trump votes to Biden. Trump also suggested that people should be injected with disinfectants, such as bleach, to cure COVID-19. When the President of the United States spews this kind of nonsense, he imbues it with the authority of his office, and millions of loyal followers believe him. But okay, that was Trump. Perhaps a more compelling example would be Thabo Mbeki, who succeeded Nelson Mandela as President of South Africa. Mbeki had been a compatriot of Mandela in the African National Congress during its long struggle to end apartheid. But as president he became notorious for denying that HIV causes AIDS, and for denying that AIDS was a serious problem in his country or in Africa as a whole. Rather than endorsing, and funding, anti-retroviral drugs to treat the disease, he promoted quackery as treatments. He also expressed the view that the theory that AIDS is transmitted by sexual contact was a form of racism, intended to bolster negative stereotypes about the sexual behavior of black people. There is little doubt that Mbeki was motivated by sincere, if ignorant beliefs, and he had experienced terrible events about which he had every right to be angry and indignant. He was a real hero to millions of long-oppressed black South Africans, who trusted him and believed what he said. And his policies killed thousands of people who could have been saved.

We're sorry. We just can't get behind this. Paper ballots are not a sinister plot to keep people with disabilities from voting. Denying the fact that paperless internet voting will never be safe for ideological reasons—even good ones—won't make it safe. Yes, get rid of New York's full-face ballot so we'll have a better choice of voting machines. Yes, demand better ballot marking machines that work more quickly and reliably and are easier to use. But voting must *never* be conducted over the internet, and *paper ballots must always exist* as part of the permanent, verifiable record of our votes. I hope that as the pandemic ebbs and the political climate relaxes, those who have felt otherwise will take a breath, think again, and revise their positions.

A Kerfuffle Becomes a Scandal

This is what happens when those we put on a pedestal inevitably fall off: Governor Cuomo has been all over the news lately following a state Attorney General's report that said his Department of Health (DOH) had seriously under-reported COVID-19 deaths of people in nursing homes and other residential facilities, and a claim by one of his closest aides that it did so to stonewall a Trump Administration investigation that Cuomo believed was politically motivated. The subsequent unraveling of the cult of Cuomo hero-worship has been so widely reported that we don't need to repeat all those details here. Instead we'll review the most important disability-related facts, which have not been emphasized in the mainstream media.

Was the Trump Department of Justice (DOJ) investigation politically motivated?

The available evidence is unclear. The investigation targeted NY, but also New Jersey, Michigan, and Pennsylvania, all states with Democratic governors, two of whom—Cuomo and Michigan's Gretchen Whitmer—were favorite Trump targets. The Albany *Times-Union* reported that at least 16 states issued orders similar to Cuomo's decree that nursing facilities may not turn away people solely because they test positive for COVID-19, but did not list those states. Several of them, however, with both Democratic and Republican governors, set aside special segregated nursing facilities, or wings of facilities, to keep COVID patients isolated, unlike NY. Also, California's governor, Democrat Gavin Newsom, another frequent Trump whipping boy, issued a similar order but revoked it after ten days, and CA, which did get an inquiring letter from DOJ early on, was not on DOJ's list of states being investigated in August.

What did the Attorney General's report actually say? Attorney General Letitia James is often said to be a Cuomo ally, and the report was not the result of a Trump DOJ investigation. Her office began investigating complaints that nursing facilities were neglecting COVID patients in early March 2020. The report came out before the investigation was finished because James was worried about the implications of the data already collected. Under-reporting was only one issue. Equally significant for disability rights advocates were her findings that the lower the staff-to-resident ratio a facility had, the more residents died, and that "the current state reimbursement model for nursing homes gives a financial incentive to

owners of for-profit nursing homes to transfer funds to related parties (ultimately increasing their own profit) instead of investing in higher levels of staffing and PPE." The report recommended that NY impose minimum staffing requirements on nursing facilities and prohibit them from shifting funds away from direct care.

What are the real numbers? Eventually DOH released the numbers it was hiding and it emerged that, after counting COVID-19 deaths of residents of nursing homes and other residential facilities, about twice as many of those people had died than the state originally reported. By late February that number was about 15,000, or about 32% of the total number of deaths. Nationally that figure has been running around 35%.

What's at the heart of the scandal? On February 10, 2021 Melissa DeRosa, Secretary to the Governor and Cuomo's right-hand aide, told some state legislators in a private Zoom call that the reason the Cuomo Administration refused to release these numbers to the legislature was because when DOJ demanded data for its investigation in *late August 2020*, "Basically, we froze because then we were in a position where we weren't sure if what we were going to give to the Department of Justice or what we give to you guys and what we start saying was going to be used against us and we weren't sure if there was going to be an investigation." In other words, they were stonewalling DOJ until they cooked up a plausible cover story. That's bad enough, but the real problem here is that Cuomo's DOH had been stalling the Democrat-controlled state legislature on this point since *April 2020*, long before Trump's DOJ investigation began. Worry about how to respond to what they thought was a politically-motivated smear job could not possibly be why they hid these figures—figures that every other state was releasing. No, the real reason is that Cuomo didn't want negative information about nursing facilities to come to light. He has been shilling for those facilities for years, because the Greater New York Hospital Association, which represents them, is a major contributor to his political campaigns: \$1.25 million in 2018, over \$126,000 in the early months of 2020, and so on. Meanwhile he's been ruthlessly attacking Medicaid-funded homecare, and especially CDPA, which are competitors of the nursing home industry: He established a special higher minimum wage for fast-food workers while keeping

wages lower for homecare workers; made it harder for people with certain types of disabilities to qualify for homecare services even though they still qualify for nursing homes; and most recently decimated the number of providers of CDPA services. He's also made special efforts to help unpopular nursing homes fill empty beds, ranging from pushing thousands of disabled Hurricane Sandy refugees into the facilities (many of whom have still not gotten out eight years later), to proposing using nursing homes as mental health crisis stabilization centers.

Facing a withering storm of criticism from across the political spectrum, and efforts to limit his pandemic emergency powers, which Cuomo could no longer stem by phoning legislators and reporters and screaming at them, a tactic he's used since his days as Bill Clinton's Secretary of Housing and Urban Development, or by claiming it's all been partisan Republican politics, he finally made some proposals to regulate nursing homes in the 30-day amendments to his budget plan. The proposals feature hefty increases to fines that nursing homes may pay for violating regulations concerning safety, infection control, and abuse and neglect of residents. There's a new requirement for organizations seeking to incorporate or establish a residential health care facility to submit "information pertaining to staffing, the source of staffing, and staff skill mix." Most interesting are rules to keep nursing homes from siphoning off funds to shell corporations and super-high executive salaries, requiring them to instead spend more on direct-care staffing.

This is a rapidly evolving story and we don't know where it will lead between now and when you read this in late March. But it's pretty likely that politicians in NY will continue to ignore the obvious fact that segregated congregate residential facilities are death traps when highly contagious and dangerous diseases are on the loose, a problem that cannot be fixed short of imposing infection control requirements so draconian and isolating that living in these places, which are supposed to be people's homes, would be like spending the rest of your life in a hospital. That is, the problem cannot be fixed at all, and NY needs to abandon its institutional bias and focus exclusively on expanding homecare and other integrated community supports.

Advocates Win CDPA Victory

People with disabilities who use Consumer Directed Personal Assistance (CDPA) services scored a major victory in January when the New York State Department of Health (DOH) issued a much-improved set of rates for providers of the service.

This long-running battle began three years ago when some people noticed that spending on the Medicaid-funded CDPA program was growing much faster than almost any other Medicaid line item in the state budget. That was happening for two reasons. First, the population is aging, and more older people are learning that nursing homes aren't their only option when they inevitably develop disabilities. A growing number of them have been choosing homecare instead. Second, CDPA is the least-costly form of homecare, and as most homecare participants were moved into Medicaid managed care programs, the managed care companies, which get a fixed monthly rate per insured person and therefore have some incentive to keep costs down, had been pushing folks out of more-expensive "traditional" homecare programs and into CDPA. That's actually a good thing for the state budget, because overall per-person Medicaid long-term care costs were going down. But that's not how bureaucrats or right-wing critics of the Cuomo Administration look at budgeting; they just see a fast-growing line item and panic. It's also not how the nursing home lobby, which represents an industry that CDPA competes with, and which funds Cuomo's campaigns, sees it. So the first thing Cuomo did was try to make it illegal for CDPA programs to publicize their services. The programs sued him in state court and won. Then he got mad.

The following spring (see *AccessAbility* Spring 2019) he had DOH propose a new rate system for CDPA providers, one that was too low to live on. (STIC would have lost a half-million dollars a year and had to lay off staff; we couldn't have kept running our CDPA program effectively, though we would have tried.) DOH first tried to set the new rates by decree, without requesting public comment. CDPA providers sued and won again. Although DOH said it would appeal (and recently changed its mind),

they did put out a request for comment on the new rate system.

That document was a joke. It didn't even accurately describe the text of the proposed new regulations, but it did show that DOH didn't understand how the CDPA program works or what it costs to run one. The agency received nearly 9500 comments from CDPA participants, their family members, personal assistants, advocates and CDPA providers (including STIC) and virtually all of them opposed the DOH plan.

At around the same time, DOH drastically increased expense reporting requirements for CDPA providers, demanding an extreme level of detail about why we charge every little thing to the program. Reams of this data went to an accounting company hired by DOH, and the company quickly saw that we were right and DOH was wrong about what it costs to provide this service.

DOH responded by nearly doubling each of the three rate tiers for CDPA Fiscal Intermediary services. Although this would still be a cut for our program, we could definitely make do and continue to provide a quality service with these rates.

It's important to remember that prior to this change, STIC received a flat rate per hour of CDPA services provided, about 10% of which paid for the "fiscal intermediary" part of the program; the rest went for wages and benefits for personal assistants. The new rate system separates attendant wages and benefits from administrative and fiscal intermediary (FI) services. FI is a service provided to CDPA participants that handles all of the technical details of employing and paying the people who help them, so they only have to make the big decisions about who to hire, when they should work, and how they want them to carry out their duties. The proposal was never going to affect personal assistants' wages or the number of hours of service.

Most of those involved with this at DOH were truly clueless about CDPA and probably not malevolent. But DOH was driven by Cuomo's political agenda, which, for the last three years, has been to hamstring homecare by various means, inevitably funneling people who can't get enough services

at home into segregated settings like assisted living and nursing facilities operated by his cronies and campaign contributors. They thought they could hide this intent by insisting that because the new system doesn't touch wages, benefits, or service hours, nobody who uses CDPA would be harmed. The people who use the service—whose lives depend on it—saw through that ruse. They came out in huge numbers to support CDPA with their comments.

They won this battle, but more battles are on the horizon to defend homecare from its enemies. Stay tuned, and stay ready.

Advocates Make Small Gains on Homecare Restrictions

As we've reported (*AccessAbility* Fall 2020), last year's state budget process revived Governor Cuomo's "Medicaid Redesign Team," a fake commission that was convened allegedly to analyze Medicaid spending growth and propose ways to slow it down, but was really just a rubber stamp for plans Cuomo had already made. Those plans included disallowing thousands of people with disabilities from getting homecare, putting them at risk of being placed in institutional settings. The changes became law in April 2020, and the Department of Health (DOH) was tasked with issuing regulations to carry them out. DOH put out a first draft in July for public comment.

The new system requires that to get homecare, most people must have an assessed need for assistance in at least three different types of self-care tasks, such as bathing, using the toilet, walking/mobility, dressing, or eating. People with Alzheimer's or other forms of dementia must need help with at least two such tasks. Also, it no longer matters how much help a person may need with other activities, such as cooking or shopping; if she doesn't need help with those basic self-care tasks, she can't get any homecare at all. This leaves out thousands of people, including those who are blind but don't have any other disabilities—they can't go shopping or to a laundromat by themselves; and those

with physical disabilities who live in partially inaccessible housing—they can't maneuver in the bathroom or kitchen in their wheelchairs.

The new system also takes responsibility for needs assessments away from managed care organizations (MCOs) and counties, and from people's personal doctors. Instead, they'll be done by an Independent Assessor. This "IA" will be a company hired by the state, most likely NY's "enrollment broker" for Medicaid managed care, Maximus. Independent needs assessment has been the holy grail for disability rights activists, who have long argued that letting MCOs assess people's needs for services is like letting the fox assess whether the chickens need to be inside a fence. Sadly, the "independence" of this new assessor is questionable at best, and irrelevant at worst. People on opposite sides of the political fence differ on whether Maximus, in deciding whether people are eligible for Medicaid managed care, does the state's bidding by keeping costs down or opens the gate too wide to people who don't really need so many services. But the IA's assessment is only a "recommendation"; the MCO must read it but it doesn't have to accept it. MCOs still make the ultimate decisions on how much of what kinds of services people need.

The new system also contains an extra second level of review for people who are found by the IA or the MCO to need more than 12 hours of homecare per day.

The proposed regs clarify some parts of the old system that still exist: there is to be a "cost effectiveness" determination as to whether a person who needs homecare could get those needs met by some other less expensive means, such as by using assistive technology ("I've fallen, and I can't get up!"), otherwise known as a personal emergency response system, or PERS, as well as computerized environmental control systems to lock and unlock doors and turn lights and appliances on or off); spending their days in a segregated day program; or by placement in a nursing or assisted living facility. Consideration must also be given to whether a funding source other than Medicaid (such as Medicare Home Health Services, which aren't available to people who work outside the home) could be used to pay for the services the person needs. Interestingly, the regulations used to include referral to hospice services in this category for people who are theoretically near death, but

DOH discovered that the legal authority for that particular cost comparison expired in 1999 and was never renewed. That doesn't mean all of the upstate counties that have been forcing people into Medicare hospice programs since then as a way to save Medicaid money did so illegally; DOH still encourages such comparisons. It just means counties can't tell people they have no choice in doing so, as they often do.

The agency received over 200 responses from consumers, homecare providers, city and county social services departments, managed care providers, and disability advocates. These comments came in three flavors: those that had mostly technical concerns about assessment timelines, review, and approval processes; those that pointed out that federal requirements for person centered planning and consideration of consumer preference had been ignored; and those that called for cancellation of the new tighter eligibility rules because they violate federal civil rights laws and will counterproductively increase rather than decrease Medicaid spending. STIC chose to focus mostly on the latter, though we also emphasized the person-centered planning issue.

We knew DOH was not going to roll back the tighter eligibility rules, because they can't. They are written into state law, and state agencies don't have any choice about following the law. We just wanted to get on the record. Letting people with certain types of disabilities be integrated in the community with homecare, while forcing people with other types of disabilities into institutions, is illegal disability discrimination under the ADA. Making such decisions on the basis of individual cost comparisons is also illegal, as federal courts have ruled. When DOH starts following these new rules they will be sued (again) in federal court and they will lose.

DOH did not quite acknowledge that fact, but they did revise the proposed wording on the cost comparisons. The regs now say that assessors must "balance" cost factors with the preferences of the people being served and DOH now insists that no one can be denied homecare based solely on grounds that a nursing home or day program would be cheaper. That's a victory, of sorts.

DOH did explicitly acknowledge that federal regulations requiring person centered planning, including input from people with disabilities, their personal physicians, and anyone else with relevant information, do apply.

They now encourage the IA to use such input, though they are careful to emphasize that the needs assessment is a recommendation to the MCO or the county Social Services Department, not a service plan; the person centered planning process is the responsibility of the care managers working for those entities. That's another small victory.

The timeline issues are important because the first draft of the regs could have resulted in people being denied services for weeks or months while waiting for the IA to collect information and complete the assessment. DOH added language tightening compliance deadlines and also stating that service provision can begin, or continue, before the process is completed. They laid out an expedited "immediate need" application process that can be initiated by a person's own doctor. This is a big improvement. They also clarified that a person, once approved for more than 12 hours a day of service, doesn't have to go through the second-level review again as long as annual re-assessments continue to call for more than 12 daily hours (if a person who was getting more than 12 hours is assessed one year to need fewer hours, and then re-assessed the next year to need more, the second-level review must be done again).

DOH also responded to comments about a common-sense challenge to denials or reductions of service: that case law interpreting the federal "medical necessity" rule prohibits managed care companies from cutting or ending services for people whose needs haven't changed. DOH insists that it is legal for MCOs to have their own definitions of "medical necessity" that may result in reductions or denials of service to people whose needs have not changed but who previously got services from the fee-for-service (county-based) system, from a different MCO, or even from the same MCO before it changed its definitions. Medicaid fair hearing judges have never bought this and probably never will, but DOH seems to think it can win this argument by coaching MCOs on how to more carefully word the decision notices they send to consumers.

Finally, DOH used better language concerning the "grandfathering" of existing consumers under the old eligibility rules. They said simply that people who "have been" assessed as eligible for homecare under the old rules "will not" be assessed under the new rules. This would seem to mean that nobody currently get-

ting homecare needs to worry about this, even if they temporarily lose their Medicaid or change the auspice (spend-down vs buy-in vs SSI vs over-age-65, etc.) under which they were made eligible for it. The new rules only apply to people seeking New York Medicaid long-term care services who have never been approved for them before.

In any case, none of this is likely to take effect this year. There's another public comment period to go through, followed by another re-write. Meanwhile the Biden Administration intends to continue the national Public Health Emergency for at least another year. That will keep in place the "maintenance of effort" (MOE) requirement for states that took extra federal COVID re-

lief Medicaid money, which prevents cuts to services or eligibility (see page 8).

There is also a move in the state legislature to repeal the minimum self-care needs requirements. Bills have been introduced in the Assembly (A.5367; Gottfried) and the Senate (S.5028; Rivera). We don't know if they have enough support to pass or override a likely Cuomo veto. Stay tuned.

Bidening Our Time on the Budget

The watchword for this spring's state budget maneuverings is: "Congress." As in the United States Congress, which, at press time, was considering Joe Biden's \$1.9 trillion COVID-19 relief bill. That bill originally included \$350 billion in direct aid to state and local governments. How much of that is actually needed is a tough question. Some states have had serious revenue losses during the pandemic, but others have actually had gains. It also matters whether you compare to an ordinary revenue year, such as 2019, or to 2020, during which income tax receipts for 2019 were delayed and real-time sales tax revenues were genuinely down, but states also got a lot of money from federal relief bills. And it matters whether you consider that to keep pace with inflation, revenues must actually grow each year. A state that didn't lose any money when all the accounting has been done would still likely have had to lay off employees and cut services because costs for a variety of necessary things, such as health benefits, rent and utilities keep going up. The National Governors Association, co-chaired by Democrat Andrew Cuomo and Republican Asa Hutchinson of Arkansas, says that state and local governments need a minimum of \$500 billion in relief this year. From their point of view, Biden's plan falls considerably short.

As we said last time (*AccessAbility* Winter 2020-21), by early October NY had no budget deficit, if by that you mean the state had the money it needed to keep going. But by the end of 2020, that included at least \$4.5 billion in borrowed funds, as well as over \$2.9 billion in delayed payments to organizations like STIC, which must be paid back. And both income tax revenue for 2020 (due in April 2021) and

sales tax revenue likely will be down this year due to economic contraction. So the state is facing a real deficit again this year. How bad that will be for disability-related programs and services depends on how much help the state gets from the feds.

Cuomo actually released two budget proposals this year. One is the "best case" scenario, in which NY gets the full \$15 billion in federal relief funding that he's been demanding for the last year or so. The other is what he considered, in January, to be the "worst case" scenario, in which the state only gets another \$6 billion in aid.

Under Biden's proposal, NY would get a total of \$23.3 billion in "direct aid," of which \$12.7 billion would go to the state, with the rest going to cities and counties. In early March, Cuomo and the legislature agreed to cut \$2.4 billion off NY's projected deficit, which, now at \$12.6 billion, nicely (if suspiciously) dovetails with Biden's plan. Biden's amount does not include additional aid for school districts to cover costs to re-open safely, and it does not include the enhanced federal share of Medicaid that the state has been getting to cover pandemic-related costs for nearly a year now, and would continue to receive through the end of this year if Biden's bill passes as proposed. So things may be looking up. That is, they may be if Congress passes this bill before New York's budget deadline of April 1. At press time the hope was to pass it by mid-March, to prevent a lapse in the expanded federal unemployment benefits that were included in the last round in December. By the time you read this, we'll know.

In the meantime, it's kind of difficult to sort out what has been proposed under the differ-

ent scenarios, so we can't present as much detail as we would like.

One bright point is that Cuomo has decided he only needs to withhold 5% of payments to organizations going forward under the worst case, not the 20% withholds that have been in effect up to now. We've also learned that Centers for Independent Living (CILs) like STIC will get a 100% payback of funds withheld against our tiny little General Operating contracts; no 5% permanent cut. On the other hand, Cuomo did not include the even tinier extra \$500,000 (combined, for all 40+ CILs) that we've been given two years in a row by the legislature, in his budget. He always does that, and the legislature restores it, and may do so again this year.

However, Cuomo's budget also would impose another 1% "across the board" Medicaid cut on top of last year's 1.5% cut, before the withholds are imposed. These cuts are not really "across the board" for all Medicaid-funded programs and services. They mostly apply to rates paid for non-waiver community-based long-term care through Medicaid managed care plans or fee-for-service. That would con-



tinue to hurt STIC, which would have to find a way not to cut wages for personal attendants under our CDPA program. We'd likely do that by cutting staff and/or by further reducing the quality of our health benefits—which already took a huge hit this year.

Additional details on damaging proposed cuts are in the NYAIL Priority Agenda on page 11.

Cuomo also finally agreed that a tax “increase” could be necessary. He's proposed to raise the top marginal tax rate for people who make over \$5 million a year from 8.82% to 10.82%, but only if the state doesn't get the full amount he wants from the feds. The word “increase” is in quotes because this is actually a loan, which would be paid back to those taxpayers at a point when the financial emergency is over. That could be just a bit of dissolving sugar glaze to help the medicine go down; it would be very easy to cancel the payback in some future budget cycle.

There are some positive proposals as well. For one thing, Cuomo wants to eliminate the premium for the state's “Essential Plan” health insurance, a very basic plan for low-income people who don't qualify for Medicaid or Child Health Plus. There are also proposals to support more use of tele-health services, and to continue some of the pandemic-related relaxations on in-person visits, assessments, and application procedures for services. The NYS Office of Mental Health and Office of Addiction Services and Supports would be merged into a single organization.

One potentially promising new idea is to create “Behavioral Crisis Stabilization Centers,” round-the-clock walk-in programs that accept people experiencing acute mental health crises. They would not require referrals and would accept drop-offs from the police or other first responders. These would be temporary residential programs that, if done

properly, might be able to hold onto people long enough to connect them with ongoing community supports before they are sent back out on their own. We have a couple of concerns about this though. This is being proposed as a mental health program, and it may be another such program that insists it will not work with people who have co-occurring developmental disabilities, even though 40% of people with DD also have mental health diagnoses. And it's been proposed to use under-filled nursing facilities for the program, which would certainly benefit Cuomo's campaign contributors, but would also subject people to a higher risk of COVID infection and potentially create a pipeline to transform people seeking temporary crisis services into permanent residents in what might end up being very similar to New York City's notoriously neglectful and dangerous “adult homes.”



The new regime in Washington has been busily making changes that affect New Yorkers with disabilities. Here's a few that have been eagerly awaited.

Review of Trump changes to MOE

The “maintenance of effort” rule, or MOE, is part of the second round of federal COVID relief, the Families First Coronavirus Response Act, passed in March 2020. It provided an increased federal matching share of Medicaid funds to states for pandemic-related medical costs. To get this match, under the plain language of the law, states must maintain their Medicaid programs as-is, without cutting services, reducing eligibility, or imposing new costs on recipients, for the duration of the federal public health

emergency. In November, Trump's CMS reinterpreted the MOE rule to mean that states could cut services or eligibility and still keep the enhanced match—in direct and obvious defiance of the law.

Some policy analysts have said that a memo issued by Biden's Chief of Staff on Inauguration Day temporarily freezes Trump's Interim Final Rule on the MOE. We're not so sure. The memo postpones the effective dates of any published rules that have not taken effect. The MOE rule took effect November 2, 2020, so the memo came too late. An “interim final rule” is one that takes effect temporarily while public comments are being submitted. The comment period for the MOE rule ended on January 4, 2021. The

key point, though, is that the rule as written is already in effect as of November 2, 2020, and states can try to modify their Medicaid programs based on it. They would still have to submit any Medicaid Plan amendments to CMS for approval before they could take effect. Cuomo was publicly opposed to the MOE rule as originally written, but as best we can tell, his Department of Health (DOH) did not submit an application to get his Medicaid home care eligibility changes approved before November 2, nor has it said it would try to get approval under the interim rule to prevent loss of the expanded federal share of Medicaid funding. When Biden's CMS gets around to reviewing the public comments on the Interim Rule, it may very well decide to revoke it, since it clearly violates the letter of the law that contains the MOE provision, but it won't be because of the regulatory “freeze” memo. It may well be that no state has had time to get any amendments approved under the Interim Rule, in which case this is just an amusing little diversion for regulatory geeks, but we don't know that for a fact.

Extension of Public Health Emergency

If Biden's COVID-19 relief bill passes intact, it will extend the emergency through the end of 2021. This would include the MOE rule, in whatever state it is ultimately found to be in.

CMS rescinds Medicaid waiver work incentives

Seema Verma, Trump’s Administrator of the Centers for Medicare and Medicaid Services (CMS), had a typical right-wing blame-the-victim attitude toward poor people, and she worked hard to infest that agency with it. A few years ago, all on her lonesome, she announced that CMS would accept Medicaid waiver applications to impose a work requirement on nondisabled people between the ages of 18 and 65 who were seeking Medicaid health insurance. This was a solution in search of a problem, because most people in that group who get Medicaid have some sort of jobs—or at least, they did before the pandemic—though they are typically part-time minimum wage positions, lots of them in states where the minimum wage is still \$7.25/hour, or “gig economy” jobs like driving for Uber or DoorDash, that typically pay less than minimum wage. The main effect of these waivers would be to periodically kick these people off Medicaid when they are between jobs, which happens a lot in those sectors of the economy. That would save money for states, which was

their stated intention. But Verma insisted that such “work incentives” were good for people’s health.

Nineteen states applied for such waivers. Currently only two are being implemented, partially (in Indiana and Utah); the rest are either pending approval, approved but not yet in effect, or blocked by federal courts. The court challenges argued that Verma made the changes without following proper procedures to carry out a rational, fact-based analysis when changing waiver rules or approving applications, and also that requiring Medicaid recipients to work was contrary to the purpose of the Medicaid program. In at least two cases, a Washington, DC federal judge ruled the waivers illegal because the purpose of Medicaid is to provide health insurance to poor people who can’t get it because they can’t afford it because they don’t have jobs, or because the crummy jobs they do have don’t provide health insurance. (We reported on one of these cases, *Stewart v Azar*, in Kentucky in *AccessAbility* Summer 2018. In an Arkansas case, *Gresham v Azar*, the judge cited that decision; he said the “administrative decision in this case shares the

same problem as the one in *Stewart* ... The Court’s job is thus easy ...: the [waiver] approval cannot stand.”) The Supreme Court has agreed to consider the AR case and one in New Hampshire.

Meanwhile, on February 12, the Biden Administration announced it was beginning a “process” to decide whether to roll back CMS’s approval of several such waivers. It seems unlikely that Biden’s CMS would approve the applications that are still pending.

Verma is gone but Biden has not yet appointed her replacement. Insiders speculated on two candidates, Chiquita Brooks-LaSure and Mandy Cohen. Brooks-LaSure was said to be the front-runner at press time. Unfortunately, she is currently a managing director at Manatt Health, a consulting firm that promotes the interests of big health insurance and medical companies; it has a pro-managed care stance and has shown little interest in disability rights issues. Cohen, on the other hand, was chief of staff for Obama’s CMS, which wrote the very pro-integration Medicaid Home and Community Based Settings rules in 2014, but Biden’s people are said not to favor her.

courts watch

D.S. v Trumbull Board of Education: Don’t Wait; Re-evaluate!

D.S. was a child in Connecticut whose developmental disabilities, including autism, involved seriously disruptive behavior. Over the course of several years in the public school system, his behaviors, which included banging his head against the wall, punching himself in the face, yelling, jumping around and throwing objects, got worse, as did his academic performance. His intellectual abilities also seem to have deteriorated. It appeared that his failure to make progress academically was at least somewhat related to the fact that he was spending an increasing amount of time outside the classroom in order to calm down and get control of himself.

His parents were very frustrated and felt the school hadn’t done an adequate job of evaluating his needs or developing effective plans to address them. The school agreed to conduct Functional Behavioral Assessments (FBAs) of D.S. to try to determine the

causes of his negative behaviors and strategies to reduce them. None of this seems to have worked, so the parents demanded the school district pay for an independent “evaluation” not provided by school district employees or contractors. The district refused and the case went to a fair hearing judge, who upheld the district. The parents then went to federal district court, which also ruled against them. They appealed to the Second Circuit and lost again, but for different reasons that are quite important.

The federal Individuals with Disabilities Education Act (IDEA) requires school districts to conduct a comprehensive evaluation of all aspects of the disabilities, capabilities, and needs of classified students with disabilities at least once every three years and as often as once a year if requested. If parents disagree with the results they can request an independent evaluation at the district’s expense. IDEA does not require FBAs unless a child is facing formal disciplinary action that would take him out of school

for a long period of time. D.S. was not being formally disciplined; he was just being “timed out” so he could calm down. His last full evaluation had taken place nearly three years before his parents demanded the independent evaluation; in fact the school had already begun planning his next evaluation and would have done it on time.

The case hinges on the definition of a school district “evaluation” that can be challenged to force an independent re-evaluation. The parents never requested more frequent comprehensive evaluations from the district, which should have been their first step when things began to go wrong. Instead they let the problem build for nearly three years and then challenged the most recent FBA and the last comprehensive evaluation. The fair hearing and federal district judges both said the FBA was an “evaluation” that could be challenged, but that the parents’ request for an independent comprehensive evaluation was asking too much. The district court also said the challenge of the last full evaluation,

conducted nearly three years previously, was outside a two-year statute of limitations given in IDEA.

The appeals court said the prior decisions were wrong in their reasoning though correct in their impact—the parents were not entitled to an independent evaluation—and delivered a lesson that is important for parents of children with disabilities and their advocates to understand.

IDEA defines the kind of evaluation that can be challenged as the mandated comprehensive evaluation that considers all of the child's abilities and needs across the full spectrum of medical, functional, behavioral, and academic domains. This is the only evaluation conferred as a right to all children with classified disabilities. An FBA is only mandatory for some children under very limited circumstances, and it is intended only to address behavioral issues and their causes.

We may be tempted to argue that in order to conduct an effective FBA, the assessor has to consider most of the factors that would be covered by a comprehensive assessment, since various medical, physical, and psychiatric conditions can contribute to negative behaviors. Still, the IDEA language is very clear that the right to challenge and demand an independent “do-over” only applies to the comprehensive evaluation that is due every child classified as disabled.

IDEA is also clear, according to the appeals court, that there is no statute of limitations on parents' right to challenge such an evaluation; the two-year limit only applies to “due process complaints,” such as if the parents challenge an evaluation and the school district does not respond within the legal timeframe. That didn't happen here; the parents challenged the nearly 3-year old evaluation, the school district responded, and then it went to a fair hearing.

Having clarified the law, the appeals court remanded the case back to the district court to re-think it. What are the lessons learned?

First, if your child's IDEA-required Individual Education Plan (IEP) isn't producing good results after a year, don't sit on your hands and wait. Request another comprehensive evaluation, to get better information, before the plan is updated. If you don't agree with the evaluation, you can then request an independent re-do—though the district is entitled to defend the correctness of its evaluation, so you need to have good reasons for your challenge.

Also, seek out expert help early in the process. You can have an expert advocate attend all of your child's meetings and participate in developing the plan. STIC offers this service for free and you should take advantage of it. You'll likely get a more effective plan to start with.

More broadly, there are lessons on trying to fix deficiencies in laws by means other than having legislators rewrite them. The federal Department of Education (DOE) twice issued guidance stating that a challenge to an FBA could result in the district being forced to pay for an independent evaluation, if the challenged FBA was conducted as part of developing an IEP. That's obviously wrong according to the law, and the court did right in pointing it out.

Our elected officials would rather not run afoul of controversies, and most of them aren't interested in the details of how the laws they pass actually work. Advocates tend to take the route of least resistance; if they can convince the DOE to issue a document that contradicts a troubling portion of the law, and nobody immediately objects, why not? But in our increasingly literal-minded federal courts, this strategy has been coming back to bite the advocates. This isn't the way our small-r republican form of government is supposed to work. There's no shortcut for citizens holding legislators responsible for the quality of the laws they write.

E.F. et. al. v NYC Department of Education: An Island within an Island

This class action suit was filed in federal district court on January 26, 2021. It alleges that the New York City Department of Education's (DOE) operation of an entirely segregated separate school district in the Borough of Staten Island solely for students with disabilities violates the Americans with Disabilities Act as well as IDEA.

The complaint indicates that DOE has been using this special district to keep children with behavioral issues out of the regular public schools. IDEA requires school districts to conduct a Functional Behavioral Assessment (FBA) of classified students with disabilities to determine the causes of negative behaviors and develop strategies to reduce them, enabling them to remain in regular classrooms in ordinary schools, if the child is facing disciplinary action that would cause them to be removed from public school for long periods. It appears the DOE gets around this rule by transfer-

ring students with behavioral issues to the separate district's segregated buildings and classrooms, not as a form of “discipline” but merely as “better” programming. Officials in the regular Staten Island schools routinely briefly suspend disabled students for behavioral issues and tell parents that the suspensions wouldn't happen in the special district, to try to get them to agree to segregation of their children. They don't suspend children for long periods or expel them, which would trigger IDEA's FBA requirement. Instead, when they decide to permanently remove a child from school they move her to a special district facility without notice or an opportunity for parents to object, and then tell the parents they just can't accommodate them in ordinary classrooms. This tends to induce the parents to accept the move.

DOE claims the regular school district on Staten Island simply can't accommodate the needs of students with significant behavior problems—but that is likely because the special district has drained away millions of dollars, as well as hundreds of expert teachers and support staff, that could be used to provide effective support services in ordinary schools and classrooms.

In doing so DOE is also effectively segregating students by race: white students with disabilities in Staten Island are much less likely to be sent to the special district than disabled children of color. We'll let you know what happens with this case in future issues.

US v Amtrak: Slow Train Coming

The Americans with Disabilities Act (ADA) contains special rules for making rail transportation accessible for people with disabilities. Congress recognized that there were problems with this industry that would be time-consuming and very expensive to resolve, such as redesign of rail cars, rebuilding platforms, and installation of elevators in subway stations, so it gave generous deadlines for compliance. The ADA was signed on July 27, 1990, and government-owned and -operated railroads were given until July 27, 2010 to reach full accessibility.

Despite having **20 years** to get this done, Amtrak missed the deadline for many stations. Complaints began coming in shortly after the deadline, and the US Department of Justice (DOJ) began investigating around 2012. In the summer of 2013

the National Disability Rights Network (NDRN) surveyed over 100 Amtrak stations across the country and sent its report to DOJ. Many of the issues they found involved things that are relatively easy and inexpensive to fix, such as moving or re-striping handicapped parking spaces, widening doorways, and improving signage. Inaccessible station restrooms were also a common theme, in some cases easily remedied by installing wing handles on faucets or replacing toilets. A few stations had more severe problems, such as platforms that weren't level with the floors of rail cars, or multiple steps on various routes through the stations. (And may God help any disabled person who tries to get on or off a train in Red Wing, Minnesota.)

However, it took DOJ nearly five years—until June of 2015—to send a “letter of findings” to Amtrak advising them that they were out of compliance.

On December 2, 2020, 5 ½ years after the letter, DOJ sued Amtrak. DOJ's complaint cited multiple stations that had still not completed even the simplest and cheapest of fixes.

Then, on the very same day, December 2, 2020, DOJ announced it had settled the lawsuit. The settlement is 39 pages of pretty technical legal language with a bunch of compliance deadlines. It surpasses credibility to suggest that DOJ could have filed the lawsuit, gotten a call back from Amtrak, sat down with their lawyers, and hammered out this settlement in 24 hours. Probably a DOJ lawyer, on his way to the federal courthouse in Washington, DC (DOJ is about a half mile from Amtrak headquarters), plopped copies of both the legal complaint and the already-written settlement on the Amtrak CEO's desk and said, “Take your pick.” And while we should certainly chastise Amtrak for failing to meet a deadline for which they had 20 years to prepare, the fact that DOJ stretched this out to **30 years** does not inspire us to treat them as the heroes in this saga.

In fact, it will be well beyond 30 years before all the stations are accessible under the settlement terms, and maybe not even then. Amtrak claims that some of its stations are not under its control. The aforementioned Red Wing station, for example, a charming stone building that looks like a cross between a Craftsman-style bun-

galow and the Alamo, was built in 1904. The tracks run just a few feet away from the door, and on the same level. Unfortunately, trains sit on wheels that raise them a foot or more above the ground. The station has no platform to allow an accessible level entrance to the cars, and there's no room to build one. Since the station is on the National Register of Historic Places, major structural changes are prohibited. Amtrak can't turn it into a museum and move to an accessible location either; the tracks run right up against the Mississippi River through an entire protected historic district. They'd have to reroute the whole railroad or build a new station somewhere, which would require environmental impact studies, zoning and permitting, public input from people who don't want train tracks or stations in their backyards, and so on. But Amtrak doesn't own any of it: Soo Line owns the tracks and Red Wing Property Conservation Fund owns the building. Amtrak is accountable only for facilities it controls.

Most of the cited stations are not in NY, but stations in Rochester, Plattsburgh, Rhinecliff, and Hudson were dinged in the complaint. So the settlement may hold some good news for New Yorkers: it includes a \$2.25 million Compensation Fund from which travelers with disabilities who were “harmed because of accessibility issues” at various stations may collect. The NY stations on the list include Hudson, Plattsburgh, and Port Henry. (Red Wing, which was heavily cited in the complaint, isn't on the compensation list at all, probably because it's a lost cause.) The full list of stations is here: https://www.ada.gov/amtrak_sa.html#ex5

To collect from the fund, you'll have to submit a claim form and prove that you have a mobility disability and that you were “harmed” by the inaccessibility of one of the listed stations between July 27, 2013 and December 2, 2020, and you'll also have to show that there was no closer accessible station that you could have used to make the trip. If you think you're entitled to compensation, don't wait. Claims must be filed before May 29, 2021. More information is here:

<https://www.amtrak.com/content/dam/projects/dotcom/english/public/documents/corporate/legal/amtrak-disability-settlement-notice-of-claims-fund-en.pdf>

NYAIL's 2021 Disability Budget and Public Policy Priorities

(abridged, from NYAIL)

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL leads statewide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. Over the past year, COVID-19 laid bare the dangers of institutionalizing people in nursing homes and other congregate care settings. Never has it been more important for the state to commit to the principles of *Olmstead* by funding vital programs that protect rights and advance the state's community integration efforts for people with disabilities.

Over the past several years, NY has advanced a number of initiatives intended to promote the independence and inclusion of people with disabilities. From the *Olmstead* Report, to the Employment First Initiative, and most recently, the ABLE Initiative, our community has supported and applauded the goals and intent of these initiatives. Yet we have seen little advancement through legislation and financial investments to make the goals of these initiatives a reality. Investing in these priorities would show real leadership from the state in providing safer and more desirable options to seniors and people with disabilities and would help save lives.

ELECTIONS

❖ **Change local, village, county, and New York City elections to coincide with the dates of state and federal elections.**

People with disabilities are still fighting for our right to vote. Progress was made through the Help America Vote Act (HAVA), mandating all polling sites to have accessible, universally designed voting machines for all state and federal elections. But local elections are not held to this standard. Moving these elections to coincide with state and federal elections, administered by the County Board of Elections, ensures they will be held in an accessible manner.

❖ **Eliminate the full-face ballot requirement in New York State.**

NY is the only state that still uses the full-face ballot, which requires that every race, no matter how many there are, be displayed on the same piece of paper. This can be problematic for people with cognitive, visual, and other disabilities. Very few manufacturers of Ballot Marking Devices (BMDs), which let people with disabilities mark their ballots privately and independently, make devices that work with a full-face ballot. This significantly limits NY's choice of machines, so those that are more efficient and/or lower-priced aren't an option here. It's past time for NY to retire the full-face ballot and use a format that displays each race individually.

EMPLOYMENT

❖ **Prohibit the practice of paying people with disabilities below the minimum wage in NY. A.3103 (Steck) and S.1828 (Skoufis).**

For too long, people with disabilities have been segregated from the rest of society, shut away in institutions and facility-based employment settings. In these settings, agencies are allowed to pay disabled workers well under minimum wage under section 14(c) of the Fair Labor Standards Act (FLSA). Most facility-based employment settings are focused on production-style work to which many people with disabilities are not well-suited; they don't provide competitive, integrated jobs. It is time NY updates its employment model away from segregated, subminimum wage settings to an Employment First model, allowing people with disabilities to become successfully and rewardingly employed like their nondisabled peers.

❖ **Waive NY's sovereign immunity to claims under the ADA and Section 504. S.1119 (Sanders).**

State workers who have been discriminated against cannot sue their employer in federal court for money damages, including lost wages. Businesses, schools, cities, counties, towns and villages and private employers cannot violate the ADA without the prospect of being held responsible in a court of law. State government must be held to the same standard. This bill would restore the same protections to state workers that they had from the passage of the ADA in 1990 until the *Garrett* decision in 2001--the same protections that ALL other workers still have.

❖ **Increase employment of people with disabilities by setting a 7% hiring goal for state agencies, contractors, the legislature, and judiciary. A.3137 (Epstein) and S.1629 (Skoufis).**

A primary goal of the ADA was to increase employment opportunities for people with disabilities. The current employment rate, roughly 34%, has barely improved since the ADA became law. A 2019 RespectAbility report ranks NY a dismal 38 among states in hiring people with disabilities. This bill would make NY a leader in hiring people with disabilities by setting a hiring goal of 7% for the state legislature, state agencies, including SUNY and CUNY, state subcontractors earning over \$10,000, state courts and the judiciary with 50 or more employees.

INDEPENDENT LIVING

❖ **Increase base funding for ILCs to \$18 million in SFY 2021-22.**

ILCs provide critical services to assist people with disabilities to navigate ever-changing service systems in order to live independent, fully integrated lives in the community. As NY continues to redesign health care in ways intended to increase quality and decrease costs, ILCs play a crucial role. ILCs provide a wide range of services based on local needs, aimed at addressing social determinants of health: education, employment, housing, transportation, and other independent living skills. Despite chronic underfunding, ILCs responded to the pandemic by helping form the first line of defense for people with disabilities in the community and in institutions.

ILCs have been severely underfunded for almost two decades while operating costs have increased dramatically, creating a crisis for centers and the people they serve. In 2018, the state's network of ILCs served 114,000 people with disabilities, family members and others, an increase of approximately 20,000 in just six years. This demonstrates the pressing need for IL services, and the number served would be higher had funding kept up with demand. In recent years, the Board of Regents and the Legislature have acknowledged that ILCs are essential providers for some of our most vulnerable citizens, yet have been unable to meet those needs due to this severe underfunding. Despite support in the Legislature, in the last two final budgets ILCs received an increase of only \$500,000. Now, Governor Cuomo's

proposed Executive Budget effectively cuts funding to the centers by omitting this increase. Centers have already created budgets relying on this promised increase and taking it away would further harm already under-funded centers.

HEALTH/MEDICAID

❖ **Eliminate the Medicaid Global Cap, which has led to harmful cuts and limited eligibility for essential community-based services. A.226 (Gottfried).**

For the past few years, the state has sought to cut long-term care and limit eligibility to deal with a "budget shortfall" in its Medicaid program, caused by spending exceeding a self-imposed cap. Essential programs and services have faced cuts as a result. Last year, the Medicaid Redesign Team II enacted cuts to eligibility for community-based long-term care, which will ultimately lead to institutionalization and worse health outcomes for many older New Yorkers and people with disabilities. Due to the pandemic, the Medicaid program has grown significantly, providing essential health services to hundreds of thousands of additional New Yorkers. The state must abandon its austerity approach to dealing with growth in the Medicaid program and spend what is needed to provide comprehensive health care and services to eligible people. NY must end the Global Cap and take factors such as an aging population and growth in the program into account.

❖ **Prohibit adoption of the Quality-Adjusted Life Years (QALY) assessment method.**

Quality-Adjusted Life Years (QALY) is a controversial method of assessing the value of medical treatments developed by the Institute for Clinical and Economic Review (ICER). The QALY method attempts to quantify the cost effectiveness of providing a patient with one year of good health, based on collective opinions about quality of life. A dollars-per-quality-of-life method should not be used in determining whether health care treatment is cost effective or will be covered by insurance. QALY would decrease the availability of effective medical treatments for many people with a disability and could increase institutionalizations. Legal analysis suggests that QALY would violate the ADA if used in state Medicaid programs because it is inherently biased and discriminatory, particularly when used on people with physical or mental disabilities.

❖ **Ensure access to homecare, personal care and consumer directed personal assistance for all who need it by paying homecare workers 150% of a region's minimum wage.**

COVID-19 highlighted the dangers that have long existed in nursing facilities. The state should prioritize access to home and community-based services as the answer to the tragic deaths in facilities during the pandemic. In much of NY, particularly upstate, there is a homecare shortage due to low wages and disparate treatment of women and people of color who comprise most homecare workers. As wages rise in fast-food restaurants and other sectors, it is increasingly difficult to find people willing to do this work, which is physically and emotionally demanding. NY has a legal obligation under *Olmstead* to ensure people have access to appropriate care in the most integrated setting, their home communities. NY needs to provide a living wage to homecare workers. NYAIL is a proud member of the NY Caring Majority, which is calling for the state to increase wages for all homecare workers to 150% of a region's highest minimum wage.

❖ **Help address the homecare crisis by creating a *Home Care Jobs Innovation Fund* at a mere \$5 million per year for 3 years.**

As NY's homecare providers struggle to recruit and retain workers, they lack the resources to test innovative solutions to this problem. This year's budget should include funding to support pilot projects throughout NY to increase recruitment and retention of homecare workers. NYAIL joins with the NY Caring Majority to propose that the state allocate a mere \$5 million per year for 3 years to support this effort. These projects can help determine statewide solutions.

❖ **Fund the Good Neighbor Program at \$500,000/year to assist people to transition out of nursing facilities.**

People in nursing facilities often lose connections to family and friends in the community. When they try to leave the facility, they find that homecare agencies, managed long-term care plans, and waivers can require them to have a backup caregiver for when personal care aides do not come. People who could otherwise live in the community, then, are stuck in nursing facilities due to lack of informal supports. NYAIL's Good Neighbor program connects these people to neighbors who, for a small monthly payment, provide

back-up care as well as connection to the community. This includes visits, check-in calls, shopping and other tasks. This pilot program, funded since January 2020 by the Mother Cabrini Foundation, has transitioned 10 people, with 15 more already matched. Funding ends in June 2021. To maintain the 25 people who will have transitioned, and to transition 25 more, will cost only \$500,000/year. This is negligible compared to the cost of nursing home care or to the value of living independently in the community.

❖ **Increase revenue to protect Medicaid and essential services for people with disabilities in a manner that does not negatively impact them.**

NYAIL understands that the state is facing a significant deficit and funding for these priorities is critical. Therefore, we join with many other groups in our support for raising revenue. We are adamant, however, that any revenue raised must be done in a manner which does not impact low-income New Yorkers, including people with disabilities. Further, it is imperative that NY use that revenue to invest in home and community-based services as the answer to the pandemic.

❖ **NYAIL strongly opposes cutting recruitment and retention funding by 50% for a variety of homecare programs.**

Recruitment and retention funding was established to provide much needed support for training, recruitment, and retention of homecare workers and personal assistants. The Executive Budget proposes reducing this funding by an additional 25% on top of the 25% cut last year. The state should not be cutting this funding when many parts of NY have a serious aide shortage. The ability of those who use Consumer-Directed Personal Assistance (CDPA) to recruit and retain aides has dropped significantly in recent years, forcing some into institutions and preventing others from returning home. The state should be investing more heavily in this funding to ensure people have access to vital homecare services that keep them out of institutions.

❖ **NYAIL opposes eliminating provider prevails. NY must ensure qualified prescribers can use their best professional judgment regarding medications their patients require.**

This proposal would repeal an important patient protection in the Medicaid program which restored "prescriber prevails" for prescription drugs in the fee-for-service and

managed care programs. A prescriber, with clinical expertise and knowledge of the patient, should be able to override a preferred drug. Individuals can respond differently to drugs in the same class, or alternative drugs may have unacceptable side effects. Prescribers are best positioned to make decisions about drug therapies for their patients. NYAIL urges NY to protect provider prevails.

AGING

❖ **Increase NY's funding for the Long-Term Care Ombudsman program by \$3 million.**

The Long-Term Care Ombudsman Program (LTCOP) serves as an advocate and resource for people living in nursing facilities and other institutions. It promotes and protects residents' rights, health and safety by receiving, investigating and resolving complaints made by or on behalf of residents. The LTCOP receives federal funds, but it is insufficient to provide adequate services. NY's commitment to this program is proportionally one of the worst in the US, at a time when residents of nursing homes and other congregate care settings have been most at risk. The State Comptroller's 2019 report on LTCOP found that many residents in LTC facilities lack representation from an Ombudsman, and that statewide there are about half the recommended number of full-time staff. NYAIL urges NY to increase its share of funding by \$3 million to ensure that people in long-term care facilities are adequately served.

HOUSING

❖ **Increase funding for Access to Home to \$10 million.**

Since funding was cut by 75% several years ago, Access to Home has been funded at a mere \$1 million statewide, leaving many parts of NY without the program and resulting in years-long wait lists. Access to Home is an important program from NYS Homes and Community Renewal (HCR) that pays for home modifications to let people with disabilities and older New Yorkers stay in their homes and out of institutions. For many people, adding a ramp to their front door makes the difference between being able to leave the house and being homebound. The pandemic has shown how vulnerable people are when they wind up in nursing homes and congregate care settings. It is critical that the state fund Access to Home to help people avoid institutionalization by making their homes safe and accessible.

❖ **NYAIL strongly supports creation of the COVID-19 Emergency Residential Tenant Late Fee Suspension and Security Deposit Utilization Act of 2021.**

This bill would temporarily allow people impacted by COVID-19 to use their security deposits to make rent payments, as well as prevent property owners from imposing late fees on tenants unable to make timely rent payments, until May 2021. This proposal would greatly help people with disabilities who have lost their jobs or faced salary cuts due to the pandemic, and will protect many from rapidly mounting fees that could lead to homelessness or institutionalization.

TRANSPORTATION

❖ **Require taxis, limousines, and Transportation Network Companies (TNCs), to provide a level of accessible service to wheelchair and other mobility-impaired users, comparable to the level of service they offer other passengers. A.3183 (Steck).**

The limited availability of accessible transportation services is a major barrier faced by people with disabilities, often leading to unemployment, inability to access medical care, and isolation. In most of the

state, neither taxis nor transportation network companies (TNCs), such as Uber, provide wheelchair-accessible service. Outside New York City, there is virtually no wheelchair-accessible taxi service. In some communities, paratransit is the only option; in others, there is nothing. It is imperative that all for-hire transportation services—including taxis and new TNCs—ensure a percentage of their fleet is accessible.

❖ **Require counties to expand paratransit beyond ADA minimums. A.3181 (Steck).**

The ADA mandates all counties to provide paratransit services to people with disabilities unable to take the fixed route bus. Service must be provided to locations within ¾ of a mile of the closest fixed route bus stop. While this is a minimum service, counties can and should provide transportation services to people with disabilities throughout their service area to ensure they can get to work, medical appointments, and participate in their community. Further, the state must not permit transit authorities to cut back paratransit services when they limit or eliminate fixed route bus lines as this will disproportionately harm people with disabilities.

❖ **Enact the recommendations of the TNC Accessibility Task Force.**

The TNC Accessibility Task Force was created as part of the legislation authorizing TNCs to operate statewide. Their February 2019 report included the following recommendations to the state to ensure comparable service is provided to wheelchair users:

- Establish an official governing entity to provide ongoing oversight of TNCs operating in NY.
- Explore ways to provide incentives to increase the number of accessible TNC vehicles statewide, i.e., offering TNC drivers low interest loans to purchase or modify accessible vehicles.

TNCs were mandated by law to implement the Task Force recommendations and directed to work with disability organizations on a plan to provide comparable wheelchair accessible service. Neither of these things has happened, despite NYAIL providing Uber and Lyft with ILC contacts across the state. Unless NY creates a mechanism for oversight (recommendation #1), nothing will change. This budget is a perfect opportunity to provide funding to get more accessible vehicles on the road and to create an oversight body to ensure the TNCs comply.



STIC NEWS



CDPA Services will Continue

By Maria Dibble

In March 2020, Southern Tier Independence Center (STIC) submitted a proposal to the state Department of Health to continue serving as a Fiscal Intermediary (FI) for the Consumer Directed Personal Assistance (CDPA) program. To our disbelief and shock, we were not awarded a contract. There were 29 organizations that were approved to serve Broome County, all but one out of the area (like from Brooklyn, NYC, Rockland, etc.), but STIC was not that one, as it should have been.

First, I want to assure consumers and personal assistants that services will not end.

You will receive services as always no matter what happens.

What are our options? We can and absolutely will appeal. The reasons we are quite flabbergasted by this result are:

- STIC has been a FI for 22 years, since 1999. We grew this program from the grassroots and have made it a success. For a very long time, we were the only FI in the counties we covered.
- STIC has had a stellar record in providing CDPA services, including an audit by the Office of Medicaid Inspector General, which was spotless, not one problematic

finding. We're so clean we practically squeak.

- We fought for the adoption of CDPA into state law in the mid-90s when most folks didn't even know what personal care was, let alone CDPA. We truly understand and practice the model as it should be, not as late-comers to the service do. Many of them are for-profit companies that care more about the bottom line than the people they serve.

We will fight this injustice to the end. Hopefully, we will win, but either way, consumers and PAs can remain with STIC

until the process is completed. We will keep providing CDPA FI services without interruption. If for some reason we do not succeed, we will still directly operate our program for the period of time allowed by NYS DOH. Minimally, we have 90 days after what is called the “contract notification date” to continue to provide FI services. The contract notification date has not

yet been set. That date will be the day that the chosen CDPA FIs have signed contracts with NYS. At a minimum, this is expected to be 2-3 months away, but could take even longer. There is no reason for concern, STIC will always have your back. There will be no gap in services no matter what the results of our efforts are, so keep us in your thoughts and wish us luck.

As always, if you have any questions, you can call STIC at 724-2111. Please ignore rumors or gossip about our potential demise. STIC isn't going anywhere. We will persevere through this as we have through many other crises we've faced. If you hear something about the program and it isn't from STIC, come to us for clarification or an explanation.



Kidz Xscapes is Back!

By Todd Fedyshyn

Xscapes is proud to reopen our kids' escape games for ages 7-12. These games are 30-minute escape room experiences that include our “Immunity Quest” and “Wizard Academy” games, which equals an hour of entertainment for younger kids.

Book a one-hour Kidz Xscapes experience for a flat rate of \$100.00 for up to 4 kids and

1 adult. Check out our website for booking times for the Kidz Xscapes experiences.

Xscapes is also offering 4 adult escape rooms at this time. Choose from “Valley of the Kings”, “Exit Protocol”, “Twilight Zone” or “Wizard and Dragon”.

We promise that you will have an enjoyable time and be challenged by our

unique escape rooms while helping our fundraiser to support individuals with disabilities in our community. Currently we have flat rate private bookings for up to 5 players:

\$100.00 for Valley of the Kings or Exit Protocol (60-minute games).

\$125.00 for Twilight Zone or Wizard and Dragon (90-minute games).

To book an escape room, please visit our website: www.xscapes-stic.com.

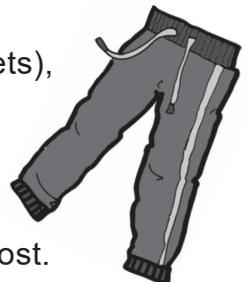
Or call (607) 760-3322.

FREE CLOTHING CLOSET



Katie's Clothing Closet, located at Christ Episcopal Church, 10 Henry Street, Binghamton (at the corner of Henry and Water streets), is open to the public at various times each month.

Please call the church office at 722-2308 for times and an appointment. Seasonal clothing for all ages is offered at no cost.





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Free Access Is Not Free

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

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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!

Southern Tier Independence Center

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