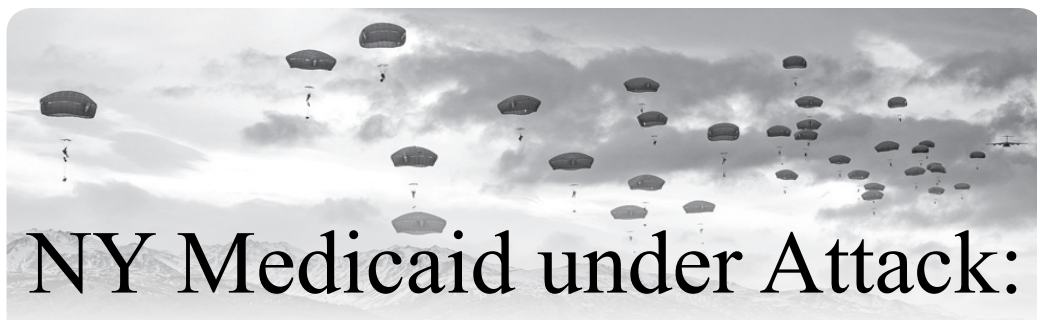


The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

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NY Medicaid under Attack: The Real Story

by Ken Dibble

There have been a lot of stories in the media this fall about how New York's Medicaid spending is out of control and there are going to have to be deep cuts. Some of this is driven by people who don't like government programs, and some is aimed at certain special interests that seem to be getting a windfall out of this increased spending. Most of the coverage, though, ignores or downplays the state's bias in favor of segregated programs while demonizing people with disabilities, including a growing number of elderly people, who rely on personal care services to remain in their own homes and participate in community life.

The anti-Medicaid charge is being led by the Empire Center for Public Policy, a right-wing think tank that generally opposes social-welfare spending and efforts to level the public-policy playing field so that poor people and people of color have an impact equal to that of the comfortable and the wealthy. For example, they think we wouldn't need the "Obamacare" Medicaid expansion for the working poor if we would just cut state taxes on insurance companies, because if we did that, surely those companies would kindly lower their premiums and not simply pocket the in-

creased profits, and then people living at or just above the poverty line (up to a maximum annual income of \$17,236 for a single person—really high on the hog, eh?) would be able to purchase insurance for themselves. This group has done a pretty good job of getting mainstream media coverage for its positions lately.

The Governor, Andrew Cuomo, has political cronies who are deeply embedded in the healthcare field, including both organizations that operate segregated facilities and health-worker unions, and he has consistently promoted their interests throughout his tenure while claiming credit for Medicaid "reforms" that have cut costs. This is why his Medicaid cost-control efforts have focused most heavily on community-based services that largely benefit people in the least influential disability groups, such as mental health and physical disabilities. People in these groups are disproportionately poor and non-white, which means that Cuomo and the Empire Center are able to use each other at times to back their otherwise different agendas.

Then there's the history: Every New York governor, whether Democrat or Republican, who has been in office long enough to

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matter since STIC was founded in 1983, has consistently attacked personal care services for people with disabilities. That attack began long before there was such a thing as consumer-directed services. From time to time members of the legislature have also joined in, calling personal care "free maid service," among other things. So by now we're used to claims that personal care is being abused and is rife with fraud, and what New York really needs is to tighten the oversight and cut out the fat and the luxuries. There's nothing really new here.

The thrust of the Empire Center's recent reporting has been that Cuomo's "Medicaid Redesign" was originally effective at keeping costs down, but no longer is, and his administration needs to enforce strict discipline on spending—especially by expanding managed care.

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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.

New York's Medicaid program spends more per recipient than any other state, and per-recipient spending has grown much faster than in most states in recent years. Since this isn't happening in other states—not even in California—this must mean that it doesn't need to happen in New York, and if we only stopped indulging ourselves we could fix this problem. So we are being told.

Lots of big numbers are being thrown around in the news, and we've not been able to sort it all out definitively. Right-wing analysts are predicting a Medicaid funding deficit of between 6 and 7 billion dollars "over the next four years," and we've also heard there's a shortfall in the current state budget of \$1.5 billion, all of which is being attributed to Medicaid. We might be looking at a deficit in the \$3 billion range for this coming fiscal year, which begins April 1. The lack of clarity contributes to a growing—but false—atmosphere of impending crisis. The question is, how much of this increased spending can realistically be cut without causing disastrous harm, and how much do we need to pay for with increased taxes?

I know that numbers are boring, but numbers are what are being used to attack us, so we need to understand them. Please bear with me.

First, we have to pay attention to how much of this "deficit" is New York state money—money that we actually have to come up with—as compared to total Medicaid spending, which includes federal matching funds that we don't have to worry about. Depending on what point people are trying to prove, we hear different numbers.

Next, from our point of view as NY taxpayers, something over \$1 billion of the non-federal share isn't a spending increase at all. It's just a shift in which of our pockets it comes out of. Ten years ago in New York, nearly all of the Medicaid spending came from three sources: 50% from the feds, 25% from state government, and 25% from county governments. Gradually, over several years, the state has been absorbing some cost increases in the program, so today the state share is much more than 25%, and the county

share is much less. (Annoyingly, it's more complicated than that; the shares vary by program type. But the bottom line is the state government pays a higher share of total Medicaid costs than it used to.) It's all our tax money though, whether we pay it via state income and sales taxes or county property and sales taxes. It's only an "increase" from the point of view of the state budget. And at least before the rise of managed care, we thought it was a good idea to transfer control along with costs to a single entity in state government, to put an end to the problem of different rules and service limits in different counties. Now we all deal with a bajillion different managed care companies, each with their own rules and limits, so from one point of view county vs state share doesn't matter so much anymore. On the other hand, if the counties had to take back a larger share, we'd see other kinds of bad news, such as even more mass transit cuts, locally.

There certainly will be a decrease in the federal share in 2020; that's not just scare-mongering. The Obamacare expansion came with an incentive for states: Those that chose to extend eligibility to nondisabled adults with incomes up to 138% of the federal poverty level would get 100% of that expansion paid for by the feds—no state match required—for two years. Then the federal match would decrease gradually, until hitting bottom at 90% next year. The state has been expecting this and planning for it—or at least should have been; it's not a surprise. (NY, by the way, was doing this before Obamacare, via Medicaid "1115" waivers, though the federal match was not as big then.)

The minimum wage increase does account for some portion of Medicaid spending growth—as it should. People on the right complain about New York's high minimum. But remember that \$17,000+ annual income figure? It's over \$2000 more than what a personal attendant making the federal minimum wage of \$7.25/hr. would make in a year if she managed to work full-time, and full time is not common for attendants in upstate NY—for logistical reasons related to low population density, not because we don't need more workers working more hours. We've reported many times that

there's a shortage of attendants upstate, and wages are too low to support adequate services. It's still true. The only way to combat that is to increase not just wages, but benefits, for attendants.

In the nine years since Cuomo took office in January 2011, the upstate hourly minimum wage for personal attendants rose from \$7.25 to \$11.80 (as of the end of 2019). That's a 63% increase. Seems like a lot, doesn't it? Yet in the nine years from 2000 to the last pre-Cuomo raise in 2009, the wage went from \$4.25 to \$7.25, a 71% bump. The percentage growth in Medicaid per-person spending during the Cuomo era isn't anywhere near that high; in fact, it's just over 7%. The Empire Center recommends that minimum wage increases be included in the Medicaid growth cap to help get costs back "under control." But there's nothing unusual about the effect of minimum wage growth on Medicaid spending. It's not a new thing. It's just that right-wingers hate government-mandated minimum wages, and they'll look for any excuse to stop them.

What else accounts for New York's higher Medicaid costs, and, especially, those for personal care, compared to those of other states?

Personal Care Services (as a specific category) are optional under Medicaid; some states don't provide them at all. Still, New York's per-capita spending for personal care is about six times higher than the average across all of the 33 states that do provide it in some fashion. "Per capita" in this context means per New York resident, not per Medicaid recipient. That figure is misleading, since overall in recent years New York is only tenth on the list of top per-recipient Medicaid spenders, despite being fifth on the list for per-capita income; we're only 27% above the national average for Medicaid spending and about 21% above average for personal income. In those terms we're only being modestly generous—and it only seems that way before we account for New York's cost of living. But "six times the national average" for personal care—the least costly, and therefore most efficient, form of Medicaid long-term care spending we could do—sounds shocking, so that's why that number gets tossed around.

That, of course, includes states whose minimum wage is no higher than the feds' \$7.25, and states that only provide personal care to a tiny percentage of people who could benefit from it, strictly limited by means of waivers that sometimes have waiting lists for services. It doesn't factor in that optional Personal Care comes with fewer training and certification requirements than the mandatory, much more expensive Certified Home Health Aide service, which is what some other states substitute for it to some extent—a higher number that apparently didn't make it into the Empire Center's calculations. What happens to the people who can't get enough—or any—personal care in those other states? They either end up in institutional settings at a much higher per-recipient annual cost (though total spending may be reduced because the life expectancy of a nursing facility resident is several years shorter than that of a person with similar needs living at home, a fact that state Department of Health (DOH) number-crunchers are aware of and may be counting on), or family members quit working to take care of them, and, as a result, go on the public dole themselves.

The next most important reason for our higher Medicaid spending is likely simply related to the overall higher cost of living in NY.

For example, my house in Conklin, NY is valued at about \$130,000. A very similar house in Smithtown, on Long Island, is valued at well over \$400,000. What's the difference? Purely location. Rents differ geographically in a similar way. How much more do you have to pay a human services worker who lives in Smithtown to enable her to feed and house and clothe herself and her family, compared to one who lives in Conklin? Now consider that the New York City metropolitan area has the most expensive cost of living for large cities in the entire United States, and the fact that fully half of New York's entire population lives there. Also, unlike upstate, many of the homecare workers down there are unionized. Do the math. Now do the math comparing New York as a whole with, say, Nebraska or North Carolina.

New York doesn't just have the most ex-

pensive place to live in the United States, it also has the 5th highest per capita income in the United States. A state that earns more per capita should, of course, spend more per capita to care for people with disabilities.

Now I'm definitely not saying there are no inequities or inefficiencies in New York Medicaid. The third most important reason for why we spend Medicaid dollars the way we do is political. Despite all the numbers being used in arguments, Medicaid funding decisions are made largely on a political basis, whether the numbers support them or not.

Although comparative data is hard to come by, we believe that New York's Office of People with Developmental Disabilities (OPWDD) outpaces all other states in the amount of group home real estate that exists. Most other states drastically reduced their group home development pace several years ago, in favor of providing less expensive fully integrated supports in people's own homes. Also, I believe that few other states have as many government-owned-and-operated group homes as New York. All other things being equal, a DD group home operated by a not-for-profit agency costs about half as much as a state-operated facility of the same size. There is no significant difference in quality; nice ones and egregious hell-holes exist in both realms. Nearly all of them, however, restrict their residents' autonomy and life options more than is necessary or healthy. (Here's an interesting read: <https://www.courts.ca.gov/documents/BTB24-PreCon1A-1.pdf>. Although aimed at children in group homes, many of the points about how destructive those places are to personal autonomy and growth can easily be applied to adults.)

Integrated supports cost less than group homes, but group homes are very popular among the people who are most influential and active in advocating for DD services. These are mostly well-to-do older parents of adults with disabilities, some of whom sit on the boards of organizations that operate segregated programs, and they see self-contained residential facilities as the "safest" way to address their children's needs. Integrated supports are

just as safe, and better for quality of life, but they are harder to manage, in part due to low wages, leading to high turn-over, for direct-care workers. Among disability activists, DD activists are the most well-organized, well-funded, and influential in the state. This is a reason why lots of people with developmental disabilities live in expensive group homes, while lots of people with significant mental health disabilities in New York (the OMH constituency), who do not have such influential support, live in jails or on the street.

Although the number of people living permanently in nursing facilities in New York has declined in the last decade (about half of the people in them are there for short-term rehab now), there are still lots of people in those places who would be better off, and less expensive to serve, in their own homes with ongoing personal care and occasional visits by more specialized staff. Currently NY Medicaid spends, on average, about one-third more to serve somebody in a nursing facility than it spends to serve a person with similar needs at home. Expanding programs that help keep people at home and get them out of nursing facilities would be a good investment for the state, but programs like that, and not the residential programs themselves, are the ones that get subjected to the spending cap.

If politics didn't matter, and humane efficiency did, nearly all New Yorkers with developmental, mental health, and physical disabilities would be living in integrated settings with appropriate levels of support. Only a small number of those with the most significant needs would be in group homes or nursing facilities, and none would be homeless or in jail.

The Empire Center promotes Medicaid managed care as an effective solution for controlling costs, and points to the fact that during the first years of the Cuomo Administration and its "Managed Care for All" push, the state's per-recipient Medicaid spending went down by almost 11%. But what actually happened during those years? Medicaid spending for a variety of non-managed-care community-based programs was frozen, not just capped at a small percentage increase. New York has required managed care for nearly all nondisabled

Medicaid recipients since the 1990s. Roll-out of managed long-term care for people with disabilities has been slow. It did not affect large numbers of people in Cuomo's first term, and as soon as it began to take hold, serious problems developed. There was some hundreds of millions of dollars in fraudulent spending on managed-care "social adult day care" for senior citizens who were not actually eligible for it, and it was not discovered, or accounted for, until several years later, when some, but not all, of it was paid back. Since then another \$1 billion or so may have been inappropriately collected by managed care plans that could not demonstrate an appropriately determined need (although that figure depends on whether you accept the common, but statistically problematic, Medicaid auditing practice of projecting small sample sizes to entire programs). Also, a pattern emerged of managed care companies arbitrarily cutting personal care in violation of federal Medicaid law and the state's own regulations. When services are cut, those cuts get counted in fiscal reporting. When those cuts are found to be illegal, they are not "repaid" retroactively, but spending goes up again when the companies start following the law. So the facts about how much money Medicaid managed care has actually "saved" in New York are hopelessly muddled. But we can tell you why managed long-term care *can't* save very much and never should have been expected to.

The assumption that managed care saves money is based on the idea that if the insurance companies' revenues are capped, they will try to limit expenditures by using a "gatekeeper" to decide which more expensive services a person will or won't

get. That's the "management" part, and the model is based on private insurance companies that exclusively pay for acute medical services like doctor visits and lab tests, which, without the gatekeeper, might be provided largely on demand. But Medicaid long-term care services have always had a gatekeeper; nobody can walk into a homecare agency and get as many hours of service as they want. You can't even do that if you have private long-term care insurance. Long-term care services are delivered only after objective needs assessments, and periodic re-assessments, determine what is appropriate. Federal Medicaid law requires that all medically necessary services, as determined by such assessments, must be delivered to all of the people who are eligible for them. If they aren't, the person can appeal, and they will win if they can show that they aren't receiving what they need. At the Medicaid Fair Hearing level, people win those appeals over 90% of the time. So prior to managed care, county social services departments were already doing at least as good a job of controlling long-term care spending as any managed care insurance company can—and unlike managed care companies, county social services departments don't get to keep a 15% profit (the historical administrative rate for so-called "fee for service"—not "managed"—Medicaid has ranged between 6% and 8%). And no arbitrary across-the-board service cuts or caps can survive a legal challenge. An appropriate and necessary amount of spending can only be delayed, not prevented. That may actually be the intent—to make each fiscal year's numbers look better. But it's still illegal. In any case, the

BAD WEATHER?

If the weather is bad, call 724-2111 (voice/TTY) to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

notion that large numbers of people have been “abusing” or “stealing” personal care before or after managed care is completely bogus.

We’d be remiss if we didn’t point out that there is obvious political bias in the state’s approach to rolling out managed long-term care. The initial plan for that included nursing facilities. State officials at the time presented the attractive argument to disability advocates that if managed care rate capitation was applied equally to institutional and community-based services, insurance companies would have a strong incentive to maximize integration and sharply reduce nursing facility placements. You can guess that the nursing home industry, some of whose former lobbyists have worked for DOH while their current lobbyists deliver campaign contributions to our elected leaders, would have had a problem with that. Well, it turns out that the insurance companies didn’t like it either; being expected to shell out any high nursing home fees at all, even for a small number of people, was unpleasant for them (just as providing community-based services to high-needs people is; see page 7). So the plan to apply managed care to nursing facilities was dropped; it’s been “carved out” for the foreseeable future. Then there’s the state’s evolving plan for managed care for OPWDD people. The most recent version we’ve seen “carves out” all OPWDD-operated and –funded group residential programs from capitation (that is, a per-person rate cap regardless of level of need), while all of the community-based services for people with developmental disabilities will be fully subject to that downward cost pressure. In New York, “Managed Care for All” is more accurately understood as “Managed Care for All Who Don’t Have Expensive Lobbyists or Friends in Government.”

As we reported last time, Cuomo gave a big rate increase to operators of the most expensive types of Medicaid-funded acute care (hospital) and long-term care (nursing home) facilities in the state, in what looks very much like a quid pro quo in response to a major campaign contribution from a lobbying organization that represents those facilities. At the same time, he tried

to cut providers of the least-expensive form of homecare, CDPA, entirely out of the system by setting administrative rates well below actual cost. CDPA’s trade associations do not have the ability to make campaign contributions of any size, let alone the \$1.25 million the Greater New York Hospital Association spent.

When the media caught him slipping snacks under the Medicaid Redesign Team’s dinner table to his preferred players, Cuomo tried to take back some of that largesse by means of another rate-setting rules change, but the nursing facilities sued him and won (see page 9). The CDPA programs also sued and won, on somewhat similar grounds, though the state has filed a notice of appeal in that case (see page 7).

The far-right Empire Center has decried Cuomo’s pandering but their fellow-travelers standing slightly to their left (the ones who actually profit financially from state spending) will never allow the state to carry out a managed care policy that seriously threatens their livelihoods.

The bottom line on all this is: A tax increase is needed.

As I’ve tried to show, most of the current flurry of dire warnings about Medicaid spending is much ado about nothing. The real deficit is probably under \$2 billion for the next budget year. The state can address it by a few simple steps: Stop subsidizing the wealthiest school districts; rescind the rate increases for segregated programs and the \$150 million the Governor dropped on a “health care education program” run by his pals in the “1199” healthcare workers union; drop the unproductive DSRIP program and renegotiate the Medicaid waiver supporting it to transfer funds to community-based Medicaid programs—especially personal care; and impose a modest tax increase (say, by adding one percentage point to the top marginal rate) on wealthy citizens.

That will take care of the immediate future, but it’s not going to be enough going forward.

Of course the anti-tax people will howl predictably about how it will drive business out of the state. That’s hogwash. If

high taxes really did drive significant numbers of people out of New York, all of the right-wing zealots would have long ago left the rest of us in peace here. Business people, including very conservative ones, love New York, especially the downstate part, and they are not going to leave anytime soon. The United States had a top marginal tax rate of around 90% during the 1950s, a very prosperous time in our history. Of course, part of that prosperity was because we had virtually no international competition while the rest of the planet dug itself out of the rubble of World War II. But right now the top federal income tax rate is 37%, and the top rate in NY is 8.82% for incomes just over \$1 million (9th highest in the US, despite, again, our 5th highest income). We could easily raise the national rate to somewhere between 50% and 60%, and the NY rate to 10% for people who earn more than \$250,000 a year, without seeing any really serious economic effects. And we’re going to have to.

The unavoidable truth is that the entire “Western world,” including the USA, is facing a demographic crisis. The largest generation in history, the Baby Boomers, is aging. The older they get, the more disabled they get, and the more help they need. Some of them have money for private-pay homecare, but lots more don’t. For reasons that are frankly beyond my comprehension, a surprisingly large number of these people—even those with good jobs—don’t have much in the way of savings. That is unutterably foolish. But we are a compassionate people and we aren’t going to let them slowly die lying unattended curled up in their own waste in bed. Right-wing ideologues can yammer about such things all they want on news channels; when the American people come face to face with that prospect, they aren’t going to accept it. In fact, I doubt that even the most obnoxious pundits on the planet will allow that to happen to their sainted mothers rather than shell out a few thousand dollars more a year to the government.

So a much larger tax increase will be necessary, and it will eventually be accepted, to pay for long-term care all over North America and Europe. We might as well

start now in New York.

As radical as that may seem, that's actually a minimally rational response to our real situation, which is probably not going to have a very happy ending no matter how much we spend.

We've reported this before: At some point in the next ten to fifteen years, the time will come where something close to one in five Americans will need some amount of hands-on long-term care, and only one in three Americans will be of working age. Since people really do need to do other things besides provide care to people with disabilities, we face the very real prospect that there simply will not be enough homecare workers to serve all the people who need them. You don't have to be a famous disabled (and dead) physicist like Stephen Hawking to see the universal space/time limitations here. We will probably be forced to curtail our dream of home-based services for all, not because of the cost, but because of the physical impossibility, at least outside the largest, most densely populated cities. But putting more people in nursing facilities, even though it kills them quicker, will only help a little if we don't raise wages, because most of the people who work in those places aren't paid any better than homecare workers.

Here's another fun fact: Because homecare pays so little, it's an attractive job for immigrants, and less so for established US citizens. So if we want to take some pressure off worker wages and our tax bills, those of us who harbor nasty attitudes about immigration are going to have to drop that nonsense pretty soon as well.

Now there's something for you to think about as we get ready for the next round of budget battles in the Empire State.

What are we at STIC thinking about? We're thinking we're pretty damn sick of having personal care—the cheapest and most life-affirming form of long-term care—targeted yet again while the big institutional boys happily go on with business as usual. Our victorious CDPA lawsuit is just the beginning. We're not taking any of this sitting down any more.

How Not to Get Screwed by Managed Care

If your managed care company tells you your services are being cut or that your needs can't be met, don't panic, and don't take "no" for an answer. With a little persistence this will most likely be resolved in your favor.

Under federal Medicaid law, "cutting costs" is not a legally allowable reason to reduce or eliminate the services you need. Managed care companies cannot arbitrarily cut hours of service. Also, all Medicaid managed care decision-making must take place in a person-centered planning process that directly involves you, or your freely-chosen representative. So a managed care company cannot just suddenly say that you've been "reassessed" and your hours will be cut. If you weren't visited by someone to do a reassessment, then there was no legal reassessment. There must also be a meeting involving your care manager, your service provider(s), and others whom you invite, in which you describe your needs and the group as a whole determines what services you will receive. If you were not invited to a meeting, your services cannot be changed.

If you are mandated to be in Medicaid managed care, your managed care company cannot legally tell you something like, "We have an hours cap" or "We don't do 24/7 care." They cannot refuse to assess your needs, and they cannot refuse to provide as much service as the assessment says is medically necessary. If you need assistance with tasks throughout the day on an unpredictable basis (such as help to go to the bathroom), the company cannot

set a cap on bathroom trips per day or limit the time an attendant is present only to the total amount of time you are in the bathroom; the attendant must be there to respond as needed. If you're getting personal care, whether "traditional" or CDPA, they should not be telling you to come to STIC's NHTD waiver instead. (We'd be happy to have you if you're eligible, but the choice is yours.)

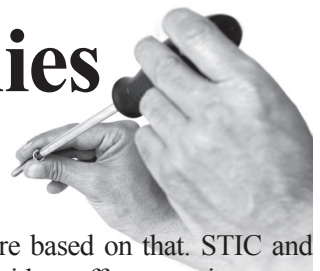
If your services are to be changed, you must be informed in writing of the facts specific to your situation that led to the change, before the change takes place. If your needs have not changed, it's very unlikely that any service cut is legal. Your first step is to appeal "internally" to the managed care company to have your services restored, and you have the right to request to have your services continued during the appeals process. If your internal appeal is rejected, you can then schedule a Medicaid "Fair Hearing" to review your case before an administrative law judge. **You should definitely do this; over 90% of service cuts are overturned by Fair Hearings.**

Contact the independent ombudsman for Medicaid managed care, the Independent Consumer Advocacy Network (ICAN), for more information:

<http://icannys.org/aboutican/what-we-do/>

Phone: (844) 614-8800
email: ican@cssny.org

Upstate Managed Care Companies Start Turning the Screws



There was a rising tide of media stories about New York's growing Medicaid budget "deficit" this summer and fall, as we discussed in our editorial. At the same time that Governor Cuomo began taking more public hits for Medicaid spending, and his Department of Health (DOH) was trying to drive providers of the least expensive form of Medicaid-funded homecare out of business, several Medicaid managed care companies suddenly started clamping down on services. Behavior that had previously only been reported at high frequencies for some downstate companies began to be seen upstate. In our region, we are getting multiple reports concerning Nascentia, iCircle, and Centene (formerly Fidelis). Here's a list as of the end of October 2019:

Nascentia: 6 cases of people losing 24/7 services, with the care manager telling people to go to STIC's NHTD waiver program instead. 4 other cases of homecare service cuts and referrals to NHTD. 2 cases of refusal to re-assess due to deterioration in self-care abilities, with referral to NHTD. 1 case of refusal to consider providing 24/7 services to a person who needs it; Nascentia would only authorize 1 hour per day, allegedly because they "only do task-based care." ("Task-based" means

that the payer only allocates the minimum amount of time it takes to actually perform specific home-care tasks; it does not consider the fact that some tasks, such as help going to the bathroom, must be done on an as-needed basis on an unpredictable schedule, and the attendant needs to be there to respond when needed.)

iCircle: 2 cases of refusing to grant or consider an increase in hours, with referral to NHTD.

Centene: 1 case of refusal to consider increasing hours due to loss of abilities, with referral to NHTD.

We've been telling people that they need to follow the appeal and fair-hearing processes, and that if they do so, they likely will prevail (see sidebar on page 6). But this is a clear pattern that emerged suddenly among several companies at the same time. It's difficult to avoid the conclusion that this is the result of pressure from DOH.

Centene and Nascentia also began demanding that CDPA providers across the state, including STIC, accept a rate cut. The companies say that they're only required to ensure that attendants are paid minimum wage and

the new rates are based on that. STIC and some other providers offer a starting wage for attendants that is above the minimum in order to improve recruitment and retention. Workers who have been in the program for several years also get cost-of-living raises and many are now making several dollars above minimum wage. If we accepted these rates we'd have to cut those people back to minimum. Many of them would likely quit and find better-paying jobs, making the homecare worker shortage even worse. We've refused to sign contracts for the lower rates. The companies threatened to transfer the people we serve to other providers who've signed the contracts, but so far they have not done so. They stopped demanding that we sign after a state Supreme Court judge ruled against DOH's CDPA rate cut (see below), though this may only be a temporary respite.

When we contacted Assemblywoman Lupardo about the attempt to cut CDPA administration rates below cost, she responded that this issue was being closely watched in the Assembly and would be a priority when the state legislature reconvenes. We sent her information about the insurance companies' behavior and we hope that there will be decisive action.

CDPA Wins in Court—For Now

We reported last time on *CDPAANYS v Zucker*, the lawsuit filed against the NYS Department of Health (DOH) by STIC and several other Centers for Independent Living that provide CDPA services, along with the Consumer Directed Personal Assistance Association of New York State and some others. On October 11, we scored a great victory when Judge Christina L. Ryba of the New York State Supreme Court for Albany County issued a decision that blocked DOH's attempt to cut the program's administrative funding to a level below actual costs. The victory may only be temporary, however.

As we reported, DOH at first agreed to negotiate with us last summer but then stopped talking after we presented a compromise that would have cut costs almost as much as DOH wanted without forcing hundreds of providers out of business.

In court the case came down to whether DOH's policy establishing a flat per-person-per-month (PMPM) administrative rate to replace the current percentage-of-billing system was a "rule change" requiring a public comment period. We raised other issues, but this one was enough to overturn the rate change so the judge stopped there. It may

seem very technical but the details are important, because DOH, under the direction of Governor Cuomo, is trying to subvert the public's right to have input on important policy decisions that affect all of us. So it's worth taking the time to understand what they did.

Under the NY State Administrative Procedure Act (SAPA), a rule is "is a fixed, general principle to be uniformly applied" to all affected systems or programs, "rather than a mere explanatory or interpretive statement of general policy which itself has no legal effect." Rules changes must be published and an opportunity for public comment provided

unless, under the New York State constitution, the rule only “relates to the organization or internal management of a state department, board, bureau, authority or commission.”

The state has for decades had a published rule explaining how personal care rates are to be set known as “505.14.” That rule says that organizations that administer personal care programs will be reimbursed for allowable administrative expenses at a percentage-of-billing rate of no more than 18%. There’s a list of allowable expenses, and reasonable costs are to be decided by cost data that the organizations submit to DOH.

Many years after that rule was created, but still many years ago, the state published rules specifically for the CDPA program, known as “505.28.” Those rules contain the following very brief text concerning payment of administrative costs: “(j) Payment. (1) The department will pay fiscal intermediaries that are enrolled as Medicaid providers and have contracts with social services districts for the provision of consumer directed personal assistance services at rates that the department establishes ...”

STIC and the other plaintiffs are “fiscal intermediaries” (FIs) for CDPA. The problem, though, is that rule doesn’t explain how DOH will “establish” those rates. Because of that, the state has continued to follow the rules in 505.14, until it issued the PMPM policy that was to take effect on September 1 of this year.

DOH has always set rates for Medicaid payments; that’s one of its main functions. All the language in 505.28 contains is a simple restatement of that fact. It might be that DOH inserted that statement into 505.28 as a placeholder and they intended to issue new rules for FI rates but never got around to doing so. But this summer the state tried to argue that because 505.28 says, specifically concerning CDPA FIs, only that DOH sets the rates, DOH then can issue a new procedure for determining payment rates for FIs that is very different from 505.14 without seeking public comment.

Now, nobody is arguing that there might not be a reason to have a different rate-setting method for CDPA FIs than the state has for “traditional” personal care agencies; their responsibilities are quite different, after all. However, issuing a (somewhat) newer regulation that only says DOH sets rates for CDPA without specifying the kind of detail we see in

the older personal care regs does not mean that SAPA does not apply. 505.28 just says that DOH sets the rates, which is a “statement of general policy”—and, we suppose, an “interpretive” one. Merely making such a statement doesn’t require public comment, because it doesn’t actually change anything. As soon as DOH changes *how* it does something, it becomes an entirely different story. And that’s what DOH did this summer. SAPA dictates how DOH (and all other state agencies) must create or change procedural rules governing their programs, including those for setting rates. Further, the state constitution says SAPA must be followed for all rules that are not about an internal departmental procedure. If DOH is no longer going to follow the procedural rules in 505.14 for setting rates, even if they think they can just make stuff up off the tops of their heads instead of following a formal procedure, that’s a rule change; DOH would at the very least have to publish for public comment its intention to stop following that procedure. Of course, after having said it will stop following 505.14 for CDPA FIs, it then issued a policy directive to the FIs defining a different procedure for those FI rates. That’s another rule change, also requiring public comment.

So the judge slapped DOH down pretty hard on that point.

In mid-November, DOH filed notice that it would like to appeal just before the deadline to do so. If they do, they’ll have to file a lot more than that pretty soon or they’ll hit another drop-dead date. They may just be keeping their options open while they think about it. The fact that they got beat on a somewhat similar case before a different judge concerning nursing home rates as well (see page 9) may make them think twice. But even if they do take this to a higher court, they might very well lose.

Judge Ryba only ruled on our claims that DOH violated SAPA and the state constitution. If an appeals judge overturns that decision, s/he will most likely tell Ryba to take the case back and consider our other claims, which are that DOH’s actions were arbitrary and capricious, an abuse of discretion, and a violation of the ADA.

The policy implementing the PMPM system did not explain how the rates were derived. It just said there would be three rate tiers based on the number of hours of service a participant uses. DOH only provided information on how it designed those tiers to us and the judge after we sued. Although it’s too much to

present here, that information doesn’t make logical sense in light of the costs of what FIs actually have to do. It’s missing big chunks of information, it doesn’t include some activities required of FIs, and what information they did have was provided by a source that doesn’t have accurate data—managed care companies. DOH doesn’t want its new rule to go out for public comment because the comments would explain how nonsensical it all is—and if DOH ignored those comments, we’d have a clear legal record of their malfeasance. We’ve heard that DOH actually thought it was going to get away with this; they were apparently shocked when we sued them, and they were very confident that they would win in court. But SAPA requires rules to be based on reliable relevant information and logical analysis. Issuing a rule regulating payment for specific services based only on a desire to cut spending or reduce the number of FIs without considering such information doesn’t satisfy that requirement; it’s the very definition of “arbitrary and capricious” and “abuse of discretion.” And a rule that defies logic and ignores data would violate a basic legal tenet that regulatory decisions must be supported by substantial evidence. Judge Ryba would have to consider at least the first two points if she takes back the case, and the appeals judge would have to consider the “substantial evidence” issue as well. Between the two of them, DOH is quite likely to take another beating.

Now there’s nothing stopping DOH from resigning itself to obeying the law, publishing a new rule that does PMPM exactly the same way, and then accepting public comment and ignoring it. However, if they don’t explain themselves a lot better than they have so far, we can sue again and win again on the “arbitrary and capricious” and “substantial evidence” points. We don’t think they can provide a better explanation, because they aren’t really trying to describe a new way to pay for FI services that will result in those services being delivered. They are trying to drive FIs out of business.

DOH could also agree to negotiate a reasonable compromise with us too, but this time they would have to do it in good faith, and not in the bogus way they did last summer, because the judge would have to approve any settlement.

We probably won’t know anything definitive until after the first of the year, and we’ll keep you informed.

courts watch

Leading Age New York v Zucker: Case Mix Up

Leading Age New York (a trade group for nursing facilities) sued the New York State Department of Health (DOH) over an attempt to change how nursing facility rates are developed, on October 25, 2019. On November 7 of that year, Judge Kimberly A. O'Connor of the New York State Supreme Court for Albany County issued a preliminary injunction blocking DOH's changes.

The changes took effect on July 1, 2019. According to Leading Age NY, the changes, if they had been sustained, would have cut nursing facility reimbursements by over \$350 million.

We're no fans of nursing facilities, but this case is important because it's another example (see page 7) of DOH trying to cut Medicaid spending arbitrarily without following proper procedures.

In this case, DOH made changes to its "case-mix" formula that bases nursing facility rates on the extent of disability (also known as "acuity") among facility residents.

As we did in the CDPA case, these plaintiffs argued that DOH's actions were "arbitrary, capricious, and contrary to law," and they asked for an injunction against them on the grounds that they would cause irreparable harm if they were allowed to take effect.

Judge O'Connor ruled against DOH primarily on the "contrary to law" point, but in this case the law was one enacted as part of the state 2019-2020 budget, passed in April, that created a workgroup to review and issue recommendations on DOH's case-mix changes. At that time DOH had already prepared the changes and was planning to enact them on July 1 without subjecting them to public input.

Nursing facility advocates got the workgroup created and that group met with DOH and issued a report at the end of June. According to the plaintiffs, DOH ig-

nored the report and made the changes it was already planning to make.

The plaintiffs claimed that DOH did not actually provide the data they said they had used to design its changes to the workgroup, as mandated by the budget law, and they said the law was clearly intended to require DOH to seriously consider the workgroup's recommendations.

DOH responded that nothing in the law required them to consider or follow the recommendations, and they said the law was "rife with discretionary language."

We haven't seen the plaintiffs' complaint and we don't know much about the case-mix formula or how it affects nursing home income, but we have seen the judge's decision and the section of law they are talking about.

That section is very brief—only 27 lines of easy-to-understand text. DOH is right that it does not explicitly require it to accept the workgroup's recommendations or make any changes to its proposed new system. And the law may indeed be "rife with discretionary language"; it's 129 pages long and we've only read the section discussed in the lawsuit. But that section does not grant any discretion to DOH at all. It is very clear in requiring the workgroup to review recent data, so if DOH did not provide that data they very clearly violated the law. The section also says, "The commissioner [of DOH] shall not modify the method used to determine the case mix adjustment for periods prior to June 30, 2019." Since DOH did modify that method by enacting its changes on July 1, it seems to have violated the law again. That's our understanding, anyway. Judge O'Connor agreed that the law had been violated, but she did not specify exactly how.

This might be a poorly-drafted law; we don't know why there is no language ordering DOH to consider the group's input and adjust its new system accordingly before putting it into effect.

It might also be true that the intent of the language was to prevent DOH from making retroactive changes to payment decisions for services provided before July 1, while silently allowing them to do so for services provided on or after that date. But as we read it, there's room to conclude that the law says that DOH shall not change its case-mix system, period.

Unlike the judge who ruled in the CDPA case, Judge O'Connor granted the preliminary injunction because she bought the plaintiffs' argument that the rate cut would cause irreparable harm to both the nursing facilities and the people who live in them. Unlike the CDPA plaintiffs, the nursing facilities' affidavits contained explicit information on planned staff cuts and in one case, impending closure.

Both this case and the CDPA case have their genesis in legislation enacted as part of Cuomo's "Medicaid Redesign" process that appeared to have granted Cuomo—through his minions at DOH—unprecedented sweeping authority to make big changes in the state's Medicaid program without public or legislative review. Since then Cuomo and DOH have been claiming more power than they actually have. For one thing, the state can make no significant changes to any part of its Medicaid program without federal approval. More than once we've seen attempts to enact changes after submitting a request to the feds but before approval is granted. Some providers are cowed by this, but all we have to do is say, "Hey, wait a minute. You haven't been given permission to do that yet, have you?" to put a stop to that. We've also seen the state get dinged by the feds for failing to follow federal "stakeholder involvement" and public comment requirements. The CDPA case shows that, whatever was in the Medicaid Redesign law, it can't be used to violate the state constitution's requirements for public comment. The nursing facility case says it also can't override legislative review.

That's good news, but these people are persistent in trying to find ways to wield unfettered power. The upcoming legislative session would be a good time for our elected representatives to reconsider the whole Medicaid Redesign process, and ensure that Cuomo and his underlings are not permitted to make any harmful changes without specific legislative review and approval.

Washington v US Dept. of Homeland Security (and others): Disability and Immigration Intersect

As part of the Trump Administration's full-court press to stave off the inevitable day when white people will no longer be an absolute majority of US citizens, Trump's Department of Homeland Security has issued a new regulation that designates people with disabilities, among others, as undesirable immigrants. The regulation modifies the 19th-century "public charge rule" to include people who can be expected to rely on Medicaid, among other things.

It's no surprise that Trump and his minions—bigoted and frequently ignorant of history—are stuck in the 19th century on this point as they are on so many others. What can be confounding is that their ideas intersect so well with the common public belief that people with disabilities can't be productive or useful. It's hard to explain this issue to some people, and we need to be clear on what we're talking about before we try to do that. That's worth devoting some space here.

The regulation has been challenged in many federal courts by many people, including people with disabilities. As of this writing, at least three courts have blocked the rule, though not all on grounds favorable to us, and appeals are moving forward. Although *AccessAbility* has a sharp focus on disability-only issues, this is an important disability concern that intersects with other important US concerns. So it's time for us to talk about immigration, and the nature of "self-reliance."

Let's get this out of the way first, so everybody knows where we're coming from: STIC does not believe in "open borders." The fact that most of the human beings on this planet have miserable lives compared to ours in the United States does not grant them a moral right, let alone a legal one, to come to live here. If we accepted more than a very tiny percentage of those billions of suffering people, the US would cease to be the "better place" that attracts so many refugees, asylum seekers, and potential immigrants today. That's got *nothing* to do with the color of those people's skin, or their religion, level of education, or ability to speak English, or anything else about them. Our economy simply does not have enough jobs, and our communities do not have enough housing or schools or hospitals, to accommodate a rapid influx of millions of people every year. When we absorb immigrants at a sane pace, nearly all of them do get jobs, education, and better lives, and they enrich our culture and our lives. But they don't do it immediately, or even very quickly. It takes time to absorb people, to build more housing and schools and hospitals, and for the economy to grow to enable new workers to make a decent living. Based on past years' data, we can reasonably accept and enthusiastically welcome perhaps 800,000 immigrants of all races, religions, languages and income levels annually. We can't reasonably accept millions, and it's insane to suggest we should.



In the event of a horrific sudden temporary crisis such as a major natural disaster or war, we should unflinchingly provide temporary refuge to many more, but we should not pretend that we can do so happily or easily. Large numbers

of refugees do not fare well in any place that has tried—or been forced—to accept them. We should always provide whatever compassionate relief we can in those situ-

ations, but on our soil we can realistically only provide temporary holding camps with humanitarian assistance in the form of food, shelter, clothing and medicine. The people we take in will inevitably be better off going back home once the crisis has been resolved.

Poverty, crime, and physical or sexual abuse, as awful as they are, are not sudden temporary crises. They are an ongoing part of the human condition, and every government on earth has its own responsibility to address them on behalf of their own people. If they don't, it does not fall to the United States to take care of those people—no matter how sad that makes us and how sympathetic we are. The fact that the US or some of its people have mistreated people from other places at times in the past, while very bad, is irrelevant. Virtually every nation or ethnic group that has ever existed in the world has mistreated people from other nations or ethnic groups at times throughout history. No one is without guilt in this regard, and no fair reparations can be made for any of this behavior now without throwing the entire planet into political and economic chaos—even if what would be "fair" could be accurately determined. Such thinking must be abandoned, not only because we are all equally guilty, but also because there can be no finite accounting for infinite harm, and there must be no cut-off of responsibility to try to redress the ongoing damage. We can only do our best to do better in the future, but sadly, we can never do enough, and we must not overload the lifeboat until it sinks with all of us in it. No one will be better off then, though some may feel avenged.

That being said, let us also make clear that we at STIC do not fear the coming loss of majority status by white people in our country. We welcome and enjoy diversity among Americans, as long as we all continue to share essential American values of support for liberal democracy, including the rights of political minorities; full freedom of public speech—including speech that upsets people; government that does not endorse, promote, or enforce any religion or religion-based belief sys-

tems, and that does not permit people to use religion as an excuse to harm or discriminate against people; and other rights secured for all of us by our Constitution and laws.

In our view, while the rate of immigration must be restricted, the only acceptable way to do that would be to exclude obvious criminals and terrorists, and accept all others up to some reasonable maximum on a first-come, first-served basis. There should be no public charge rule at all.

Now that we've insulated ourselves as best we can from the inevitable outrage that continuously boils on both extreme ends of the political spectrum on this issue, we can move on to talk about disabled immigrants and that rule.

A "public charge" is a person who depends on the public for survival; someone who cannot make a living on their own or is not "self-sufficient." If that's the definition, the notion that there has ever been any person who was not, in some way, a "public charge" is questionable, going back to prehistoric times when the group was your only defense against predators and your only means to collect enough food to avoid starvation, but if it has any meaning at all, that meaning must evolve with the rest of our society's beliefs and practices.

The "public charge" concept was first incorporated into federal immigration law in 1882 (it goes back to the 1840s in some state laws, before the federal government asserted its sole authority over immigration). Since that time, the minimum skill-set required to be self-supporting has increased along with our ability to provide help, and bigotry has been a constant motivation throughout. But we still can't accommodate huge numbers quickly.

Another thing that's changed is our notion of what it means to be "dependent." Today many people would agree that people literally need motorized transportation, telephones, and reliable health-care as minimum requirements for what we would call self-sufficiency. But are we not then "dependent" on government

assistance? How can we have motorized transport without roads, or telephones or healthcare without government oversight? How can we claim to be self-sufficient under those circumstances?

A few people cling to 19th-century notions of what it takes to survive. But as a society, we have a right to evolve our consensus on this issue. Few humans in modern society are fully self-sufficient in the old sense, not even most of the libertarians who think that they are. Most of us have moved on from thinking that we should be. But some have refused to evolve, and others disguise bigotry with demands for "self-reliance" that they selectively apply to people who don't look or believe like them, whom they label "lazy," while urging government support for others, whom they call "unfortunate."

Still, today most Americans, including those who are thoughtful and kind, think that most people should try very hard to take care of themselves, because self-sufficiency and productivity are intrinsically better for our spirits and sense of well-being, while still accepting that sometimes people need help that we, as taxpayers, should pay for. But when it comes to people with disabilities, many of us think differently.

A common notion about being a "public charge" involves illness or disability. Until the second half of the 19th century the notion that people could bring a disease across the ocean and spread it wasn't all that common, though the notion that they could bring "vermin" was. The late 1800s brought growing concern, based on science, about transmission of disease and the need to keep "sick" people out. Later, eugenics theory emerged—a belief, rooted in flawed science, that "mental defects" led to "character flaws" and therefore should be weeded out of the human race. That's so morally repugnant now that it's hard to remember that it was mainstream thinking for several decades among some of the most educated people living at that time. And although in those days it was easier for "able bodied" unskilled people to make a living, the primitive state of medical and rehabilitative technology meant that very few people with significant disabilities could expect

to do so—if they lived very long, which they did not. Things have improved a lot since then.

However, most people today still do not think that most people with disabilities can ever take care of themselves, or should try hard to do so. The Independent Living philosophy says otherwise, though not all disability rights activists are followers of that philosophy. But disability activism has brought something new to the table: the idea that "disability" is largely a social construct, created by society's failure to design its physical spaces, procedures, and laws to accommodate most of the natural physical, mental, and cognitive variations that occur among humans. When a technologically advanced society makes a concerted effort to do so, then characteristics that we call "disabilities" have much less power to limit our ability to get along in life. Still, when we cross the line from ramped entrances and lowered cabinets, which are different from the norm but not really more expensive to provide than what we used to build, to providing personal attendants and motorized wheelchairs, we cross, in the old sense, from being "independent" to being "dependent," don't we? Yes, in the old sense. But in today's world, most people believe that expensive and highly technological things that none of us can create for ourselves are basic needs, and more people accept paying taxes to facilitate the meeting of those needs. So today, needing Medicaid to pay for your attendant or wheelchair should not make you a "public charge," any more than needing a road to drive to work, or a cell phone whose signals are not jammed by radio broadcasters or your microwave, or a professional police force (something else that did not exist in the early 19th century) to keep you from being mugged, should make you one.

In this context of competing views of the meaning of "dependence," Trump's racist and religious bigotry are obvious, but the indefensibility of outmoded attitudes about disability may seem less so. Let's look at how the rule expresses those attitudes.

The new rule has a "scoring" mechanism for potential immigrants. You get points in favor for things like a post-

secondary education, English language proficiency, or an actual job offer in the US. You get points against you for various other things. If your positive points don't outweigh your negative points, you get rejected. One of the negative points is "a medical condition that is likely to require extensive medical treatment or institutionalization or that will interfere with the alien's ability to provide and care for himself or herself, to attend school, or to work upon admission or adjustment of status." You get more points against you if you don't have private medical insurance. For many people with disabilities, it is precisely Medicaid's coverage of long-term care services that makes it possible to earn a living and make productive contributions to the economy and society. That's an illustration of disability as social construct. There is no private medical insurance that covers permanent long-term care services. That's an entirely different point that courts may view separately. The institutionalization thing is not likely to be interpreted in favor of people who can live in the community with supports. Having a disability that "requires" institutionalization is the only way to get any Medicaid-funded long-term care at all in most cases, regardless of whether it's in an institution or in the community. (We've long said that disability advocates should be working on getting that "level of care" requirement dropped.) So those two items cover pretty much anybody who has a significant disability.

A footnote in Trump's rule cited federal court cases from the early 20th century concerning exclusion of people with various diseases or physical disabilities as evidence that it can add them to the public charge rule. Disability activists submitted a "friend of the court" brief in many of the cases challenging the new rule. The brief pointed out that, right after the Americans with Disabilities Act (ADA) was passed in 1990, Congress also modified the nation's immigration rules to remove language that excluded "[a]liens who are mentally retarded" or who are "afflicted with ... a mental defect." In 2008, language excluding people with HIV/AIDS was removed. The activists' brief uses that

to argue that Trump's rule violates previous federal law.

The activists don't have a slam-dunk here; they're only showing Congressional intent to end exclusions for intellectual and mental disabilities, and one particular infectious disease. The change for HIV/AIDS was part of a law that addressed programs related to other infectious diseases, including tuberculosis and malaria, but Congress did not choose to end those exclusions. The ADA also updated language in the federal Rehabilitation Act ("Section 504") that bars discrimination on the basis of disability by entities that receive federal funds, but it explicitly kept hands off anything that could be considered "health insurance" or its rules for providing or denying coverage. It can be argued that Section 504 prohibits the Immigration and Naturalization Service from discriminating against people with physical disabilities by keeping them out of the country, but neither that nor the ADA can probably be used to outlaw discrimination on the basis of needing Medicaid. And it would be pretty difficult to show that Congress had any intent to specifically let in immigrants with any other disabilities or diseases.

In 1996, as part of Bill Clinton's welfare reforms, Congress passed a law that specifically stated that all immigrants, regardless of legal status, were eligible for "emergency Medicaid, crisis counseling, and mental health and substance use disorder treatment." In trying to clarify what this meant, the Immigration and Naturalization Service issued "guidance" that revised the definition of "public charge" to say it meant people who are "primarily dependent on the government for subsistence, as demonstrated by either (i) the receipt of public cash assistance for income maintenance or (ii) institutionalization for long-term care at government expense." The activists claimed this means that needing "non-cash" benefits doesn't make you a public charge. That's logically wrong, because "institutionalization ... at government expense" is a non-cash benefit. But is there an intentional loophole for non-institutional long-term care here? Maybe, but in 1996 there wasn't a lot of that being paid for by Medicaid, so it might not have been in the minds of many Congress members. In any case,

there's nothing preventing the feds from issuing a new regulation that changes a guidance document, as long as they can provide a rational, fact-based explanation that meets the requirements of the federal Administrative Procedure Act.

The US District Court for southern New York bought the Section 504 argument and noted that the new rule simply assumes that disability is a negative thing without explaining why. But it did not clearly dispute the medical insurance requirement; it only said that a need for *temporary* public assistance wasn't a good enough reason to exclude immigrants.

The federal District Court for northern California, while it ruled against the Trump Administration on other grounds, didn't accept the Section 504 argument, because Section 504 prohibits discrimination "solely" on the basis of disability, and the point system is supposedly designed to prevent people from being denied entry on a single point. That argument is nonsense; what happens if a disabled person wants to immigrate and she doesn't have any positive points? But we'd probably have to wait for the rule to go into effect and have that happen before we could win on that one. The California court didn't get into medical insurance at all.

A federal District Court in Washington State opined that a rule issued by the Department of Homeland Security that excludes people from immigration because they use Medicaid is wrong because, under federal law, Medicaid is regulated only by the Department of Health and Human Services and the states. There's no conceivable way this rule could be construed as an attempt to regulate Medicaid; that's just flat-out bizarre. This court did agree that the rule likely violates Section 504, and it also supported the point that discriminating against people who need Medicaid is a form of discrimination against people with disabilities—though we don't know how valid that is, because most of the people who use Medicaid in the United States don't have disabilities on the record.

These cases will be in the courts for a long time to come; we'll continue to cover them here.



STIC NEWS



Susan Ruff: 2019 David Veatch Advocacy Award Winner

by Maria Dibble

Susan Ruff, STIC's Advocacy Director, received the David Veatch Advocacy Award from the New York Association on Independent Living (NYAIL) in September. This award is named for a steadfast and dedicated advocate who fought hard for the passage of the Consumer Directed Personal Assistance Program (CDPA) into NYS law in the early 1990s. He was only in his early to mid-twenties at the time, but demonstrated a level of sophistication and strategic abilities usually found in a more seasoned advocate. He passed away before CDPA became law in NY, many believe partly from a lack of sufficient personal care services. This award is special to NYAIL members who remember David as I do, so I was pleased to nominate Sue and see her receive the award.

Sue has been an advocate for disability rights for most of her adult life. She adopted a daughter with Down syndrome, and had to constantly advocate to have her included in regular classrooms, as well as religious, recreational and social activities. She believed in and advocated for inclusion before it ever became a concept on the horizon, and very long before it became a reality in law.

In the mid 1990s Sue began work as our Supported Employment Coordinator, followed by leading our ECDC program, until she truly found her niche, her passion and

her love as STIC's Statewide Systems Advocacy Network (SSAN) Director.

For the last twelve years she has served in this capacity, where she has been stellar in making connections with other groups, developing advocacy strategies, organizing consumers around issues, helping to build coalitions, and all the other pieces that make for an outstanding advocate. She was instrumental in working with other staff at STIC to form the Southern Tier ADAPT chapter, and she has participated in several ADAPT actions in Albany and Washington DC. In fact, she was arrested a few times in DC and at the rally in Albany in 2017 that targeted the Governor, a badge of honor at STIC, and in our advocacy circle.

She is passionate about affordable accessible health care, prison reform for people with mental illness and other disabilities, inclusion in schools, equal employment opportunities, accessible affordable housing, election reform and voting rights, county and city emergency response plans to include the needs of people with disabilities, and of course, the Americans with Disabilities Act, to mention just a few of the issues that she covers at STIC.

Sue has served as a board member of the New York State Independent Living Council, Vice President of Empire State Association of People Supporting Employment (APSE), and is the past President of the League of Women Voters of Broome and Tioga Counties. She currently chairs NYAIL's Education Committee, and attends

others, and is also involved with Medicaid Matters NY. She belongs to or participates on innumerable other boards, work groups, committees and the like. No issue is too small or too big for her to tackle, and she won't give up as long as there is any hope for success and even then, she doesn't stop.

In her personal life, Sue is equally passionate about advocating for social justice, civil and economic rights,

and so much more. I often ask if she ever sleeps, since she is so actively involved in her community.

There is no one I can think of, at least who hasn't been similarly honored, who embodies and lives advocacy like Susan Ruff. She is a knowledgeable, effective and passionate life-long advocate and leader who truly deserved and earned this award.

STIC is highly fortunate to have Sue as one of our employees and we thank her for her years of service and commitment to the rights of people with disabilities.

FYI, We're an FI

by Maria Dibble

STIC is pleased to announce a new program, which is under the auspices of the Office of People with Developmental Disabilities. We are now serving as a Fiscal Intermediary (FI) for the provision of Self Direction Services (SDS), coordinated by Rhonda White, who has been working with the program since its inception. Rhonda has served in the Self-Direction program as a Care Manager and Service Broker. She has collaborated with many different Brokers, FI Specialists and Care Managers to develop her knowledge of the program.

Our service area includes Broome, Chenango and Tioga Counties. We welcome new consumers to the program, as well as others who wish to transition to STIC from elsewhere.

Our benefits package for SDS staff who work 20 hours or more a week includes paid vacation and sick leave, as well as six paid holidays. For those working 30 hours or more a month, in addition to the aforementioned benefits, we also offer health, dental, and vision insurance.

We are excited about providing this new service, since self-direction fits in with our core philosophy of supporting and empowering people with disabilities to live as independently as possible in the community. Consumers' wishes and needs will guide the process, as we assist them in successfully achieving their goals.

For more information, please call Rhonda White at (607) 724-2111, extension 386.



Susan Ruff (center) is congratulated by STIC Executive Director Maria Dibble (left) and NYAIL Executive Director Lindsay Miller (right).

X SCAPES

SOUTHERN TIER'S PREMIER ESCAPE ROOMS

Xscapes is a fundraiser for Southern Tier Independence Center (STIC) and all of the funds go to help with STIC's mission of helping people in our community with various disabilities. We run games through online reservations which must be made at least 24 hours in advance. We do not accept walk-ins off the street; the games are by appointment only.

We have 4 exciting escape rooms to choose from. Our escape rooms are designed for groups of 4 to 8 people. You must either join a booking that has other players and reaches the minimum of 4 players, or find at least four friends to play a game you book with us.

Game start times are typically available from 1 pm to 7:30 pm seven days a week. To book online, go to: <https://xscapes-stic.com/>

Xscapes can also be contacted for last minute bookings or corporate team building events by calling (607) 760-3322.

Check out Xscapes gift certificates with a 20% discount!

Closed for the Holidays

STIC's offices will be closed

December 21 – January 1

We Reopen on January 2, 2020

Happy Holidays to All!

THE TWILIGHT ZONE

BINGHAMTON'S
ROD SERLING EXPERIENCE

VALLEY OF THE KINGS

Your archaeological team's quest is to attempt to unlock the secrets of Pharaoh's Tomb. Other teams have attempted and vanished during their search. The Ancient Egyptians were known for their mystical ways, opulence and power. Upon the death of a pharaoh, the corpse was enclosed inside a sarcophagus, with provisions for the after life. Work together with your team to find the tomb and escape the Valley of the Kings.



PULSE

See the Forest for the Trees

(from the Roberson Center)



The lights, trees, magic of a Binghamton tradition. Home for the Holidays will be on view November 14 – January 5, open 7 days a week with extended hours!

Home for the Holidays features hundreds of elaborately decorated trees, dazzling holiday displays, and the International Forest—a collection of adorned trees and displays that represent the holiday tradition of cultures from around the world. The excitement and magic of Home for the Holidays has made it a community favorite for more than 60 years. If you're seeking a place to immerse yourself in the wonder of the season, you have arrived.

This year we've got a whole room! Stop by and visit the blue room on the second floor of the mansion to see a winter wonderland STIC display decorated by our employees Sue Lozinak and Cathy Sostre.





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

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RETURN SERVICE REQUESTED

Free Access Is Not Free

STIC is a 501(c)(3) corporation, and governing documents, conflict-of-interest policy, and financial statements are available to the public upon request.

If you would like to support STIC, please use this form. Minimum membership dues are \$5.00 per person, per year. If you want to be a member, you must check one of the **first five boxes** and the "Make Me a Member" box. **NEWSLETTER SUBSCRIPTIONS DO NOT COUNT AS MEMBERSHIP DUES.**

- | | |
|--|--|
| <input type="checkbox"/> Individual \$5 | <input type="checkbox"/> Contributing \$100 |
| <input type="checkbox"/> Supporting \$25 | <input type="checkbox"/> Complimentary \$_____ |
| <input type="checkbox"/> Patron \$50 | <input type="checkbox"/> Newsletter Subscription \$10/year |
| <input type="checkbox"/> Make Me A Member | |

MAIL TO: Southern Tier Independence Center, Inc.
 135 E. Frederick St.
 Binghamton, NY 13904

Name _____

Address _____

City _____ State ____ Zip _____

Phone _____

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

THANK YOU!

Southern Tier Independence Center

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 Maria Dibble

ASSISTANT DIRECTOR
 Jennifer Watson

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ADA SERVICES: Frank Pennisi

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