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Thanks a Lot, Richard Nixon

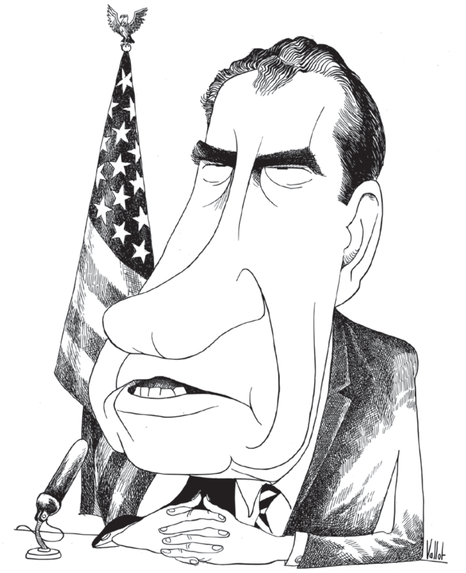
by Ken Dibble

That's right, Richard Nixon. He of the double V-for-victory gesture, his wife's "respectable Republican cloth coat", and his daughter's little dog Checkers too. He of the mining of Haiphong Harbor, the secret war in Cambodia, and the fostering of the war crimes of Henry Kissinger. Richard Nixon of Watergate, who went on national TV to say he was "not a crook".

Well, he was a crook, as conclusively demonstrated by the trials and convictions of his henchmen, and by the books they wrote later. As journalist Hunter Thompson said, Nixon was "so crooked he had to screw his pants on in the morning."

So what's this got to do with disability? Nixon's only alleged disability was alcoholism—but really, he was a functional drunk so he doesn't fit the clinical definition. (Hunter Thompson was clearly mentally ill, too, but, again, functional, and absolutely right most of the time as well.)

I blame Nixon for Watergate, and Watergate was actually the watershed moment for America's second great loss of faith in itself as a functioning democracy. Sure, a lot of people were disillusioned by Lyndon Johnson and his conduct of the Vietnam War. But, looking back, a lot of people also were inspired by his War on Poverty and his contributions to civil rights. And opposition to the war forced him to drop his re-election plans and fade away into history. The people spoke and Johnson listened. But Nixon only resigned because he was about to be not just impeached (Bill Clinton was impeached), but convicted and removed from office. And right after his resignation, Gerald Ford, the man who became his vice-president because his first vice-president, Spiro Agnew, was also a crook who was forced to resign, pardoned him to make sure he would never have to appear in criminal court and wear a grey jumpsuit in Club Fed like his underlings did, so he could go on to write his self-serving lying memoirs, and get periodic brief, if lukewarm, kudos as a sort-of-respected elder statesman who, after all, went to China.



And that's affable, avuncular Gerald Ford, who seemed to be very earnest and reasonable, but who, evidence also suggests, knew a lot more about Watergate and related crimes than he claimed, and who may very well have made a secret deal with Nixon on the pardon. The fact that I can easily speculate about such a deal and nobody will even raise an eyebrow is one of the symptoms of the very serious, and perhaps ultimately fatal, disease that Nixon infected us with.

The more dedicated John ("Cougar") Mellencamp fans may remember his album, *Nothin' Matters and What if It Did?* (The album itself didn't matter; it came before any of his memorable hits and its author disavows it now.) The reason why all this is important for people with disabilities is because, as a result of Nixon's perfidy, the refusal of many members of his own political party to fully repudiate him, the ability of his sociopathic underling G. Gordon Liddy and his spiritual descendants Col. Oliver North and Scooter Libby, among others, to gain popular heroic status for breaking important federal laws in their romantic quests to demonstrate fanatical personal loyalty to their leaders, the growing weariness of the people with scandal that made it easier for partisan politicians to sharply limit the fallout from subsequent episodes like "Irangate", "Contragate", "Chinagate", and others, and to manipulate public opinion by blaming the media for revealing their lies and criminal acts.... all of it began with Nixon.

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During World War II, Harry Truman, then a Democratic Senator in a solidly Democratic Senate, conducted a major public investigation of corruption in the military procurement activities of the Democratic administration of Franklin Roosevelt, and he let the chips fall where they may. Even during Watergate, some Republicans in the Democratic House of Representatives had enough integrity to recognize that Nixon was a criminal, and to say so, and to vote to impeach him.

We did not see anything of the sort among Democrats in the late 1990s when facts emerged to suggest that Al Gore and Bill Clinton peddled their influence to the Chinese government in exchange for campaign contributions. And we did not see any prominent Democrats (except for Bernie Sanders' allies) expressing outrage at the shameless manipulations by pro-Hilary Clinton Democratic Party staffers that sabotaged Sanders' candidacy.

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

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Does anyone seriously believe that any Republicans in today's Congress will say or do anything if it is revealed that the Trump campaign colluded with Russia to rig the election? Or that any Democrats in Congress would have said or done anything if Hilary Clinton had been elected and then was found to have used the Clinton Foundation to sell her influence to foreign governments?

The crud has, by now, crept so far up the spine of American politics that almost no decent, honest, creative, intelligent and rational person is willing to risk his or her reputation by running for office—and it is clear that any such brave soul who makes the attempt will lose because s/he will have no effective defense against the outrageous public attacks and secret "dirty tricks" that his or her opponents will use to defeat him or her. This is why the only choices we now get to vote for are either cynical corrupt political hacks, or fanatical egotistical demagogues.

As a result, a large number of American voters increasingly believe that it doesn't matter how or even if they vote. It doesn't even matter if the President is a thoroughgoing criminal or an idiotic buffoon. No matter who wins an election, the real reins of our government will continue to be in the hands of self-serving liars who will take orders from the obscenely wealthy corporate leaders who funded their campaigns.

And because of that belief, another growing group of Americans now thinks that only radical action by a determined small group that doesn't care about decency, fairness, rules, or laws, can actually force the government to change how it behaves.

The extent to which both of those propositions are true is another symptom of Nixon's disease. Nixon's cover-up of Watergate was, in the words of his White House Counsel John Dean, "a cancer growing on the presidency". Today's disease is a cancer growing on America's traditions of pluralistic democracy and the rule of law.

We should not delude ourselves that the Constitution will prevent any real damage. The Constitution is only an agreement, on paper, among gentlemen and gentlewomen. When the government is no longer run by gentlepersons, no one will enforce that agreement. An example of what can happen came early in our history, in the administration of President Andrew Jackson. Jackson believed that the United States was to be a white man's country, and while he was frequently decent toward individual Native Americans, he could not stomach organized groups of them who were able to exercise economic and political power. When the State of Georgia sought to seize Cherokee land and force its owners out of the state, the Cherokees fought in federal court and eventually won in the Supreme Court, in an opinion written by John Marshall. It fell upon Jackson to take action to block Georgia's seizure, but Jackson said, "John Marshall has made his decision, now let him enforce it." The result was the genocidal death march of thousands of Native Americans across the South along the "Trail of Tears".

And we should also not delude ourselves that it can't get a whole lot worse. The current political climate, with opposing politicians verbally abusing each other, state governments threatening to defy federal authority, and gun-toting militias growing larger and bolder, is starting to resemble America in the 1850s—the decade of America's first great loss of faith in itself—and we all know what happened after that. At least I hope we do. Along with the decline in respect for politics has come a decline in respect for education among Americans, and with it a growing inability to understand history or separate truth from fiction.

Authoritarian strongmen have always gained and held power by manipulating angry and ignorant people. In an America that no longer has a consensus on what truth is, in an internet-based media environment when everybody can make sure that they only hear news that they agree with, a climate in which media fact-checking is now only a political fad, instead of the very definition of journalism that it used to be, it is much easier for an authoritarian figurehead backed by corporate money to trick the public into believing that he actually will bring real change.

And so we arrive at 2017. Trump's populist tweets aside, the result is likely to be that conventionally anti-tax, pro-corporate politicians will finally be able to achieve their decades-old goal of dismantling Medicaid and putting the money back into the pockets of the people who bought their elections, and when they do they will destroy its ability to help release people with disabilities from institutions and raise them out of poverty. And that's just for starters. That's what all this has to do with disability.

Our founders believed, and frequently said, that the survival of America's experiment with democracy would depend on a sophisticated, educated, and well-informed electorate that would be able to see through attempts by power-hungry leaders to manipulate them. We no longer have such an electorate. We only have, on the one hand, a mob of increasingly angry, frightened, disillusioned, and helpless-feeling people grasping desperately for any hand that purports to save them, and on the other hand, a group of dispirited cynics who don't believe it's worth the effort. And we have Richard Nixon to thank for it.

American Pluralistic Democracy: You break it, you bought it.

That Big Long Annual Budget Article Again

Yep, it's that time of year, when the sun returns, a hundred crocuses bloom, and we can hear the happy trickling of snow-melt running through the creeks, along with the whooshing of gasbags in Albany and the steady clink-clink-clink of coins being transferred from the budgets of not-for-profit agencies into the coffers of for-profit medical insurance companies. It's spring!

There's lots of bad news, and some good news, in Governor Cuomo's budget-season proposals this year. But one of the most interesting concerns possible fallout from the inauguration of the new Trump Administration.

Although Trump has occasionally tweeted that he has no interest in cutting Social Security, Medicare, or Medicaid, the Republican-controlled Congress has gained courage from the election of a Republican president who won't necessarily veto any such cuts that they choose to make. So they have resurrected a long-cherished idea first brought forth during the Reagan Administration: Medicaid block grants. (We explained what these are in our editorial last time; see *AccessAbility* Winter '16-'17.) This, along with Trump's clearly-stated intent to repeal the Affordable Care Act (ObamaCare), whose Medicaid expansion provisions have brought a lot of money into New York, would seem to pose a substantial threat to the state's budget.

Citing this situation, Cuomo has asked the state legislature for the authority to have his underlings immediately cut off the flow of money to various programs if these threats actually materialize. Although that sounds reasonable and prudent, it is really an attempt at a massive power-grab by the executive branch of government. One of the biggest reasons why democracies have separations of power between the executive and legislative branches is to prevent the executive from completely controlling the money. Cuomo has an authoritarian bent in his personality, exhibited most famously by his takeover of some fiscal oversight duties from the separately-elected state Comptroller, which led to the "Buffalo Billion" scandal. Anything the feds do to ObamaCare or Medicaid will not be done quickly. Even if they get some legislation enacted later this year, it would be impossible for any real changes to the cash flow to happen before 2018, and maybe not even before the 2018 elections. That's plenty of time for the government to operate normally, where the legislature and the governor negotiate what needs to be done, including raising taxes or cutting something less critical to people's lives than health care, and the legislature has final approval of money matters.

Authoritarians on the right and the left are equally bad. Just as there is no real "American carnage" that requires an authoritarian leader on the national level, there is, and will be, no instant fiscal crisis in New York that requires disrupting a basic principle of government that was established nearly 800 years ago by the *Magna Carta*.

Independent Living

This year the Centers for Independent Living (CILs, like STIC) in NY asked for a $5 million increase to our general operating grants. That's about $135,000 per center. It's not a lot considering that this grant has only been increased slightly, once, over the past 13 years, while medical inflation alone has raised the cost of providing decent benefits to our staff by several times that amount during that period. The NYS Board of Regents, which oversees ACCES-VR, which oversees our grant, supported our request. But Cuomo refused to include any increase in his budget. There seems to be some interest in an increase in the Assembly and Senate, so something may yet get passed.

Transportation

You'll recall that a few years ago, the Cuomo Administration ripped Medicaid subsidies away from public transportation providers, apparently not realizing how important they were to smaller towns and cities. As a result, Tioga County was forced to eliminate all public transportation, and BC Transit has severely cut back service. Similar major disruptions have occurred all over upstate New York. Instead, the state contracted with a couple of for-profit companies to manage Medicaid transportation upstate and downstate. The upstate company finds it more profitable to use cabs and the occasional ambulette than to purchase bus/paratransit passes.

You may object that people could use a monthly bus pass for purposes that weren't strictly medical. But millions of Medicaid dollars are spent to provide services that aren't strictly medical to New Yorkers with disabilities every year—services such as supported employment and housecleaning, and even learning how to take the bus. The new Medicaid Transportation Managers only pay for rides to medical appointments. If you have Medicaid waiver services, you can use them to get a job, or to learn how to do a job, or to learn how to take the bus to the job, and Medicaid will pay for rides related to those processes—but Medicaid will not pay for your ride to the job once you get one. And if you get the typical low-wage, part-time job that most people with significant disabilities end up with, you won't make enough to pay for your rides if you want to pay for anything else, like food, or housing, or clothes.

Of course, our friendly politicians have been told about this little glitch. Their response has been, "Well, we'll study that." They've studied it for several years now, and there are more plans to study more of it. One such plan has been issued, though, OPWDD's *Study to Design a Mobility Management Program*.

The plan recommends that NY spend a lot more money on transportation. Some of that would come from expanding Medicaid waiver transportation services to include any rides an eligible person needs for any purpose. Other states already do this. Maryland actually uses waiver money to buy bus passes for people. The study also calls for spending additional state dollars on rides for people with disabilities or seniors who aren't eligible for waivers. Some states use lottery or casino proceeds for such programs. But we already know that NY won't do these things. Indeed, Cuomo wants to remove transportation from the Medicaid Managed Long Term Care (MLTC) waiver benefit package. MLTC participants would have to use one of those Transportation Manager companies instead. That by itself won't have much impact, since the individual MLTC transportation benefit is limited to strictly medical purposes. Unfortunately, that's not true for supplemental payments the state was funneling through MLTC companies to small rural transportation networks. Cuomo wants to stop those as well. These are clear signals that he won't accept the waiver expansion idea. Nor is he likely to transfer gambling income away from public education.

The OPWDD study proposes three pilot projects for "mobility management". "Mobility management" means coordinating various types of transportation, including public transit, cab service, those vans that disability service agencies have, and volunteers, to try to use those resources more efficiently to provide more trips for more people. It does work—in areas that have a lot of transportation to coordinate. It does not work where there is little or no transportation, because, by itself, it doesn't pay for more buses or drivers or cab rides.

The pilot projects would serve three upstate regions that have a mix of urban, suburban, and rural areas—but our region isn't one of them. Further, the pilots will only offer three types of service: "one-call/one-click" transportation, travel training, and transportation vouchers. Only the last option—can you say "bus passes"?—could really have an impact, but only if the state forks over money to pay for them, which it won't.

Travel training is already available in abundance to people who need it, from habilitation programs, prevocational training programs, and Centers for Independent Living like STIC. But getting trained to use various types of transportation will not help anyone if there is no available transportation to use, and no money to pay for it. "One-call/one-click" services can be anything from a website listing the phone numbers of local transportation providers to an automated website or smart phone app that people can use to schedule rides. The Transportation Managers already have these, or you can call them on the phone. Again, making it easier to schedule a ride will not help if there is nothing to ride in or no money to pay for it.

Meanwhile, Cuomo wants the legislature to approve the use of Uber and Lyft and similar "transportation network companies" in upstate NY. Some think this could help with the Medicaid transportation problem. Certainly it fits nicely with the upstate Transportation Manager's preference for cab services; these are just cab services that are, allegedly, cheaper than cabs. Unfortunately, they are also just as physically inaccessible for people with disabilities as cabs, a problem that is not easy to solve, as we've reported (*AccessAbility* Winter '16-'17). Also, Uber requires either a smart phone or a computer to access, which many low-income people don't have. You can't use an ordinary phone to call Uber like you can with a real cab company. There are accessibility issues with the Uber app as well; we have heard (but not verified) that speech for blind users requires an iPhone and may not work on a cheaper Android phone. And these companies are no solution at all if people can't afford to use them. (See page 13 for more.)

Minimum Wage and COLAs

New York has adopted a multi-year phased plan to increase the minimum wage to $15/hour in New York City and surrounding areas, and to $12.50/hour upstate (actually it's not really as simple as that; if you want more details, you can go to Cuomo's remarkably blatant self-promotional website on the topic: https://www.ny.gov/programs/new-york-states-minimum-wage). This is an excellent idea and we support it. However, there are some problems with it.

First, Cuomo did not initially make any commitment to increase Medicaid rates to cover the cost of paying these higher wages for not-for-profit agencies. That may have been remedied by his new budget proposal. It includes $17 million to address minimum wage increases during the state fiscal year April 1, 2017 - March 31, 2018 for OPWDD, OMH, and OASAS, and $225 million for other "health care" workers (including homecare workers and aides in hospitals and nursing facilities). However, this just makes more money theoretically available for that period for accounting purposes. Changes to rates typically take a couple of years to filter down, and meanwhile not-for-profit agencies will have to borrow more money, and pay more interest, than usual to keep going. Interest is payable under contracts with the state, but contractual amounts are not increased to cover extra interest, so something else has to be cut. (See page 14 for more.)

Second, the minimum wage will eventually reach $15/hour upstate for fast-food workers, while remaining at $12.50/hour for homecare workers. There's already a growing shortage of homecare workers that makes the backup-coverage issue much harder to manage. The impossibility of maintaining reliable backup coverage keeps people in segregated settings in NY, and adding new types of services to what's already available won't help with that. The only way to fix the backup problem is to increase wages and benefits for these workers. If the minimum wage is not raised to $15/hour statewide for all types of jobs, then the fast food industry will drain off workers who we need to help people with disabilities stay in their own homes.

Meanwhile, Cuomo also wants to skip providing the annual cost-of-living adjustment (COLA) for wages paid to providers of community support services for people with disabilities this year. These COLAs are based on inflation measures commonly used to show how much more ordinary folks have to pay for food, gas, housing, etc. every year, and that kind of inflation has been very low (around 2%) for a long time. But service provider agencies have to cope with medical inflation, which raises the cost of medical insurance benefits for staff from anywhere from 10% to 35% every year, not to mention the constantly increasing cost of hiring staff to comply with the ever-more-complex regulations issued by state agencies. So the COLA would not help us much—but it would help some, especially with the requirement to lay out more money for wages years before our rates will actually be increased to cover it.

START

Our region of the state has a tremendous problem with adequately serving people who have both developmental and mental health disabilities. Particularly when these people experience crises, they are turned away from all of the available crisis service providers. There is a "memorandum of understanding" (MOU) that was signed by the heads of the regional developmental disabilities (Broome Developmental Services) and mental health (Broome County Department of Mental Health) agencies that requires both of those agencies to maintain crisis-response programs, and forbids them to turn away any person in crisis. Both of these agencies are flat-out refusing to obey these requirements. But because there is an MOU on paper, when we complain to the people in Albany who are supposed to force these agencies to do what they're told, they say, "Hey! There's an MOU all about this. Problem solved!"

(And by the way, the new Southern Tier Mobile Integration Team, an OMH program for which we had high hopes, whose promoters swore up and down that they would not turn away people with both developmental and mental health disabilities, is doing precisely that.)

This sort of thing happens in some, but not all, other parts of the state. In fact, people from our region sometimes, if they can manage it, go to Syracuse to get crisis services because the responsible agencies up there don't turn people away on the basis of diagnosis.

To address problems like this, OPWDD said it would introduce a new Medicaid waiver service statewide called START (Systemic Therapeutic Assessment, Respite and Treatment). They said it several years ago, and they have been rolling it out across the state, but for some reason, they saved the region that has the least effective crisis response services—ours—for last. Actually we know the reason. Although the original START model developed by the national Center for START Services calls for massive infusions of cash to pay people to provide rapid crisis response services (and the Center warns that without such funding the model will fail), New York's version isn't going to do that. It's going to rely primarily on two things: Using space in closed developmental centers or ICFs to provide temporary crisis respite, and "coordinating existing services." Similar to the transportation issue, coordinating services doesn't work when there are no services to coordinate. Our region is very service poor. Most of the developmental disabilities services staff are tied to group "homes" which they can't leave in order to respond to a crisis. Ditto for mental health staff, and there are a whole lot fewer of them. Plus, this region has some of the least cooperative and most bullheaded mental health and developmental disabilities services administrators in the state. So OPWDD Central probably knows that this program is going to fall flat on its face around here, and they are stalling on making the attempt.

Indeed, we had been told for the last year or so that START would roll out here in January 2017. Now, however, the START website just says "2017." That website also says that each region is supposed to involve people with developmental disabilities, their families, service providers, and advocates in the planning for START roll-out. We are the largest provider of OPWDD service coordination in the Greater Binghamton Region, and a major provider of Community Habilitation services, and STIC is, by far, the squeakiest wheel on the topic of developmental disability/mental health dual diagnosis around here, and we haven't been invited to participate in any such planning, if there is any happening at all. Meanwhile, Cuomo's budget proposal's only mention of START is a $12 million increase "to continue expansion of START services in the downstate area." The Greater Binghamton Region is, geographically, "downstate" from the folks in Albany, but we all know that's not what they're talking about.

OPWDD's budget does includes what appear to be discretionary dollars, which in the past have been used to increase rental subsidies, funding for respite services, and construction of new low-income housing. These are all ideas that we support, of course.

Disrespect

Cuomo is famous for promising all kinds of cool-sounding things and then refusing to make any effort to get them done. This includes empty promises to the disability community.

For example, he has done virtually nothing to carry out his "Employment First" agenda since he announced it two years ago (see *AccessAbility* Summer 2015, and page 13).

More recently he agreed to support proposals that the disability community has been offering for years to establish tax credits for "visitability" (construction of homes that provide enough accessibility to enable people with disabilities to visit), and a tax credit for businesses that hire people with disabilities. However, these did not appear in his budget proposal.

Other Unpleasantness

Funding for the "No Wrong Door" program would be cut by $4 million. It may be that this is because the state has delayed the start-up of this program for so long that it's accumulated a bunch of unspent money that will now be pared away. The program "enhances" the NYConnects program, which is, itself, an enhanced "2-1-1" information and referral program for people with disabilities and seniors. STIC was awarded a No Wrong Door project in conjunction with the Broome County Office for Aging, which would have enabled us to do home visits and provide individualized counseling to help people with disabilities understand their service options, but it seems to be in limbo now. Meanwhile, Cuomo won't actually cut NYConnects, but he plans to replace its state funding with federal Medicaid "Balancing Incentive Program" money.

Once again the general-focus Access to Home program, which pays for ramps and other accessibility modifications for income-eligible people with disabilities who can't get them through other means, such as Medicaid waivers, would receive level funding of $1 million. Meanwhile, much of last year's much larger Access to Home appropriation exclusively for veterans has not been spent due to low demand, and could be used to shorten the waiting list for the general-focus program. Although a lot of people do get this kind of assistance through waivers, there are a lot of other people, including elderly folks, who don't qualify for those programs. So this is an important and useful service that is severely underfunded.

There is also a proposal to eliminate Medicaid payments for "reserved bed days" that allow people in nursing facilities to return home to their families for up to 10 nights per year, and to spend up to 14 nights per year in temporary hospitalizations, without losing their placement in the nursing facility. This idea doesn't seem to benefit anybody, and it will hurt nursing facility residents who will face homelessness when the facilities give their beds to paying customers.

Early Voting and Same-Day Voter Registration

Currently New York requires registration forms to be postmarked no later than 25 days before the election, and received no later than 20 days before the election.

According to the Rock the Vote website, twelve states already do same-day registration, although some of them require you to register at your county clerk's office, not at polling places. It's unclear whether Cuomo's proposal allows registration at the polling place. There's also an automatic registration proposal, meaning that when you fill out a form for the Department of Motor Vehicles (DMV), they will automatically send your information to the county voting registrar unless you check a box to opt out. Although not a lot of people with disabilities drive, this is still very helpful since the DMV also provides non-driver IDs.

The proposal also includes early voting, which 37 states already do. In Cuomo's version, every county would have to offer at least one early voting site beginning 12 days before the election, and at least one site per 50,000 in population.

These are great ideas. They can increase voter turnout among people for whom it would be difficult to make separate trips to obtain a form and vote, while shortening lines at polling places.

Some disability advocates have criticized the proposal because it requires publicity about early voting sites to say whether the sites are accessible to people with disabilities. Critics have said this is tantamount to permitting inaccessible voting sites. That's nonsense. The reality is that some sites are inaccessible, because some county election boards don't obey the law, and there isn't any easy enforcement mechanism. But NY law requires that if your polling place is inaccessible, you can vote at any accessible location that has the same ballot as your district. Therefore, it is essential that any publicity about early voting say if the sites are accessible.

Cuomo's proposal does not repeal the state law that requires accessibility. Also, his proposal clearly states that, when determining which sites will be open for early voting, local election boards must adhere to "standards of accessibility." That's about as good as it gets. After all, nobody is going to take the members of a county Board of Election out and shoot them if they don't obey current law and ensure that all polling places are accessible, or put them in jail or fine them; the current law can't even get them kicked off the Board.

Sure, something ought to be done about the remaining inaccessible polling places. However, you have to start that process by talking to your local Board of Elections and escalating from there, probably by filing a civil lawsuit and hoping that if you win, the Board will actually be embarrassed or ashamed enough to correct the problem. Some of the pols on those boards have very thick skins. This is typical American electioneering politics.

Bottom line: Any New Yorker can request an absentee ballot to be sent to them—no need to go anywhere to pick it up—and fill it out and mail it in, without gambling on whether the accessibility features of your precinct's Rube Goldberg voting machine will be working that day, or whether any of the poll volunteers will know what to do if they aren't. Three states do all of their voting by mail, and nobody except the people who want to make it harder for citizens to vote complains about it there. Given what is going on in this country with attempts to keep all kinds of low-income people from voting, disability rights advocates should strongly support ***any*** action that makes it easier for ***anyone*** to vote. They should not sow confusion and help perpetuate other forms of discrimination by hijacking this issue to get attention.

Early Intervention

Every year Cuomo takes a few hacks at NY's Early Intervention (EI) program, which provides important medical assessment and therapy services to infants and very young children with disabilities. He seems to think the program is being abused by people who should be able to get these services paid for by private insurance companies or Medicaid waivers. On the waiver side, there are some children who clearly have disabilities that will get worse without immediate attention, but due to their age they can't qualify for the OPWDD waiver because a firm diagnosis that establishes waiver eligibility can't reliably be made in infants or toddlers. On the private insurance side, Cuomo's probably right about abuse, but only because it is usually easier and faster to get the EI program to pay for things than to get insurance reimbursement. For a few years his approach was to try to make the EI payment process just as difficult and unreliable as that for private insurance. Nice, eh? That has not been popular with the legislature, so now he is proposing some measures to force the insurance companies to be a little more friendly. These include mandating higher levels of reimbursement, requiring companies to clearly disclose what coverage they provide for these conditions, and streamlining their coverage determinations.

Other Good Stuff

There's a proposal to establish a "Health Care Regulation Modernization Team" in the Department of Health, which would involve multiple stakeholders, including people with disabilities, in a process to "modernize the state's health regulatory framework." One of the focus areas would be "aligning care models around home and community based services consistent with New York State's Olmstead Report." We aren't super-enthusiastic about the ability of planning groups to achieve anything notable, but we do agree that there are a lot of healthcare regulations that are counterproductive, and the existing system is currently "aligned" in the wrong direction, in favor of segregation and institutions, so this is at least a positive move.

After much advocacy from the disability community, Cuomo has agreed to create a "high-needs community rate cell" for Medicaid managed long-term care (MLTC). Under managed care, MLTC insurance companies get a standard monthly rate to pay for any and all services for each person in their plans. Up to now, New York's MLTC rate has been the same regardless of how disabled the person is, or how expensive it is to provide enough community support services to ensure s/he can remain in the community. This has been one reason why MLTC companies have refused to enroll a lot of people with disabilities who are supposed to be "mandated" to be in managed care. The result is that those people are thrown back upon the county Social Services departments, which typically take the easy way out and get them admitted to nursing facilities. As is common with disability issues in New York, the "mandate" is only enforced against individual people with disabilities, not against wealthy insurance companies. A separate and higher rate for people with higher needs will at least remove this excuse from those companies.

In something of a surprise move, Cuomo proposed to end the 20-visit cap on physical therapy, occupational therapy, and speech therapy in Medicaid. However, the legality of arbitrary caps like this is questionable. Federal Medicaid law requires that if a state opts to cover these kinds of services through Medicaid at all, then as many visits as are medically necessary must be provided and paid for, in both fee-for-service and managed care systems, period.

Repeal and Deface

President Trump says he supports repealing the Affordable Care Act ("ObamaCare"). He also says he is opposed to big changes to Social Security, Medicare, or Medicaid. However, as a Republican president, he has, for the first time in many decades, provided the linchpin to a government that could enact laws to make such changes.

We said last time that there was a lot of talk about this stuff but no firm plans. That's still pretty much true today. But there are some developments on the fringes.

Trump issued an executive order requiring federal agencies to take any measures they can to reduce hardships that might be caused by ObamaCare while it's still in effect. Executive orders cannot repeal, or require any agencies to violate, federal law. For the most part this order is symbolic. However, one concrete result is that the Internal Revenue Service has said it will go ahead and process income tax filings that don't comply with the ObamaCare requirements related to the "individual mandate" to buy health insurance.

Insurance companies are already complaining that the ObamaCare "marketplaces" have not generated enough income to cover the costs of insuring everybody, and more major companies have said they will drop out of the markets. This isn't just anti-Obama propaganda, but it also isn't 100% truth. There's a loophole in the "individual mandate" that lets people wait to buy insurance until after they need it. The provision provides an exception to the limited annual enrollment period for people who get pregnant or suddenly ill. Medical insurance requires a "pool" of funds that is large enough not only to pay for medical services but also to pay the costs of operating a medical insurance company, and to provide profits to the shareholders if the company is for-profit. It only works if most of the people who pay premiums for insurance don't need medical services most of the time. And because of the way accounting systems work, these cash inflow/outflow calculations are done annually. If you're allowed to, say, go eight months of the year without paying a $150 premium each month, and then only buy insurance and make payments because you get pregnant in the ninth month, and then, say, the following year after the baby is born you drop your insurance because it will be cheaper to pay the IRS penalty, then you are effectively cheating the system. And if the IRS doesn't enforce the "individual mandate," that creates a theoretical deficit in the total funding that makes ObamaCare work.

It's only theoretical because whether or not individuals pay the IRS penalty for not buying health insurance, the federal government is still going to pay the agreed subsidies to the health insurance companies. The federal government runs a real, not theoretical, budget deficit every year, but unpaid penalties would never amount to more than a drop in that bucket. Also, the situation for insurance companies is not as dire as they portray it, because they have ample cash reserves and they make most of their money not from the premiums themselves but from investments they put the premiums into. What they're really losing is the opportunity to make more money; they aren't running "in the red." So the insurance companies are effectively lying about how bad this is.

But the whole point of ObamaCare was its promise to hold insurance companies harmless—that is, to make sure they could collect their usual profits and provide the usual compensation to their employees even with the new requirements to insure everybody who comes through the door. If ObamaCare creates a situation in which insurance companies can only survive by cutting profits and/or their executives' salaries and bonuses, then that promise is broken. Do-gooder impulses aside, that's a non-starter. Unless you start putting insurance executives in jail for dropping out of the individual market, that's what they're going to do.

In reality, an effectively functioning national health insurance system has only two options:

1. Stick with the insurance pool model, but heavily regulate insurance companies and the insurance market, as well as employers, with the expectations that insurance companies will stay "in the black" but the days of high profits will be over, that employers will not be able to drop or significantly reduce insurance benefits, and that the taxpayers will always have to chip in with subsidies, for both individuals and employers, that will be much larger than those required under ObamaCare today. This, at least, could enable elimination of the individual mandate on ordinary folks and of the most expensive requirements for employers that are in the current law.

2. Drop the insurance pool model and treat health care coverage as a benefit, like Social Security. Yes, everybody pays into Social Security while they are working, but Social Security payroll taxes are not invested to generate income to cover the costs of paying out benefits, nor are those taxes the only source of the money that is paid out. A portion of your federal income tax, as well as other types of annual federal revenue, are also used for that purpose. We already do national health care coverage on the Social Security model; it's called Medicare. All you need to do is expand eligibility for Medicare to everybody, and collect more federal taxes to pay for it. Taxes would go up, but in order to keep those increases manageable, we would also have to impose hefty copayments on most people, limit their choices of providers and impose various types of rationing on services, and heavily regulate hospitals, doctors, and medical supply and equipment manufacturers to keep costs down. This is known as "single payer." Lots of people who love the single-payer idea also hate managed care, but the reality is that any workable single-payer system would be managed care on steroids. And then there's the side-effect that the private health insurance industry, and tens of thousands of jobs in it, would become extinct. That's not to say it can't be done; lots of wealthy countries do it, and get better overall results in terms of public health than the United States does, though there are always anecdotal examples of how those systems really hurt some individuals.

The insurance companies are effectively lying about how bad this is.

Needless to say, there is no political will in the US to do either of these things, which is why we have the ridiculous duct-tape and tinfoil botch job known as ObamaCare. Unfortunately, even a broken clock is right twice a day, and ObamaCare does confer some benefits on some people, so repealing it without replacing it with something better would really hurt a lot of folks.

As for block grants, it's pretty clear that Congress is going to make a serious effort to enact them. Just because Trump says he isn't interested in changing Medicaid doesn't mean he won't sign a block grant bill. (And for those who believe that Trump will get himself impeached, remember that his vice-president, Mike Pence, is even more fully "conservative" than Trump, and not as likely to shoot himself in the foot.) But it's too early to speculate about what this might mean.

We might say it's just too early to worry, period. We should be cautious about that though.

The Republicans in Congress are clearly feuding about how far to go with all of this, and it is certainly possible that they won't settle their arguments until much later this year. They will probably try hard to have something in place for the new federal fiscal year beginning in October. However, unless they are insanely indifferent to the potential for massively disrupting the health insurance and health care markets and industries (and there is certainly some evidence of such insanity out there), they will not do anything this year that would significantly change anything related to the flow of money before the beginning of the following fiscal year in October 2018. Even then, again unless insanity prevails, there would be a multi-year phased plan to enact whatever they decide to do, and it won't be far enough along that it can't be mostly undone by the November 2018 election.

The thing is, in order for that election to really undo anything, the Democrats, perhaps in combination with a few moderate Republicans who are willing to stand up to Trump, would have to get veto-proof majorities in both houses of Congress. That's pretty unlikely. However, if the Democrats get control of at least one of those houses, they might be able to delay things further and prevent massive damage before the 2020 presidential election. That's a more plausible scenario, though it's too early to say that the Democrats really have a good chance of making gains in 2018. There is also no guarantee that Trump won't get himself re-elected.

So what can we do? A ferocious letter-writing campaign opposing both a quick-and-nasty repeal of ObamaCare and any sort of block-grant bill, coupled with large crowds expressing the same views at every "town hall meeting" held by Congress members in their districts, would give some of the more sane and reasonable Republicans ammunition to slow things down enough for the electoral climate to change. That's probably our best option, so be sure to take advantage of every opportunity to contact your representatives and tell them what you think.

Another Short Medicaid Waiver Article

The Department of Health (DOH)'s plan to begin moving people on the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid waivers into managed care has been pushed back four months, from January 2018 to April 2018. No reason was given for this. DOH has been negotiating with the federal Centers for Medicare and Medicaid Services (CMS) on a transition plan for those waivers, and has been mostly silent on that process since its request for public comment on the plan last August. At a recent meeting Cuomo's Medicaid Reform point man Jason Helgerson lambasted consumer advocates for delaying this process and threatened them with the possibility that the delay could result in a Trump-era CMS simply terminating those waivers, since they have been on 90-day extensions for years. The reason for those extensions is DOH's failure to submit a plan that meets CMS's requirements, which are closer to those of the advocates than to Helgerson's. As we pointed out in our comments, DOH's draft plan utterly failed to address key managed care components such as ensuring the adequacy of the network of providers for these services (people are on long waiting lists because they can't get service coordinators, and people using waiver Home and Community Support Services are having trouble getting attendants), and it did not include a clear response to the new conflict-of-interest regulations that apply to all Medicaid community long-term services and supports, whether delivered through waivers or managed care. But the fact that he lost his cool in a public meeting suggests that there is some pressure on him to deliver.

On the other hand, Trump's nominee to lead CMS said during her confirmation hearing that she would support rolling back the newest Medicaid managed care regulations that require states to do a better job of ensuring network adequacy and service quality, so we may be about to lose an important tool to keep DOH honest.

Meanwhile, powerful NYS Assembly Health Committee Chair Gottfried is preparing to resubmit his bill to carve these waivers out of managed care due to DOH's failure to fully acknowledge advocates' concerns about inadequate managed care rates and the unreliability of DOH's needs assessment tool.

DOH also submitted an updated NY Statewide HCBS Transition Plan in January. We did not have time to fully review the plan for this issue of *AccessAbility*. However, DOH said the plan only contained "clarifying," not substantive, changes, so it didn't need to resubmit it for public comment. The response-to-comment section for OPWDD's portion of the plan included some more reasonable and clear, if not necessarily satisfactory, responses, to some of STIC's criticisms. Also, DOH did clearly acknowledge that new federal Medicaid managed care regulations issued last spring would subject every Medicaid-funded home-and-community based long term service and support program in the state to the same set of regulations governing person centered planning, the definitions of allowable "settings," and conflicts of interest. Regardless of the separate state agencies administering these programs, and regardless of diagnosis or whether services are delivered through managed care or fee-for-service systems, all of these programs will be subject to the exact same set of federal rules. Acknowledging that point is an important first step toward getting decision-makers to grasp the full extent of their obligations to make sure that all settings, such as group homes, assisted living programs, senior day centers, and habilitation programs, do not isolate people with disabilities from the surrounding communities or interfere with their rights to come and go as they please, associate with whomever they wish, and engage in their individually preferred activities.

On the conflict-of-interest front, OPWDD is now promoting so-called "Care Coordination Organizations" (CCOs), which would be separate corporations that only provide what is now called "service coordination." The agency is encouraging disability provider organizations to form CCOs, though it is not clear whether such structures would actually comply with the federal conflict-of-interest rules. We have tried, and failed, to get CMS to issue independent guidance on what that compliance requires, and OPWDD has refused to allow STIC to participate on its closed "stakeholder group" that is working on this issue, so we don't really know what is going on in any detail. OPWDD had hoped the CCOs could be classified as "health homes," which, under the Affordable Care Act can receive extra Medicaid reimbursement from the feds, but we have more recently gained the impression that CMS is not going to endorse that idea. OPWDD also expects that all of the current Medicaid Service Coordinators working for voluntary agencies would have to leave those agencies and go to work for the CCOs.

We proposed a mechanism that could work with this CCO model without making Service Coordinators move or risking destroying their relationships with the people they serve. The idea is to divide the job descriptions of current Service Coordinators to create two positions: Care Managers and Community Navigators. The Care Managers would work for the CCO and do all the formal paperwork and referral/arranging/service planning functions. The people who are now Service Coordinators would become Community Navigators, which would be defined as a new Medicaid habilitation or personal care direct support service. They would not do any of the jobs assigned to Care Managers; instead they would do the day-to-day advocacy, troubleshooting, advising, and consulting work that takes up most of a service coordinator's time. This new service definition, which must be done in a formal Medicaid waiver or State Plan amendment and approved by CMS, is key to solving the conflict-of-interest problem, because it enables the Community Navigators (who used to be Service Coordinators) to stay with their agencies and do most of what they had been doing, without violating the requirement that an organization that provides care coordination cannot also provide direct Medicaid services to the same individual.

We are having a very hard time getting people to understand this idea. If you like it, it might be good for you to write to Kate Marlay at the OPWDD Central Office and tell her so:

Katherine.Marlay@opwdd.ny.gov

courts watch

Endrew F. v Douglas County School District: Out of the Frying Pan?

Endrew F. (known as “Drew”) is an autistic child who, as he grew older, exhibited increasingly difficult-to-control behavior in his public primary school. He would yell and cry, drop to the floor, bang his head, and run away from school, in a couple of cases tearing off his clothes when he was returned.

Partially as a result of these behaviors, Drew’s academic progress slowed, and the school reacted by reducing expectations in each of his annual individual education plans (IEPs). When the school produced a plan for fifth grade that contained essentially the same goals as his fourth grade plan, his parents gave up on the public school and placed him in a segregated private school for autistic children. There, Drew made “academic, social and behavioral progress.”

Drew’s parents then requested tuition reimbursement from the school district, which the district refused. This is what brought them into court.

The federal district court and the tenth Circuit Court of Appeals both ruled against Drew’s parents, and the case is now before the US Supreme Court, which heard arguments in January.

The federal Individuals with Disabilities Education Act (IDEA) requires public schools to provide a “free and appropriate public education (FAPE)” to students with disabilities, but the original law wasn’t clear on how to determine whether a FAPE was adequate. In 1982 the Supremes, in a case involving a sign language interpreter for a deaf student, said that IDEA requires that, while students must have “meaningful access” to an education and receive “some benefit” from it, it does not require schools to maximize student achievement, and the Court expressly refused to define any of these terms. (This was the *Rowley* decision. The deaf student was making good grades and keeping up with her peers academically without the interpreter.)

As a result, the issue has come up in federal courts many times over the last 30 years, and different circuit courts have ruled different ways. Some courts, like the Tenth Circuit, have interpreted “some” to mean, essentially, that “any” benefit, no matter how “minimal” or “trivial” or small, would meet the legal requirements. Drew, they said, got “some” benefit from his public school classes, so the district wasn’t required to pay for private school. Other courts have said that “meaningful access” to an education means the student must achieve a “substantial” benefit.

All of these terms are hazy, and if you think about it for a while you probably will see that it would be pretty difficult to provide a precise definition of exactly how much benefit must be required, especially since the amount of progress a particular child can reasonably be expected to make can vary widely. The federal Department of Education, in a “friend of the court” brief, took the position that the standard should be that IDEA requires an IEP that is “aimed at significant educational progress in light of the child’s circumstances.” And if you think about that, you’ll probably conclude that it doesn’t really mean much either.

A writer for the SCOTUS Blog website (http://www.scotusblog.com/2017/01/argument-analysis-justices-grapple-proper-standard-measuring-educational-benefits-children-disabilities/) said that in oral arguments most of the justices seemed upset with those courts that have called for a “minimal” or “trivial” benefit, so it seems likely that they will issue a stricter standard when they release their opinion, probably in June.

Naturally, we have some further observations about this.

Most public schools aren’t doing all that they reasonably can to address challenging behaviors in students with disabilities. Even 40+ years after IDEA was first passed, lots of teachers and school administrators are still resisting the idea that it’s their job to deal with anything beyond strict academic achievement—unless it’s sports, of course. And they are still lamenting the fact that lots of families don’t do that great a job of ensuring their kids come to school prepared to learn. Well folks, we’re here to tell you, that train left the station long ago. Regardless of what your grandparents believed about the roles of schools and families in the raising of children, it is clear that for at least the past two decades American society as a whole believes that schools must take on the jobs that parents don’t have time to do.

This isn’t because America is on some kind of long-term moral and economic decline. We keep forgetting: the era when certain people could tell themselves that one-earner, two-parent families were the norm was extremely brief—just about 20 years or so, immediately following World War II, an exceptional time in history when most of the developed world was a pile of rubble and Americans, not having to compete with anyone else, could rake in a hugely disproportionate share of the world’s wealth and pay white men comparably disproportionate salaries. Before that time (and even during it if you were not white or middle-class), in most families, both parents worked full-time either on the farm or in the factory, and many children did too. The job of child-rearing fell quite frequently to grandparents, who, due to age and infirmity, couldn’t do more strenuous jobs, or to older children in the large families that were common then. Today most households don’t include any non-working people who are capable of childcare. As a result, schools get the duty. That’s been decided. It isn’t going to change. It’s time educators stopped making excuses for failing to get on with the job.

Today many schools serve breakfast as well as lunch. Children come early and stay late so their parents can work. They provide extensive summer programs for the same reason. They provide health and social services. This is common. What is less common are schools in which the actual teachers are expected to help with stuff that doesn’t involve “the three Rs”—like teaching kids how to behave in class. Yes, it can be harder with children who have significant

recognized disabilities. But let's not forget that, for decades, schools have been labeling impoverished and disadvantaged children as "disabled" and dumping them into segregated "special" classes because their behavior is what you would expect of children who are malnourished, infused with environmental toxins by crummy housing, neglected, and/or abused at home. Schools in NY have, for quite a while, been legally required to provide individualized supports to ALL students as needed, whether they are "classified" as disabled or not, to ensure they can get the most out of education, but this fact seems to be news to a lot of teachers and school administrators.

If a student with identified disabilities—and less-than-stellar parents—has behavioral issues in these schools, it's up to the special ed teacher and, maybe, the district psychologist, to figure out how to "fix" them, and it's up to the aides to control them, and if the fixing or controlling don't go so well, the child gets booted into a "special" class or maybe even a "special" school.

Which is largely what happened to Drew—though in his case, the parents pulled him out before he was booted out. But we would bet that what happened in Douglas County, Colorado is what happens with kids like this all over the United States: The school resisted doing a proper functional behavioral assessment and implementing a consistent positive behavioral support plan early on, when the behaviors first began to appear and were relatively easy to manage, and instead allowed things to escalate until they couldn't be ignored anymore. And then they probably told the special ed coordinator and school psychologist to come up with something, and they probably refused to allow the classroom teacher(s) and aide(s) and other staff who interact with the child to take part in developing the plan, and they probably refused to properly train those people on how to carry out the plan, and they probably didn't even think of enlisting the child's peers to help with the plan.

This doesn't happen because these kids are impossible to serve in ordinary classrooms. It happens because lots of people in our schools don't want these kids in ordinary classrooms and they try to engineer things so the kids get thrown out.

Which is sad. What is even more sad is that even if the Supremes rule that schools should do more to help children with disabilities get a decent education, the result could simply be that school districts stop fighting against providing tuition reimbursement for segregated "special" schools like the one Drew is in now, instead of stopping fighting against serving these children properly in their own classrooms.

But we'll let you know what the Court decides.

Congress Blocks Gun Regulations

That headline is no surprise. However, this particular event concerns regulations issued by the Social Security Administration last year to enforce federal law that prohibits people who have been "adjudicated mentally defective" from owning firearms.

To understand this we first have to get past our distaste for that language. What it really means is, if someone has a mental health, cognitive, or developmental disability that is severe enough that s/he has been formally found, by due legal process, to be incapable of managing his/her own affairs, then s/he cannot have a gun.

Advocates opposed this regulation because it reinforces false stereotypes about people with mental illness. It is true that only a tiny minority of people with mental health disabilities are violent; the rest are much more likely to be victims of violent crimes than to commit them.

The thing is, that's not all that's at stake here.

First, a much higher percentage of people with mental illness attempts, or succeeds, in committing suicide every year, and guns make it easier for them to do that. Second, a person who is legally deemed incapable of managing his or her affairs, while not very likely to deliberately and intentionally shoot someone even while in a delusional state, is quite likely to have lapses in judgment that make owning a gun much riskier for them. Consider, for example, what can happen if such a person lets children play with the gun, or loses track of it, or doesn't secure or maintain it properly, or has hallucinations that distort their understanding of what the gun is or what it does, or simply doesn't understand the consequences of treating the gun as a toy.

As for what Congress did: People like Senator Charles Grassley (R-IA) are putting on disability-rights camouflage and saying it's all about being fair to people with disabilities and not enforcing stereotypes. Oddly, these people did not have the same attitude last year when right-wingers were trying to get bills through Congress that would have required states to increase use of forced mental health treatment as a condition of receiving funding for mental health services, and would have terminated funding for protection and advocacy programs that helped people with mental health disabilities fight forced treatment. Let's not kid ourselves: this is just more gun-nuttiness being perpetrated by the NRA, which gets most of its money from gun manufacturers. The NRA's patriotic Second Amendment civil rights stance is a sham; in survey after survey, most American gun owners, including most NRA members, have agreed with a variety of sane legal limits on who can own what kinds of guns and where they can be taken.

The regulation in question simply implements longstanding federal law. Blocking the regulation does not change the law: people who have formal determinations of incapacity are still not allowed to own guns. Congress was able to block the regulation because there's another federal law that lets Congress revert recently-issued regulations, or those that have not yet taken effect. This one would have taken effect in December 2017. The regulations were issued last year as a result of an Obama executive order—but the order just required government agencies to actually carry out the requirements of the 2007 G.W. Bush-era National Instant Criminal Background Check System Improvement Act. That law is what requires the SSA to notify the Bureau of Alcohol, Tobacco and Firearms (ATF) when it makes a determination that a person with a disability must have a representative payee, and it simply puts some teeth into the much older federal law prohibiting gun ownership by people who it is reasonable to believe will not handle guns properly. ATF would then get the person into its database, which gun sellers would have to check before making a sale.

That's all this was about. It only applied to people receiving government benefits related to disability, and among those, only to people who were found by SSA's formal process to be disabled enough to need a rep payee, a pretty small subset of people with mental or developmental disabilities. The regulation stated that SSA would only notify ATF about people with the most severe levels of disabilities, so it would not even apply to all people who had rep payees. Further, as soon as a person applied for benefits, or requested a rep payee, the person would receive written notification that they might end up on the no-gun list, and instructions on how to appeal the notification to ATF. If you submitted, essentially, a doctor's note stating that you're not a threat to yourself or others, then SSA wouldn't pass your name on to the ATF. Grassley and his supporters said that's not good enough; there should be a separate formal hearing on whether a person should be denied the right to own a gun due to disability. That's all well and good—but that would require passing a new law, and neither Grassley nor any of his cohorts are going to pass any law that would have the effect of limiting how much money gun manufacturers can make, because if they do, the NRA, which is a front for those manufacturers, will yank their campaign contributions from them and actively work to get them replaced by people who will do their bidding in the next election.

NYAIL's 2017 Disability Policy Agenda

(abridged, from NYAIL)

The New York Association on Independent Living (NYAIL) represents Centers for Independent Living (CILs) and the people with disabilities they serve. NYAIL is dedicated to removing barriers to full community integration and safeguarding the civil rights of people with disabilities of all ages. More than 25 years after the passage of the Americans with Disabilities Act, New Yorkers with disabilities continue to experience lower educational attainment, lower levels of employment and wages, greater social isolation, worse health outcomes, and greater levels of poverty than their nondisabled counterparts. Despite these gross inequalities and further threats to people with disabilities' rights and services at the federal level, the 2017-18 Executive Budget fails to advance the state's community integration efforts. We urge legislative and administrative action toward the full integration of New Yorkers with disabilities.

INDEPENDENT LIVING PRIORITIES

● Increase base funding for CILs to $18 million as recommended by the State Education Department (SED) and Board of Regents.

CILs provide critical services to people with disabilities, based on local needs, to assist them in navigating the ever-changing service system and address the social determinants of health in order to live independent, fully integrated lives in the community. As the state continues to redesign health care, CILs play a crucial role to meet increasing demand.

CILs have been woefully underfunded for the past twelve years, while the cost of doing business and demand for services has ballooned. In 2015/2016, the state's network of CILs served 103,573 people with disabilities, family members, and others, an increase of more than 20,000 in just five years. Had funding been available, these numbers would have been even higher.

Investing in CILs saves the state money. Data from ACCES-VR show that CIL efforts to transition and divert people with disabilities from costly institutional placements saved the state more than $2.3 billion since 2001. CIL transition and diversion activities save NY more than $9 in institutionalization costs for every state dollar invested in CILs.

● Provide a voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities.

The Office, formerly within the Commission on Quality Care (CQC), was intended to advise and assist the Governor in developing policies to meet the needs of people with disabilities, and serve as the state's coordinator for the implementation of Section 504 of the Federal Rehabilitation Act of 1973 (which now includes the Americans with Disabilities Act and *Olmstead*). The office was dissolved with the CQC and succeeded by The Justice Center, which reorganized itself without any advocacy functions for people with disabilities. At a minimum, the responsibilities of the Office for the Advocate must exist in state government and the Governor should reaffirm his commitment to this Executive Order.

HEALTH/MEDICAID

● Address the homecare crisis by providing a living wage to homecare workers.

The State allocated $225 million to support the cost of the FY 2018 minimum wage increases for health care workers that provide Medicaid-reimbursed services. This only brings homecare workers up to minimum wage, but these are not minimum wage jobs. They are demanding jobs critical to addressing the homecare crisis. Homecare workers help our most vulnerable citizens by giving them the care they need to live at home. And many upstate residents can't get care at home because low pay deters potential workers. The state also provided insufficient funding to cover the additional costs associated with new labor laws, putting homecare, particularly the Consumer Directed Personal Assistance Services (CDPAS) program at risk.

● Fully fund the Community Health Advocates (CHA) program at $4.75 million.

The CHA program assists New Yorkers, including many people with disabilities, to navigate the complex and ever changing health care system. Governor Cuomo proposed funding the CHA program at $2.5 million, however increasing that funding to $4.75 million would allow CHA to provide services to more communities and handle the influx of cases from constituents who are fearful and confused about the potential repeal of the Affordable Care Act.

● NYAIL strongly opposes prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that individual to obtain Medicaid.

● NYAIL strongly opposes eliminating provider prevails.

(See back issues of *AccessAbility* for explanations of the above two items.)

● NYAIL opposes eliminating Medicaid payments for bed holds for nursing facilities.

The Governor proposes to eliminate Medicaid payments to nursing facilities to reserve a bed after a resident temporarily leaves the facility for reasons such as hospitalizations. Eliminating this payment undermines the stability and continuity of care for nursing facility residents.

● NYAIL opposes the proposed $4 million reduction to NY's No Wrong Door system.

The state expanded its No Wrong Door system to align the federally funded Area Agencies on Aging, the state's "mental hygiene" service agencies, and CILs, to create a single point of entry system for accessing long-term services and supports. Ensuring access to comprehensive, accurate, and unbiased information about long term service and support and linkages to services is essential as NY continues to implement major systemic reforms to its Medicaid system.

● NYAIL opposes the proposed $20 million reduction to the state's investments in the Medicaid Redesign Team Supportive Housing workgroup initiatives.

The lack of affordable and accessible housing is the biggest barrier to transition for people with disabilities and older adults. The MRT Supportive Housing workgroup funds critical programs that assist people with disabilities to return to or stay in their community. The 2017-18 budget proposes reducing MRT investments by $20 million. NY must continue to invest in MRT programs so people with disabilities and older adults have affordable, accessible, integrated housing.

● NYAIL opposes granting the Governor broad authority to make mid-fiscal-year budget changes.

The looming changes at the federal level create uncertainties for all programs and the people they serve. Any sudden changes to federal support that require State action must be addressed jointly by the Executive and Legislature and should include a process for stakeholder input.

(Editor's note: The NYAIL agenda supported establishment of a "high needs rate cell" for Medicaid managed long-term care, and removal of the 20-visit cap on Medicaid-funded physical, occupational and speech therapy services. The Governor's budget proposal includes these items, for which we are grateful.)

ACCESS TO HOUSING

There is a housing crisis in New York State for people with disabilities due to the lack of affordable and accessible housing. More than a third of people with disabilities are severely rent-burdened, spending more than 50% of their income on housing. A modest one-bedroom apartment costs an average of 133% of a person's SSI in NY. Avoiding institutionalization or homelessness depends on having a rental subsidy and adequate accessible housing options.

● Restore Access to Home funding to $4 million.

Access to Home is an important program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow individuals with disabilities and older New Yorkers to stay in their homes and out of costly institutions. For several years, the program has been severely underfunded, leaving parts of the state without the program and resulting in years-long waiting lists. The state did allocate $19.6 million to the program in the 2015-16 SFY from the J.P. Morgan settlement funds, but those funds were only for veterans with disabilities. As much of this funding has gone unspent, NY should use JP Morgan Chase settlement funds to adequately fund Access to Home for all people with disabilities.

● Create a Visitability tax credit to help homeowners retrofit their homes to make them more accessible, or to incentivize including visitable features at the time of construction.

Despite strong support from the legislature, Governor Cuomo has vetoed legislation to create a visitability tax credit for the past two years. In both veto messages, he indicated support for the program, but stated that it would need to be addressed during budget negotiations. Again, Governor Cuomo failed to include this tax credit in his proposed executive budget. This important tax credit would help people stay in their homes and out of institutions by assisting with the cost of making their homes accessible. NYAIL urges the legislature to include the $1 million pilot program as proposed in A.9303B/S.6943A of 2016.

● Prevent homelessness for people with disabilities and other vulnerable populations by enacting the Home Stability Support (HSS) program.

HSS provides a statewide rental subsidy for those facing eviction, homelessness, or loss of housing due to domestic violence or hazardous living conditions. When people become disabled and unable to work, they are at great risk of eviction. Shelters are inappropriate for people with illness or disability due to unsafe and unsanitary living conditions, and often, inaccessibility. Current shelter supplements are inadequate, and other programs, such as Section 8, typically take years to obtain. This rental subsidy would stabilize many of our most vulnerable citizens.

- **Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law.** A.3059 (Weprin) of 2016.

EMPLOYMENT

Currently, working-age New Yorkers with disabilities have a 32% employment rate. The poverty rate for New Yorkers with disabilities is 17% higher than for nondisabled New Yorkers. Such levels of unemployment and poverty affect all areas of life, including health, as recognized by the creation of the Medicaid Redesign Team's Social Determinants of Health workgroup.

- **Prioritize employment for people with disabilities by implementing policies in the Employment First Commission's report.**

In the two years since it was issued, little progress has been made to implement the policies of the Commission's report. Several of the recommendations had existing legislation in place at the time of the report's issuance and could have been advanced immediately. Despite assurances that the establishment of a small business tax credit would be in the Executive budget, it was not.

Governor Cuomo made NY an Employment First State in Executive Order # 136, which made competitive, integrated employment with appropriate supports the first option. He recognized the dire need to address unemployment and poverty levels among people with disabilities. The overall goal of the Employment First policy is to decrease poverty among New Yorkers with disabilities by 5% and to increase employment of people with disabilities by a commensurate 5%.

- **Establish a small business tax credit for employing people with disabilities.** A.1369 (Cusick) and S.3688 (Addabbo).

- **Add disability-owned businesses to the Minority and Women Business Enterprise (MWBE) program.** S.3785 (Marcellino).

CIVIL RIGHTS

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 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.

- **Waive the State's sovereign immunity to claims under the ADA and Section 504.** A.5388 (Lifton) of 2016.

People with disabilities are still fighting for our right to a private, independent vote. The Help America Vote Act (HAVA) mandated all polling sites have accessible voting machines for all state and federal elections. But local elections are not held to the same standard, and some use paper ballots, which are inaccessible to many people with disabilities. Moving these elections to coincide with state and federal elections, and be administered by the County Board of Elections, will ensure they will be held in an accessible manner.

- **Change local, village, county, and City of New York elections to coincide with the dates of state and federal elections.** S.382 (Carlucci).

GOVERNMENT OPERATIONS

Currently, people with physical disabilities have no state agency representing their needs and interests. The creation of an Office of Community Living (OCL) would provide a focal point within state government to address the community integration needs of people with disabilities. An OCL would also house some misplaced disability programs, including CILs, Access to Home, the Technology-Related Assistance for Individuals with Disabilities program, and the Most Integrated Setting Coordinating Council.

- **Create an Office of Community Living.** A.9479 (Weprin) and S.7247 (Seward) of 2016.

TRANSPORTATION

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, lack of access to voting sites, and isolation from friends, family, and full community participation. Providing accessible transportation is essential to the State's community integration obligations under *Olmstead*.

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 new transportation network companies—ensure a percentage of their fleet is accessible.

- **Require transportation service providers, such as taxis and limousines, to have accessible vehicles.**

- **Require transportation network companies, such as Uber and Lyft, to provide accessible vehicles before operating outside of New York City.**

The lack of accessible and affordable transportation is a major barrier for New Yorkers with disabilities, affecting their ability to work and participate in the community. This is particularly true upstate. Allowing ridesharing services to operate throughout the state could dramatically increase transportation opportunities for people with disabilities.

However, any new transportation option must not discriminate against people with disabilities. Proposals from Governor Cuomo and the Senate would provide transportation network companies (TNCs) such as Uber and Lyft with statewide authority without ensuring wheelchair access, and would prevent localities from imposing any accessibility requirements. Without accessibility requirements, this proposal has the potential to make the situation worse by putting what accessible transit options there are upstate out of business. The state must include wheelchair-accessibility as part of any rideshare proposal.

- **Cap fares for paratransit at levels no higher than the base fares for transportation of non-disabled adults using the public transit system.** S.3720 (Espaillat) of 2016.

Many paratransit systems across the state charge far more for their services than fixed route buses, making the only accessible transportation option unaffordable. In Westchester County, for example, a paratransit round trip is $10.

Da Doo-RON-RON

by Maria Dibble

STIC Executive Director Maria Dibble, NYS Senator Fred Akshar, and Assemblymember Donna Lupardo's Communications Director Chris Whalen, at STIC's RON press conference (from left)

STIC is very proud to be the leader in the Southern Tier of "Restore Opportunity Now" (RON), a coalition of over 340 not-for-profit organizations around the state, working to overcome the challenges of our current budget environment, and the many uncertainties due to the election of Donald Trump.

Why RON at this juncture? Not-for-profits have encountered stagnant funding for years, increased health insurance and other costs, and tighter oversight (to the point of micro-management) of state contracts without any compensation. Minimum wages are going up, which we certainly support, but contracts and Medicaid rates are not following suit. For-profit businesses can raise their prices, but we don't have that luxury.

Restore Opportunity Now Invest in Human Services

The Governor has systematically ignored the contributions of the human services sector, most of which are not-for-profit organizations, and he has once again stuck to that trend with his budget proposals for the next fiscal year.

We can no longer afford to see the State Fair funded above people with disabilities, or new stadiums and trails proposed over supporting decent wages for homecare workers, people who are living on the edge of, if not in, poverty.

To publicize our plight, as well as the Restore Opportunity Now campaign, STIC held a press conference on February 2 to introduce the coalition to the community and invite organizations to join us in educating the Governor and the legislature. The event was very successful, with many agencies attending, as well as the enthusiastic support of Senator Fred Akshar, and a representative of Assembly Member Donna Lupardo's office (Lupardo planned to attend, but was delayed in Albany at the last minute).

The Governor needs to recognize that not-for-profits are employers as well, and that we provide jobs for hundreds of thousands of New Yorkers across the state. (For example, you may be surprised to learn that at any given time, STIC has between 600 and 800 people on its payroll.) We offer invaluable services that the state can't do without, yet we are consistently asked to do just that: "do without", "make the best of things", "tighten our belts". There is only so much belt-tightening we can do, before we are strangled out of existence.

We'd like to thank those who support us, and our local representatives for picking up the gauntlet and publicly expressing support for our agenda. If there are any not-for-profit organizations that wish to join RON, there are no dues, and you'd be welcome. Contact me at (607) 724-2111 and I can provide you with the pertinent information.

Imagine

by Bill Bartlow
(with VERY abject apologies to John Lennon)

Imagine there's no power
It's scary if you try
All hell upon us
A nuke above the sky
Imagine all the people chaos every day

Imagine there's no country
Extremely hard to do
No one to call or cry for
No transportation too
Imagine all the people looting for a piece

You may say I'm a schemer
But I'm not the only one
I hope someday you'll get it
Or our comfy culture's done

Imagine eighteen hundred
Survival if you can
A constant need and hunger
Living off the land
Imagine all the people who'd perish in that world

You could say it's a screamer
But it's a possible one
An EMP could do it
And our way of life is done.

Imagine Armageddon
Coming from on high
A nuclear explosion
all electronics fried
Imagine all the power gone for every day
Imagine there's no smart phone
No more iPads too
No one to tweet or Facebook
TV and cable blew
Cars and trucks are toasted
Planes fell to the ground
You're living in a nightmare. It's real for everyone.
Around you death and chaos
The enemy has won.

Imagine Three Mile Island at all nuke power sites
No one to fight the fires or to protect your rights
The healthcare system crumbled
Stores emptied trashed and closed
The food supply has vanished
America's been hosed.

The powers saw it coming,
They knew it years ago.
They sat there on their backsides
Pretending not to know.

Imagine if they'd acted
to save the power grid
We wouldn't have this problem
But the traitors....never did.

Imagine your team coming to the new "PULSE" escape room. Your team's mission is to keep the above scenario from happening. 60 minutes to detonation: and counting down.

Book your PULSE experience here: https://www-1554a.bookeo.com/bookeo/b_xscapes_start.html?ctlsrc=1487693667019&src=02i

Bookings are available Thursdays, Fridays and Saturdays, at 5:00 pm, 6:30 pm and 8:00 pm.

Valley of the Kings is still available too!

In Memoriam: Beth Pedersen

STIC mourns the loss of Elizabeth A. "Beth" Pedersen, 58, of Norwich, who passed away on Saturday, January 21, 2017 from multiple sclerosis. A former member of our Board of Directors, she contributed years of her time and support to our agency. She had a strong belief that people with disabilities should be allowed to live full and active independent lives as participants of their communities, and she was very dedicated to our mission and philosophy. We extend our heartfelt condolences to her husband Daniel Pedersen, who was the love of her life since high school. An active member of her community, she advocated for curb cuts and handicapped parking in Norwich, and trained dogs to visit nursing homes as a form of therapy for the residents. She was a kind, compassionate and gentle person who was well liked by everyone who knew her, and she leaves behind a large empty space in the lives of those who loved her.

XSCAPES

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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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