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INSIDE

A RIDE ON THE MERRY-GO-ROUND

By Maria Dibble

Let's just for a moment think about the points below:

- A program exists that creates hundreds of thousands of jobs for New Yorkers. I imagine most of us would think such an achievement is a remarkable thing.
- A program exists that provides millions of New Yorkers with health care, reducing the number of those without insurance to the lowest margin we've likely ever experienced. We'd probably all agree that this is a desirable outcome as well.
- A program exists that allows hundreds of thousands of New Yorkers to avoid placement in nursing homes and other institutions, and remain in their own homes. Most of us would believe that this is a program worth preserving.

You may have guessed by now that I am writing about Medicaid, which always seems to be the nasty scary monster in the room when we are discussing the budget. Little recognition is ever given to the benefits of the Medicaid program, only its cost.

But we need to ask ourselves, is the cost worth it?

Is it worth it to ensure that people working in hospitals, home care, and other aspects of health care keep their jobs? Medicaid isn't just about services to people whose low-wage jobs don't include health insurance, or who are elderly or have disabilities, as important as that is. It also pays for the jobs that serve these people. Would we rather they were all on the unemployment rolls, instead of paying taxes and doing their part to give back to the state's coffers? I think that question is a no-brainer.

Some say we have the richest Medicaid program in the country, which is likely true. But it isn't because we are spending money frivolously on vacations in Hawaii, lavish condos in NYC or a house on the lake upstate. The money is going to pay for medical exams and procedures, prescription drugs, physical therapy and the like. It is also paying for various forms of homecare, including Consumer Directed Personal Assistance (CDPA), that assist people with significant disabilities to live and function in the communities where they live. They help people out of bed, to bathe, use the toilet and clean themselves, shop for groceries and prepare meals, and the myriad of other tasks that are part of life. Many people with disabilities can't do these things by themselves, they need some help because they are unable to perform them. If you think that it is something people would use if they didn't need it, think again. Would you want strangers coming into your home, performing very intimate tasks on or for

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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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you, if you could do them yourself? I seriously doubt that.

Furthermore, CDPA is an especially sought-after program, because it allows people to hire and train almost anyone they wish, someone they are comfortable with playing a significant role in their lives. And the other benefit of this program is that it is the least expensive type of homecare. Yet NY is targeting this particular program for major cuts.

A few years ago the Governor ordered that all physically disabled people with Medicaid should go into managed care. They had no choice, so they did as instructed. The managed care companies immediately saw the cost benefit of CDPA and funneled anyone they could into the program. So the CDPA program has been growing rapidly, as of course, is managed care. But now, what do the Governor and his Department of Health say? "Managed care and CDPA are growing too fast and we need to cut them back." What exactly did he expect would happen when he gave that order?

Everyone knows that the population is aging, and that more and more people are requiring assistance to remain independent, productive and to stay in their own homes. Similarly, as medicine progresses, new treatments are developed, more people are surviving illnesses and accidents and living with disabilities. So why is NY so surprised that costs are rising in Medicaid, which then employs more people, provides health care for those who have low incomes, and supports individuals who are elderly and those who have disabilities? See page 3 for the answer to that question.

I think it's time to applaud Medicaid for what it does and not to continuously bash a program that gives so much to NY. Yes, it's expensive, yes it can benefit from some efficiencies, and yes it will continue to grow, but would it be better to have long unemployment lines, even more crowded emergency rooms, and packed nursing homes, all of which are far more expensive than CDPA? Then we'd begin the whole cycle again. They would instead be saying, Look how much our Medicaid budget has grown! Nursing homes are over capacity and are breaking the budget. We need to find a less costly way to support people. Oh, look, CDPA is much cheaper than nursing home services, why not move people into the community and help connect them with community-based programs like CDPA? Then, when CDPA begins to grow again, they will attack it again.

The merry-go-round is getting old, squeaky and is about to fall apart. If we don't start to recognize the needs of our aging population, accept that cost will rise in the next few years until things level off, and plan to take advantage of the least expensive services to meet those needs, than our economy and the state budget will implode.

The new Medicaid Redesign Team appointed by the governor to supposedly solve the alleged deficit problem in a month and a half, is packed with hospital, nursing home and managed care insurance company executives, and has virtually no representation from the community-based programs that can save the budget. Perhaps, you'll ask yourself, why we were excluded? (See page 5 for more on that.)

Sadly, those who use the services, as well as others who assist them, and we who advocate for changes and improvements, are never called upon to share our thoughts, though we can all contribute to the discussion. The problem is that we don't hold the power, political or otherwise, and we don't have the money, which creates the power in the first place.

This doesn't mean we are completely helpless, because we do have one thing that no one can take away, the power to vote. It is, after all, the most important tool in a democracy, and I hope you will use it to make your voice heard. Remember, a vote isn't just what you do on election day, but the calls, emails or letters you send to your representatives; they honestly can make a difference, especially if we all speak up. A single voice is a rather lonely thing, but all of us together create a resounding chorus that no one will ignore.

NYS Budget: *Not Boring This Time!*

The big hoopla in the New York State budget this time around concerns Medicaid. As we said last time (*AccessAbility* Winter 2019-20), it's mostly much ado about nothing, a little ember fanned into a roaring flame by right-wing media and by Governor Cuomo, who may be attempting an end-run around progressive forces in the legislature. He's reconvened his famous Medicaid Redesign Team (MRT) to provide cover for the things he already plans to do; you can read about that on page 5.

Consumer Directed Personal Assistance (CDPA) program costs are widely targeted as part of the problem. We cover that separately on page 7.

Medicaid

Having been caught creating a Medicaid budget overrun for the current fiscal year, which ends March 31, 2020, by granting rate increases to hospitals and nursing homes in return for a huge campaign donation from a lobbying organization that represents those facilities, Cuomo used his legislature-granted budget super powers to decree a 1% "across the board" cut in Medicaid payments for the rest of that year and beyond. That's expected to save about $190 million by April 1. This is not actually a budget "deficit". The rate increases came from a windfall payment NY got from the sale of the not-for-profit Fidelis insurance company to for-profit Centene, and that payment had not been factored into the "balanced" 2018-19 budget. It was $200 million in "free money" (as long as the feds don't retroactively kill the deal; they are investigating), but Cuomo cut current Medicaid spending by almost that much anyway. In other words, he fixed an accounting/paperwork-only "deficit" by taking real money away from real programs. "Across the board" is also fiction. The cuts don't apply to any program where federal laws or regulations prohibit them, and that's almost everything except managed long-term care and some fee-for-service programs like homecare.

For the 2020-21 fiscal year beginning April 1, Cuomo told the MRT to reduce the "deficit" by $2.5 billion. (Sometimes you hear it's $5 billion, but that's actually projected for next year.) Why he chose this number we don't know, because his Department of Health reported at the end of 2019 that measures already taken will cut the amount to $2 billion. On December 3, 2019, Assembly Speaker Carl Heastie publicly supported "raising revenue" as a way to address the forthcoming budget "deficit", and some state senators have since echoed him.

When it comes to Medicaid, there is no "deficit". There is just an arbitrary "Global Cap" on increases in NY State spending for some Medicaid programs, and lately the state has been exceeding that cap. The cap is set at the ten-year average of the US "medical inflation rate". That number has been going up recently; it's now at 3.2%, and will likely continue to increase. US medical costs went up 4.6% in 2019, more than twice the rate for everything else.

But the cap is a political stunt. It's not global; it's only for a relatively small portion of Medicaid spending. And it was never based on a serious analysis of the most important facts about the Medicaid program in NY. Here are those facts:

<u>Fact 1</u>: Many years ago, NY began enrolling nondisabled childless adults with incomes above the standard federal eligibility level into Medicaid. They got permission to do this using a Medicaid waiver. Then ObamaCare came along and let NY keep doing it and have the feds pay 100% of the cost for a few years. NY abandoned the waiver route and took the ObamaCare detour. That detour was temporary, a fact that everyone knew but apparently forgot. So now NY's per-recipient cost for the Medicaid expansion is increasing—though not to what it was in the 2000s under the waiver.

<u>Fact 2</u>: In 2012 the state legislature approved Cuomo's proposal to freeze the county share of Medicaid funds and have the state absorb all future increases in Medicaid spending. However, the counties still retained some decision-making authority for Medicaid eligibility. Cuomo now apparently regrets that and is blaming counties for approving too many Medicaid services, but under state regulations counties have very little leeway when making those decisions.

<u>Fact 3</u>: The Baby Boom generation, the largest generation on the face of the earth, is aging. Every year more of them acquire significant disabilities for which they require assistance.

<u>Fact 4</u>: The Baby Boomers did not save enough money for retirement. So when they reach retirement age, their only income is Social Security. That income is so low in most cases that they become entitled to Medicaid. (They get Medicare, for which there's no income threshold, but Medicare does not pay for much long-term care.)

<u>Fact 5</u>: At the same time that he set the spending cap, Cuomo also mandated "Managed Care for All". As a result, in recent years people are being forced to get Medicaid-funded long-term care through managed care insurance companies. Managed care administrative costs are about twice as high as those for fee-for-service Medicaid, because managed care companies are guaranteed a 15% rate, much of which is pure profit.

<u>Fact 6</u>: Managed care companies get a capped rate to serve each person. When people need some kind of homecare, the companies push them to use CDPA, because its rates are much lower than those for other types of homecare. That's exact-

ly what managed care is supposed to do; find cost savings.

Fact 7: NY State, as it periodically does, began a phased plan a few years ago to increase the minimum wage, including wages for homecare workers, nursing facility aides, and everybody else who does low-level, low-skill hands-on work.

When the Global Cap was created, NY was in a recession and tax revenue was down. Since the state constitution requires a balanced budget, something had to be done to make spending match revenue. The cap was touted as a way to do this, but it was always a fiction. It was not applied to anything in the "mental hygiene" arena (OPWDD, OMH, OASAS). And although the cap allows spending to grow at around 3% per year, some programs—those with expensive lobbyists and/or Cuomo cronies backing them (think nursing facilities, hospitals, and various unionized downstate programs) "need" to grow faster than that (because otherwise those VIPs would get mad), which means that other programs (CDPA, for example) that don't have that kind of clout were held to much less than 3% growth, or even to zero or "negative" growth (that is, cuts).

This worked okay for a short while. But then reality set in. The Baby Boomers continued to age, about which nothing can be done. Their disabilities and need for hands-on services increased, about which nothing can be done. Wages increased, about which nothing can be done if we want to continue to have anybody provide those services instead of flipping burgers or running shopping carts back into the store from the parking lot or any of a variety of other things that pay better than homecare did. Meanwhile, the recession ended, and tax revenues went back up.

And the number of people in Medicaid managed long-term care has increased dramatically. Here's how *Crain's Health Pulse* reported it in January:

"Last month Gov. Andrew Cuomo addressed the state's multibillion-dollar Medicaid deficit in his 2021 budget proposal, saying that managed long-term care and the personal assistance program within it have been the biggest drivers of spending growth. From 2014 to 2019, enrollment in the program grew by 88%, well beyond the 23% increase in mainstream managed-care enrollment. Between 2017 and 2018, spending through the program grew by 82%, from $1.7 billion to a staggering $3.1 billion."

That sure seems shocking. What's behind those crazy numbers?

Nothing more than Cuomo's order that all disabled Medicaid recipients go into managed care. Although managed care has been mandatory for nondisabled NY Medicaid recipients since the mid-1990s, it was in some cases voluntary, and in others prohibited, for people with disabilities. "Mainstream" and "long-term" managed care are just insurance plans that cover different things. But both types have covered personal care, of which the cheapest form is CDPA, for quite some time. "Managed care for all"—meaning forced enrollment for physically disabled Medicaid recipients—rolled out in stages, first involving only mainstream plans in the New York City area. Gradually upstate mainstream plans began serving people with disabilities. Then the long-term plans started growing downstate, followed by upstate long-term plans most recently. The dates for those phases correspond roughly to the dates cited by *Crain's*.

Although the Medicaid expansion mentioned above did initially bring a lot more people into the Medicaid program than NY had before, virtually all of them were nondisabled, and the initial increase happened under a Medicaid waiver long before ObamaCare. That had ***nothing to do*** with Cuomo's current obsession with Medicaid managed care and CDPA spending.

The number of Medicaid ***recipients*** with disabilities is only increasing as quickly as the Baby Boom aging process ***requires.*** Again, nothing can be done about that.

The number of Medicaid ***managed care*** enrollments is increasing much faster solely because Cuomo has decreed that Medicaid ***recipients*** with disabilities must now use managed care. That is ***not a big increase in people on Medicaid***. It's mostly people ***already on Medicaid*** moving from non-managed ("fee for service") programs into managed care. As that has happened, the number of people with disabilities receiving fee-for-service Medicaid long-term care is declining—but nobody ever reports that.

And the increase in use of CDPA is, again, mostly people ***already on Medicaid*** who used to be in more expensive homecare programs now moving to the least expensive homecare option.

The people who cooked up the Global Cap back in 2011 did not seriously consider the impact that any of the important facts we've listed here would have on Medicaid spending over time, although all of those impacts were predictable then. If they had, they never would have set the cap so low. But they weren't trying to do careful public policy. They were staging a political stunt. And the people who are screaming about a disastrous massive increase in Medicaid spending now aren't considering the facts either. Those facts are easy to summarize: Medicaid spending ***<u>must</u> grow much faster than it has in the past***, for at least the next 10 to 15 years, because ***the medical needs of the largest generation in history are growing much faster than ever before.*** The state must actually ***pay*** those increased costs because it ***cannot cut*** them.

Other Budget Items

Cuomo's 2020-21 budget proposal included doubling funding for the state's Homeless Housing Assistance program, and increases for supported housing services. There are also capital increases for programs to repair and renovate existing housing or build new units. Initially the so-called "MRT Supportive Housing" program, which largely provides rent subsidies but also pays for STIC's program to find housing for people coming out of institutions, was cut drastically. However, this was an error that was corrected in the governor's 30-day amendments.

Cuomo is again proposing to offer waivers to school districts to get out of compliance with various special education regulations.

Centers for Independent Living like STIC were cut back to their pre-2019-20 levels, before we got that piddling $12,500 per-center raise.

More details on Cuomo's budget appear in NYAIL's 2020 Agenda on page 8.

MRT for You and Me

The MRT is the “Medicaid Redesign Team”. We’ve been hearing about it in the news a lot recently, though by the time you read this, it may, like a fast-moving comet, have flashed by rapidly, raining little chunks of crud from its shiny tail down upon us, and returned to the outer reaches of the solar system, or perhaps just to the wings of the NY political theater, for the second time.

Right wing media pundits have been ranting about “uncontrollable Medicaid spending” in NY for about a year now. More recently, there’s been evidence that at least some relatively influential Democrats in the state legislature are willing to consider raising taxes to pay for what actually is a necessary if rapid increase in Medicaid costs. In fact, some Assembly members have even mentioned reversing New York’s rush toward “Managed Care for All”. Governor Cuomo has said that he does not want to raise general taxes, though he is willing to consider “industry revenues” (taxes on insurance companies or healthcare providers) to address the problem.

After Cuomo forced disabled New Yorkers into managed care insurance plans run by companies that get a guaranteed minimum profit margin of somewhere around 7% from the state, advocates may find it delicious that he now has to tax much of that profit back out of those companies. We could also imagine that many or most of those companies will drop out of the market as a result, forcing the reversal of Managed Care for All without any legislators having to put themselves on the line for it. But that’s down the road apiece. For now, briefly once again, there is the MRT.

This is actually MRT II. MRT I, back in 2011, gave birth to the Medicaid Global Cap, among other things. This time, Cuomo has reconvened the group to find ways to reduce Medicaid spending that allegedly do not reduce services, or to pay for increased spending without raising general taxes. The current MRT is under heavy attack from a variety of sources, including members of the legislature, various industry trade groups, and disability advocates. Some of that is based on fear of a repeat of MRT I; the rest concerns discouraging recent events.

“Giving birth” to Medicaid plans is an apt analogy. Every birth requires a mother to carry the baby and a father to inject half the DNA. In MRT 1, though, the plan was a test-tube baby. Cuomo had been talking to cronies and campaign funders about Medicaid since before his first election in 2010. By the time the MRT convened in January 2011, his minions already had a detailed set of “recommendations” for the team’s review. The team had less than two months to work on this, but much of what work they did was apparently wasted, according to Judy Wessler, a long-time New York City healthcare activist who worked with Medicaid Matters Coordinator Lara Kassel. Medicaid Matters is an advocacy group that primarily works on consumer-related issues. Kassel was the only MRT I member who represented Medicaid consumers. Although the team was allowed to propose additional ideas, many were rejected. Some proposals on the original list mysteriously disappeared. Less mysterious but even more shocking, shortly before the final meeting, DOH shuffled the deck completely. Half of the original 49 proposals were removed and 17 new ones were added. The team was supposed to get two days to evaluate all of these changes. However, after a private members-only luncheon on the first day, Team Chairman Michael Dowling said there had probably been enough talk and called for a vote on the package. Only two members, Kassel and Assemblyman Richard Gottfried, objected, and they abstained from the vote. The package was approved. Although negotiations among the Assembly Speaker, Senate Majority Leader, and Cuomo resulted in some changes (including removal of perennial red herrings like ending “spousal refusal”), almost all of it was passed into law by the legislature.

Governor Andrew Cuomo

Today advocates are warning about a repeat of this travesty. Cuomo appointed the same two people to co-chair the team: Michael Dowling, formerly of Cuomo’s father Mario’s cabinet and now President and CEO of New York’s largest healthcare business, Northwell Health, which owns hospitals, rehab facilities, and other medical enterprises throughout New York City; and Dennis Rivera, a former Chairman of SEIU Healthcare, a nationwide union representing healthcare workers that includes SEIU 1199, one of Andrew Cuomo’s biggest campaign funders. There is, again, only one “consumer” member on the team: T. K. Small is a well-known disabled lawyer and activist in New York City. He is Director of Policy for perhaps the largest CDPA provider agency in NY, Concepts of Independence, but some behind-the-scenes people have said he may be too close to 1199 to be independent. (Kassel was offered the slot but refused, not wanting to lend legitimacy to an obvious sham.) Unlike last time, there are no state legislators onboard, but top staffers for the Assembly Ways & Means and Senate Finance Committees are members. The others include four state agency commissioners, another union rep, some managed care insurance company and provider agency executives, a SUNY Vice Chancellor, and Paul Francis, Cuomo’s Secretary for Health and Human Services. Bryan O’Malley, Executive

Director of the CDPA Association of New York State (CDPAANYS), was named to the MRT's Long Term Care Advisory Group. This group was supposed to "generate ideas and proposals on long term care for presentation to the MRT II at upcoming meetings." Their first meeting was on February 19. CDPAANYS is a trade group that represents most CDPA providers in the state, including many that do not actually fully comply with the CDPA model. In any event, the group is, as its name says, "advisory"; it doesn't vote on the final list of proposals.

The process looked to be the same as last time as well. The team will have a very short time-frame in which to review a canned package of ideas provided by Cuomo's DOH. Probably those will include the usual items that did not get explicitly mentioned in Cuomo's budget proposal, such as eliminating "spousal refusal" and "provider prevails". There's "opportunity for public input" but it's already clear that MRT II is taking that even less seriously than MRT I did. Cuomo announced the team members on February 4. The team had its first meeting on February 11. The first meeting to collect public comment was held on February 14 in New York City, with less than 24 hours' notice for those who might want to attend, and the announcement gave the wrong address for the meeting. A second meeting was held on February 18 in Rochester, and a third on February 21 in Albany. There was also an online form for members of the public to submit formal proposals, but the deadline was February 21. Work is supposed to be completed by "mid-March", in time for the legislature to vote on the final budget before April 1.

Cuomo has set some conditions on the proposals to be developed by the MRT, and they have been spun by various Cuomo minions and MRT supporters as:

"Zero impact on local government spending": Actually, Cuomo has said that as long as counties stay inside the state's long-running 2% property tax increase cap they won't be held accountable for Medicaid increases, but if they raise property taxes too much, they will have to foot the bill for Medicaid spending hikes that exceed the 3.2% "global cap".

"Zero impact on beneficiaries": That should be translated as "as far as we up here in the executive suite understand it". For example, DOH claims its new rate structure for CDPA Fiscal Intermediaries won't have any impact on consumers, but in fact it will destroy the program and force thousands of people into more expensive and restrictive forms of homecare or institutional settings.

"Industry efficiencies or additional revenue": That means cutting rates to providers and/or taxing them.

"Root out waste, fraud, and abuse": There certainly is Medicaid fraud, nearly all of which is perpetrated by managed care insurance companies and large providers of acute medical or segregated residential services. The biggest source of waste is NY's hand-over of Medicaid administration to for-profit companies. Historically, fee-for-service Medicaid has an average administrative rate of about 8%. Managed care insurance companies are allowed 15%, of which 7% is pure profit. NY's "conflict-free" managed care enrollment broker, Maximus, also gets 15%—all of it profit. We do need conflict-free needs assessments; without them, the state would succumb to pressure to arbitrarily deny services to save money. But the company has annual contracts totaling $3 billion. That's $450 million in profits—excessive by any measure. Waste in service-provision is not common at all. Most programs have already had their rates cut to the bone; in fact, those rates don't pay the full freight for many services, and providers have to "donate" money from other sources to cover the gaps. The notion that there is a lot of "abuse"—that is, people getting services they don't need—is just nonsense. Most people can't get all of the services they need, due to constant shortages of homecare workers and of acute-care providers who accept Medicaid all across upstate New York.

Despite the short notice there were some protesters at both the February 11 kick-off meeting and the public hearing on Valentine's Day. Only seven MRT members showed up at the first public hearing. Small was not among them, because due to the short notice he could not arrange a paratransit ride in time.

Legislative leaders are not impressed. Gustavo Rivera (D), Chair of the Senate Health Committee, issued a statement: "Simply put, it is unacceptable for a government meeting of this magnitude to offer less than 24 hours notice to the general public and expect people to attend. New York's Medicaid program is seriously at risk, yet the Governor is treating the healthcare needs of some of the most vulnerable New Yorkers as an afterthought. This hastily called meeting is the clearest demonstration yet that this administration is not genuinely seeking recommendations or input from stakeholders." This matched Rivera's indignation at an earlier legislative joint budget hearing where DOH Commissioner Howard Zucker and Medicaid Director Donna Frescatore refused to provide details to support Cuomo's claims regarding Medicaid costs and the MRT, and Rivera told them, "You're asking us to trust you. Folks, this don't build trust. … We don't trust you! You gotta build that! This ain't helping." Rivera also said the state should be considering taxing the wealthy.

Assembly Health Committee Chairman Richard Gottfried (D) told an interviewer from *Politico*, "My belief is that the package the MRT will produce was almost entirely written back in December and the MRT's function is to ratify it and tie it up in a nice ribbon with an aura of being somehow the product of a wise and fair collective body."

(At press time we heard that the MRT had added another NYC public hearing on March 2, and the submission portal was re-opened.)

Some legislators may be outraged, but Assembly Speaker Heastie is the only one of the "big three" to say he would consider raising general taxes to solve this problem. Senate Majority Leader Andrea Stewart Cousins has been silent on that point. Cuomo's budget proposal presents the legislature with a stark choice: either approve $2.5 million worth of options presented by the MRT, or sit back and wait for DOH to make its own cuts. The legislature forfeited full control over the public purse back in 2011 when it bought the original MRT package. To get it back they will have to pass a bill to repeal that law, and then come up with two thirds votes in both houses to override Cuomo's inevitable veto. No doubt the minority Republicans in both houses would be happy to oblige, but the rest of those votes must come from Democrats in Cuomo's own party. There's no indication that the considerable verbal eloquence our representatives have voiced so far will translate into backbone strong enough to make that happen. But stay tuned.

CDPA: Fie! On FI Filing!

We reported our court victory in *CDPAA-NYS v Zucker* last time (*AccessAbility* Winter 2019-20). The judge ruled that the NY State Department of Health (DOH) cannot change how it pays for CDPA Fiscal Intermediary (FI) services without submitting its plans for public comment.

DOH indicated they wanted to appeal the decision but so far they have not filed papers to do so. As of late February they still had a little more time for that. But they did two other things: They went ahead and filed their proposal as a "Notice of Rulemaking" for public comment, and they also put out a "Request for Offers" (RFO) to FIs that want to apply to continue the program.

Under the NY State Administrative Procedure Act (SAPA), there are legal standards for rulemaking that DOH has to follow. Basically, they have to analyze substantial evidence from authoritative sources to determine the effects of their proposed rules, and they have to make decisions that are reasonable and logical in light of that evidence. If they don't do that, the rule can be struck down in court as "arbitrary and capricious" and an "abuse of discretion".

The Consumer Directed Personal Assistance (CDPA) program lets people choose the personal assistants (PAs) who will help them with the most intimate tasks, like bathing, dressing, using the toilet, eating, and more. Not only can they choose those people, they decide when and where they work and, within guidelines set by a needs assessment, what things they will and won't do. They also show them how they want those tasks done. They supervise their PAs, correct them, and, if necessary, fire them. "Fiscal Intermediary" is a service that is provided to CDPA participants to enable them to make these decisions about their care without having to be Medicaid legal compliance experts, operate a payroll service, or run an employment agency.

Currently CDPA FIs are paid to provide that service based on the actual costs of doing so. DOH reviews and approves those costs from the prior year and sets payment for the next year. For convenience' sake, that payment is then calculated as a percentage of the annual total the FI receives to pay PAs and run the program.

DOH wants to change this to a per-member-per-month (PMPM) fixed fee. They proposed three "tiers" of fees, based on how many monthly hours of service the consumers get. Although our FI percentage is among the lowest in the state, we would lose fully 65% of our funding to operate the program. We simply couldn't continue to do most of what we do. As a result, services for many people would be suspended so often, and for so long, that they could no longer depend on them. They would have to use much more expensive "traditional" homecare services that they can't control, or move out of their homes and into segregated settings like nursing facilities.

The Rulemaking provided even less information about how DOH arrived at its new PMPM FI rate than the agency gave the judge in the lawsuit. In particular, DOH did not explain how the fees they set for each tier relate to the very minimal cost data they presented. But what they did provide clearly showed that DOH officials do not understand what the program really does or how it works. We don't want to bore you with financial details, but here's a short summary:

Despite their claim that all FIs do is "process payroll", DOH figured out how many full-time employees it takes to do all of the actual FI work for a specific number of CDPA participants. That includes very labor-intensive tasks like enrolling new consumers and "onboarding" new personal assistants (PAs); training consumers in how to manage their services and providing legally required training to PAs; making sure PA time records are accurate before we pay them; monitoring consumers' health and safety; constantly hounding county Departments of Social Services, managed care organizations (MCOs), and doctors, as well as consumers and PAs to keep their paperwork up to date so we don't have to cut off services; billing for those services and hounding MCOs to pay those bills—oh yeah, and processing payroll. But then DOH said they could cut our rate by 65% and we would ***still*** be able to pay all those people to do that work while keeping the lights on in their offices and buying office supplies, among other things, and paying for necessary support work like keeping the computers running, administrative oversight, and general record-keeping. That, of course, is ridiculous.

DOH also says this plan won't have a "substantial" effect on jobs around the state. But we've calculated that if the PMPM rate affects other CDPA FIs the way it would affect us, more than 1600 FI staff would lose their jobs. We think that's pretty substantial.

And that's not all! The RFO described requirements for CDPA FIs that will take effect after July 1, 2020—for any organizations that DOH approves to continue to provide that service. The RFO says FIs will have to do a lot more than they do now, including collecting and reporting much more data, and purchasing really expensive software and computer network control systems to meet "cyber security" requirements.

We're not nearly done fighting. As you read this, we've submitted extensive comments to DOH explaining exactly what is wrong with their PMPM system and their numbers. We fully expect DOH to ignore those comments. But we've also been keeping state legislators informed on this insane proposal, and we are preparing a strong legal case to take back into court if necessary. We'll let you know how it comes out next time.

Rotenberg: Still Current

The Rotenberg Center is an organization in Massachusetts that operates a residential school, a developmental center, and many group homes for children and adults with developmental disabilities, including some NY citizens. It is also the only organization in the US that uses electric shock as punishment. We've reported on Rotenberg many times (see *AccessAbility* Summer 2018, for example).

A family court judge ruled in *Sudders v Rotenberg* in June 2018 (*AccessAbility* Fall 2018) that shock opponents "failed to demonstrate that there is now a professional consensus" that shock punishment is harmful. We didn't get to read the court papers, so we don't know what evidence was presented, but it clearly couldn't have been much of a presentation. When the federal Food and Drug Administration (FDA) proposed to ban the use of the shock devices in 2016, they received thousands of comments, many from a broad array of medical and behavioral health professionals, supporting the ban (see *AccessAbility* Summer 2016 for details). There clearly is such a consensus; either the plaintiff's lawyers botched the case or the judge was an idiot. The MA Attorney General appealed the decision and there has not been any further news on it. A previous decision had limited use of shocks to 54 people whose families had sued to continue the "treatment", and prohibited it for anyone else except by future court orders—of which none have been issued so far. But after the *Sudder* decision Rotenberg Executive Director Glenda Crookes expressed optimism that the organization would soon be able to start shocking new people.

When Trump took office, several federal departments issued schedules for handling stalled plans to finalize hundreds of regulations. Some plans begun under Obama were completely dropped. But the FDA ban on shock devices remained on the schedule, and was supposed to have been issued by the end of 2019. When that didn't happen, a Boston NPR reporter jumped on the story. She interviewed an FDA spokesperson in January 2020 who said, of the missed deadline, "We estimate the best we can." But the FDA insists it still plans to ban the devices.

Abuses at Rotenberg aren't limited to electric shocks. In 2016 a MA state investigation of 28 residential schools found that Rotenberg group homes had the highest rate of reports of "noncompliance" with state regulations, mostly related to abuse and neglect. State regulators also said that Rotenberg group homes had the second highest rate of violations among all such homes for children between 2011 and 2016.

Disability advocates have been concerned about the delays at the FDA for a while. Protesters from ADAPT and the Autistic Self Advocacy Network have appeared at FDA offices many times, most recently in April 2019. Advocates have also written to members of Congress, urging them to contact the FDA and demand that the regulations be issued. When Congressman Anthony Brindisi (D-NY) visited STIC in the spring of 2019 we asked him to write such a letter. He did not do so until January of this year, after the FDA missed its deadline.

Advocates also organized a group of US Senators to issue a letter in February. Senator Patty Murray (D-WA), the senior Democrat on the Senate Health, Education, Labor and Pensions Committee, said, "We have an obligation to protect children and adults with disabilities from archaic and inhumane forms of punishment. No more excuses, the FDA needs to finalize this rule immediately." Seven other Democrats and Socialist Bernie Sanders signed the letters. An FDA spokesperson said they got the letter and they will respond to the Senators.

The fact that no Republicans took part is disturbing, and raised concerns that the issue, which should be non-partisan, will become a political football if it gets portrayed as Democrats attacking the Trump Administration. We'll let you know what happens.

The Holocaust Happened

January 2020 saw the 75th anniversary of the liberation of Auschwitz. Anti-Semitic incidents in the US are rising rapidly, and many young people don't seem to know what happened in Europe under the Nazis. A 2018 survey found that 66% of millennials did not know what Auschwitz was, and 22% did not know what the Holocaust was. And there ***is*** a disability connection.

Kids: The Holocaust was a deliberate effort to exterminate Jews, Roma ("Gypsies"), LGBTQ people and people with disabilities that was carried out under Adolf Hitler's Nazi regime before and during World War II. 6 million Jews and many millions of other people were murdered in planned, organized massacres. Auschwitz was a set of concentration camps in Poland where 1.1 million Jews were hauled in by railroad cattle cars and killed—most of them gassed to death with insecticide—and their bodies were burned in crematoriums.

We don't know why younger people don't know about this. Maybe the current obsession with avoiding "triggering" people has something to with it. People NEED to be "triggered" by the Holocaust. ***Humanity must never forget.*** We are ***all*** responsible for reminding each other.

REMEMBER—and teach your own children.

NYAIL 2020 Disability Priority Agenda

From NYAIL (abridged)

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL leads statewide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. This year marks seven years since NY issued its Olmstead Plan to advance community integration for people with disabilities. Yet, over the past couple of years, we've had to fight off major cuts to programs that keep many people in the community and out of costly institutions. From carving nursing homes out of MLTC, to the devastating cuts to the Consumer Directed Personal Assistance (CDPA) program last year, the state has tried to cut Medicaid at the expense of some of its most vulnerable citizens. Those cuts will likely pale in comparison to this year's plan to cut $5 billion from Medicaid. In addition, other vital programs are still underfunded, like ILCs and Access to Home, further illustrating a lack of commitment to Olmstead. We urge the Legislature to take legislative and administrative action in the 2020-21 budget as outlined below.

INDEPENDENT LIVING

• Increase base funding for ILCs to $18 million.

ILCs provide critical services to people with disabilities, all designed to assist them to navigate the ever-changing service system in order to live independent, fully integrated lives in the community. As NY continues to redesign healthcare, ILCs play a crucial role. They provide a wide range of services based on local needs, aimed at addressing the social determinants of health: education, employment, housing, transportation, and independent living skills. ILCs have been severely underfunded for the past 15 years while the cost of providing services has increased dramatically. In 2018, NY's network of ILCs served 114,000 people with disabilities, family members and others; an increase of approximately 20,000 in just six years. This shows the pressing need for IL services, and the number served would likely be higher had the funding kept up with the needs of centers. Over the past few years, the Board of Regents and the Legislature have acknowledged that ILCs are essential providers for some of our most vulnerable citizens, yet have not been able to meet the needs of their local communities due to this severe underfunding. We've had strong support in the legislature and in last year's final budget, the ILCs received a modest increase of $500,000. However, Governor Cuomo's proposed budget cuts that increase back out. Centers have already created budgets relying on this increased amount in base funding and taking it away would further harm already under-funded centers.

HEALTH/MEDICAID

• NYAIL strongly opposes a Medicaid Redesign Team II approach to cutting Medicaid.

The proposed budget reconvenes the Medicaid Redesign Team (MRT), which will report back before April 1 with a plan to deliver $2.5 billion in cuts to Medicaid. Medicaid is an essential program that provides vital services to people with disabilities and other low-income individuals. We are gravely concerned that directing a group of providers to find savings in such a short time will create a process that does not allow for public input, or time to consider the implications of the proposals and how they will impact access to vital services. NYAIL does not oppose looking for savings in Medicaid, or rooting out fraud, waste, and abuse. But we are deeply concerned that this process, which so far appears to be solely provider-driven, will not prioritize NY's obligations under *Olmstead* to ensure people have access to the supports and services they need to live in the community. We call on the state to also implement the following recommendations:

- Include representatives from community-based organizations, advocates, and people with disabilities on the MRT.
- Allow for an open process that provides stakeholders a say in how savings are achieved in a manner that does not impact access to vital services.
- Do not rely solely on program cuts to address the budget shortfall. Instead, NY must address both sides of the equation by also seeking ways to raise revenue.

• CDPA should be handled separately from the larger MRT process and the draconian reimbursement changes put forward last year must be reconsidered.

Many people have been able to leave institutions and live independently in the community thanks to the Consumer Directed Personal Assistance (CDPA) program. Unfortunately, CDPA is being blamed in part for recent growth in Medicaid.

Growth in CDPA should be viewed as a positive considering the current budget shortfall. CDPA is less expensive to provide than traditional homecare or nursing homes. Part of the reason CDPA has grown in recent years is the homecare crisis. People who could not get traditional homecare because agencies did not have anyone to staff the hours turned to CDPA and were able to recruit their own aides. Without CDPA, many of these people would likely have been forced into institutions. The future of CDPA is still in peril due to last year's disastrous rate cuts which do not adequately fund Fiscal Intermediaries for the services they provide and would put most providers out of business. Any further cuts to CDPA will undoubtedly reduce people's ability to access this vital service they rely on to live in the community.

Fiscal Intermediaries and consumers are the experts on CDPA; they need to have input in how savings are achieved in the program. The state should handle CDPA separately from the MRT process. A smaller workgroup should be created with stakeholders who are knowledgeable about the program. We call on the state to rescind the proposed regulations regarding administrative reimbursements, implement the ideas NYAIL, the Consumer Directed Personal Assistance Association of NYS and the NYS Association of Home Care Providers collectively put forward to achieve immediate savings, and begin a more thoughtful process to identify additional savings to the program, including any change to reimbursement.

• Reconsider the Medicaid Global Cap.

Much of the reason for the so-called budget shortfall is due to spending simply exceeding the Medicaid Global Cap. The cap was first established when NY was in fiscal crisis. And while it did constrain Medicaid growth for a time, essential programs and services have already faced significant cuts in recent years as a result of the cap. Years later, NY's economy is doing well, and such austerity seems cruel and unnecessary. The state needs to continue in its tradition of providing community-based services to low-income individuals and people with disabilities. In order to do so, NY needs to re-examine the Global Cap and take factors such as an aging population and growth in the program into account.

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

As NY's homecare providers struggle to recruit and retain workers, they unfortunately lack the resources to test innovative solutions to this problem. This year's budget should include funding to support pilot projects throughout the state that help to increase recruitment and retention of home care workers. We are proposing that NY allocate a mere $5 million per year for 3 years to support this effort. The findings from these projects can help determine statewide solutions.

• Increase funding for Community Health Advocates (CHA), the state's health care consumer assistance program, to $5 million.

Since 2010, CHA has helped 359,000 New Yorkers, including many with disabilities, all over the state navigate their health insurance plans to get what they need and saved over $47 million. People with serious illnesses and disabilities especially need this assistance to get the services and supports that are right for them. CHA's contact information is listed on commercial, but not Medicaid Managed Care, notices. Medicaid patients now have to "exhaust" their plan's internal appeal systems before going to an independent appeal process. Medicaid enrollees should receive CHA's information to manage the appeal process as people in the commercial markets already do. The Governor proposes a budget for the program of $2.5 million. We urge the Legislature to add $2.5 million for a total of $5 million for fiscal year 2021.

AGING

• Increase NY's share of funding for the Long-Term Care Ombudsman (LTCOP) program by $3 million.

LTCOP is an advocate and resource for people living in nursing facilities and other institutions. It is intended to promote and protect residents' rights as well as their health and safety by receiving, investigating and resolving complaints made by or on behalf of residents. The program's federal funding is insufficient to provide adequate services. The State Comptroller released a report in 2019 on the program and found that many residents in LTC facilities lack representation from an ombudsman due to lack of volunteers and paid staff. The report found that statewide, there are about half the recommended number of full-time staff. Five of eleven regions require at least three additional staff to meet recommended levels, and New York City alone requires 23 more full-time staff. NYAIL urges NY to increase its share of funding by $3 million to ensure that people in long-term care facilities are adequately served.

HOUSING

• Increase funding for Access to Home to $10 million.

Access to Home is an important program administered by NYS Homes and Community Renewal that provides funding for home modifications to allow people with disabilities and older New Yorkers to stay in their homes and out of costly institutions. For many people, the addition of a ramp to their front door makes the difference between being able to leave the house and being homebound. Access to Home was cut by 75% several years ago. Ever since, it has been funded at a mere $1 million statewide, leaving many parts of the state without the program and resulting in years-long waiting lists. Investing in Access to Home will help seniors and people with disabilities around the state to remain in their homes and out of institutions.

• 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 vetoed legislation to create a visitability tax credit for the fourth time. In the veto messages, the Governor indicated support for the proposal, but said it should be handled in budget negotiations. Despite his stated support, Governor Cuomo has yet again failed to include this tax credit in his proposed budget. This is a priority for the disability community as a tax credit would help keep people in their homes and out of institutions by assisting them with the costs of making their homes more accessible. NYAIL urges the legislature to include the $1 million pilot program in the state budget.

EMPLOYMENT

• Establish a small business tax credit for employing people with disabilities.

There is a dire need to address the extremely high rates of unemployment and poverty among people with disabilities. Governor Cuomo recognized this when he issued Executive Order 136, establishing an Employment First Commission. Included in the Employment First report was a recommendation to create a cross-disability tax credit. Legislation which would have established such a tax credit for small businesses was passed by the legislature last session for the second year in a row. The legislation was vetoed, and the only reason provided in the most recent veto message was it needs to be included in the budget, which it was not. This tax credit would provide a real incentive for small businesses to take a chance and hire people with disabilities.

• Prohibit the practice of paying people with disabilities below the minimum wage in New York State. A.7077 (Steck) and S.4018 (Skoufis).

For too long, people with disabilities have been segregated from the rest of society, shut away in institutions and facility-based employment settings. At these segregated settings and enclave type jobs in the community, agencies have been allowed to pay people with disabilities well under minimum wage under section 14(c) of the Fair Labor Standards Act. However, the Supreme Court 1999 *Olmstead* decision held that people with disabilities have the right to live and receive services in the most integrated setting. This is in large part why CMS required NY to phase out subminimum wage jobs in their Transformation Agreement. The majority of facility-based employment settings are segregated, focused on production-style work, and fail to provide adequate training, and thus do not result in competitive, integrated employment. Many people with disabilities are not suited to production work and it is time we stop equating them with this form of employment. We have also developed many successful employment models in the decades since 14(c) was enacted. It is time for NY to update its employment model away from segregated, subminimum wage settings to an Employment First model, developing each person's latent skills and talents so they can become successfully employed like their nondisabled peers.

• **Waive the State's sovereign immunity to claims under the Americans with Disabilities Act (ADA) and Section 504.** A.1092 (Lifton) and S.5208 (Sanders).

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

TRANSPORTATION

• **Enact the recommendations of the Transportation Network Company (TNC) Accessibility Task Force.**

Their report was published in February 2019 and included two recommendations to the state intended to ensure comparable service is provided to wheelchair users:

- Establish an official governing entity to provide ongoing oversight of TNCs operating in NY.
- Explore creative ways to provide incentives to increase the number of accessible TNC vehicles statewide. For example, potential TNC drivers could get tax breaks or access to low interest loans for the purchase and/or modification of accessible vehicles.

The TNC Accessibility Task Force was created as part of the law authorizing TNCs to operate statewide. That law mandated that TNCs implement the Task Force recommendations. However, there is little to no evidence the TNCs are doing anything about this. The TNCs were directed to spend this year working with disability organizations regionally on a plan to provide comparable wheelchair accessible service. NYAIL provided both Uber and Lyft with contacts at ILCs across the state. Yet, we are not aware of any ILCs hearing from either company about this. Unless NY creates a mechanism for oversight, it seems very unlikely the recommendations in this report will be implemented. This budget is a perfect opportunity to provide funding to help get more accessible vehicles on the road and to create an oversight body to ensure the TNCs comply.

• **Require transportation service providers, including taxis, limousines, and TNCs, to provide an equivalent level of accessible service to wheelchair and other mobility-impaired users, comparable to the level of service they offer other passengers.** A.7344 (Steck).

• **Require counties to expand paratransit beyond ADA minimums.** A.8515 (Steck)

The limited availability of accessible transportation services is a major barrier for people with disabilities, often leading to unemployment, inability to access medical care or voting sites, and isolation from friends, family, and full community participation. The lack of on-demand accessible transportation is a large part of this problem across NY. Throughout most of the state, neither taxis nor TNCs provide wheelchair-accessible service. New York City made some gains in getting a percentage of taxis wheelchair-accessible, but much of this progress has been undermined by TNCs such as Uber, which are putting accessible taxis out of business. Outside New York City, there is virtually no wheelchair accessible taxi service. In some communities, paratransit is the only option; others have nothing. It is imperative that all for-hire transportation services—including TNCs—ensure a percentage of their fleet is accessible. The ADA mandates all counties to provide paratransit services to people with disabilities unable to take the fixed route bus. Service must be provided to locations within ¾ of a mile of the closest fixed route bus stop. While this is a minimum service, counties can and should provide transportation to people with disabilities throughout their service area to ensure they can get to work, doctor appointments, and generally participate in their community.

GOVERNMENT OPERATIONS

• **Provide a necessary voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities.** A.9004 (Steck).

The disability community desperately needs a voice in state government that represents all people with disabilities. Reinstating the Office for the Advocate is a critical first step. Originally established by Governor Mario Cuomo, this office was responsible for advising and assisting the Governor in developing policies designed to help meet the needs of people with disabilities and serving as NY's coordinator for the implementation of the Federal Rehabilitation Act of 1973 (this would now include the ADA and *Olmstead*).

As one of his first acts in office, Governor Cuomo continued Executive Order 26. However, despite the existence of the Office on the books, any advocacy function in state government disappeared when the Justice Center reorganized itself without any advocacy functions. Though this bill passed the legislature in 2019, Governor Cuomo vetoed the bill, stating he would instead hire a Chief Disability Officer. While an important position, it has not yet been created, and the disability community does not feel a single person in the Executive Chamber can fulfill the same role as a state agency. A new home for advocacy and independent living must be established.

STIC NEWS

Xscape with or from Your Kids!

By Bill Bartlow

We are expanding into a new category of escape adventures: Escape rooms for children ages 7 through 12. The "Wizard Academy" and "Immunity Quest" are now available for bookings of up to 12 children, who will be split into two teams of six for two thirty-minute games in each room, and one-hour availability in our decorated party room. The children must be accompanied by two adults; one for each team of six kids. This program is ideal for birthday celebrations or simply a fun outing. We will supply the plates, cups and flatware for the party. Food and beverages will be provided by those who reserve the rooms.

Also, we are retiring our "Pulse" escape room after three years to introduce a new adventure in espionage and classified covert intelligence operations. Yeah, sure; the front is that it's an insurance agency, "Chenango Insurance Associates", but behind the facade, clandestine international intrigue is transpiring. We'll close "Pulse" at the end of February. On May 1 the new room, "Exit Protocol", will open.

Searching the internet for escape rooms that accommodate blind participants, I found one in London. We recently enhanced our "Valley of the Kings" escape room to be playable for vision impaired individuals. Certainly we're the first in the northeast, and possibly in the country, to accomplish that, and on January 9 we welcomed our first blind player to our escape rooms.

Xscapes keeps growing and continues to be a great fundraiser and crowd-pleasing adventure. Schedule your games at www.xscapes-stic.com.

SAVE *the* DATE

May 12, 2020

STIC's Housing Forum will host a **CONFERENCE For Landlords and Tenants**

A Conversation with Carol Kay Nutter-Lawton and Portia Barnett

By Sue Ruff

Carol Kay Nutter-Lawton left a nursing facility and moved into her own apartment in November. STIC staff who work in the Open Doors, Traumatic Brain Injury, Nursing Home Transition and Diversion (NHTD), and Peer Counseling programs observe the terrible conditions people experience in nursing facilities and when they are able to help people move into the community, we all rejoice. Carol and her daughter, Portia Barnett, agreed to share her story with our readers.

First, however, we have to look back in history. Since the beginning of our nation segregation has affected Native Americans, African Americans, and other people of diverse racial, ethnic, or cultural backgrounds. Segregation has also negatively impacted the lives of people with disabilities for centuries.

The Supreme Court upheld the constitutionality of racial segregation under the "separate but equal" doctrine in an 1896 case, *Plessy v Ferguson.* Four years before the court ruling Homer Plessy refused to sit in a train car designated for blacks. Although Mr. Plessy's attorneys argued that his constitutional rights were violated, the Supreme Court ruled that "a law that 'implies merely a legal distinction' between whites and blacks was not unconstitutional." After this decision Jim Crow legislation and separate accommodations spread across the country.

www.history.com/topics/black-history/plessy-v-ferguson

Many states had racially segregated schools, claiming they were "separate but equal." Native American and African American children, however, were not receiving equal educational opportunities. In the early 1950s parents began to file class action lawsuits in several states. One of these class actions, *Brown v Board of Education*, was filed against the Topeka, Kansas, school board by representative-plaintiff Reverend Oliver Brown, parent of one of the children denied access to Topeka's white schools. In addition to Reverend Brown, "thirteen groups of parents and their 20 children were represented in the suit in Topeka. All of the parents had attempted to enroll their children in white-only schools, but were denied, thus creating the basis for the suit." www.cnn.com/2013/07/04/us/brown-v-board-of-education/index.html

The parents claimed that the city's schools violated the Equal Protection Clause of the 14th Amendment of the Constitution. A federal district court dismissed the claim, ruling that the schools were "substantially" equal. On appeal to the Supreme Court, the several class action suits were consolidated. Thurgood Marshall argued the case for the children and parents in 1954. (Thirteen years later, Marshall became the first black justice of the Supreme Court.)

www.thirteen.org/wnet/supremecourt/rights/landmark_brown.html

The decision of the Supreme Court in 1954 was unanimous and it ruled separate was not equal. School desegregation took many more years and many more battles. Additionally, this decision became critically important for students with disabilities. It laid the foundation for a 1975 law, the Individuals with Disabilities Education Act (IDEA). This law requires access to a free appropriate public education for all children with disabilities. Prior to the passage and implementation of this law, more than a million students with disabilities received no public education and many were placed in institutions.

www.acslaw.org/expertforum/the-meaning-of-brown-for-children-with-disabilities/

The fight to integrate people into every aspect of society (education, employment, community-based services) continues to this day.

Carol Kay Nutter-Lawton was one of the children who was a plaintiff in *Brown v Board of Education.* Carol's parents, Maude Sudduth and Richard Lawton, raised their family of five girls and four boys in Topeka. Mrs. Lawton was Native American and German; Mr. Lawton was Irish and English. I asked Carol if she knew Reverend Brown and she said, "He married me to my first husband." Carol and some of the other child plaintiffs attended the segregated Buchanan School, one of only four schools African American or mixed-race children could attend in the city. Carol said her younger brother was the first sibling to go to an integrated school.

After high school, Carol attended different colleges. Her mother had taken her to ballet and tap dancing classes as a child. Carol was a dancer for several years with the Leon Claxton Harlem Review (Royal American Shows). She showed me a beautiful picture of her in one of her calypso costumes in a dancer line-up. She travelled extensively with the Review. Carol had four children; her son, Dana, very sadly, died as a toddler, but she is very close to her three daughters, Portia, Crystal, and Monica. Over her life Carol lived in different states: Florida, Oklahoma, North Carolina, and New York. For thirty-six years she was a cosmetologist, having a shop in her home for twelve of those years. "I was a platinum blond at one time and I want to do it again," she said.

Carol had a stroke about three years ago, which affected her left side. Living in North Carolina at the time, she had the help and support of her daughter, Crystal. At a rehab site she was using a walker to get around and was strengthening her body in an exercise pool. Her daughter had to leave North Carolina for a job in Oregon and the family encouraged Carol to move to Binghamton to be near Portia and her husband, Reverend Frank Barnett. Carol became ill during the trip north and ended up in Wilson Hospital. From there she was transitioned to Bridgewater Nursing Facility.

Carol's story is an example of the painful stories we hear from residents at nursing facilities. Carol said she had her walker when she entered Bridgewater, but when they moved her from the second to the third floor, her walker was taken away and not returned. Portia shared her observations of the facility, pointing out the high turnover rate of staff and the poor care her mother often received. Room lights would blink and staff would not answer requests for assistance. Nurses would admit to her that it was "not a good place" and told her of their problems giving care. Carol and Portia experienced disrespect. Portia said, "Some staff have no regard for humans, no compassion. I tried to always show respect to the staff and offered to help them. Our parents are owed good care." In addition to turnover of nurses and aides, there were several administration turnovers while Carol was at this facility. Physical therapy was stopped; they had to request re-evaluations and re-instatement. This therapy interruption led to more physical weakness. Sometimes Portia and her sister asked for staff re-training. "You are entrusting them with other people's lives, people who are completely dependent and in total need. It is important for family to be around and to advocate for their loved ones."

Looking for help for her mother was discouraging for Portia and her sisters. She reached out to the Office for Aging and to STIC. Our Open Doors and NHTD staff became involved, together with a very good service coordinator from another community agency. Portia said, "They changed her life." They were a team that worked to help Carol get out of the facility and into her own home. "I'm so grateful, they all worked together." Carol has several personal care assistants, including a dear friend from her son-in-law's church. Carol said, "She got me some hair color and we are going to fix my hair soon." Carol also has an appointment with a physical therapist coming up. "I want to walk again. And I need a sliding board to get from my bed to my wheelchair. I have to get stronger." As she begins to integrate back into the community, she has the encouragement of family, friends and staff. Her eight grandchildren and seventeen great-grandchildren are part of the loving team that motivates her.

Carol and Portia said, "Your voice is important. You can change life with one voice. Our mother and grandmother, Maude, was strong and her voice mattered in 1954." Sixty-five years later, Carol's and Portia's voices matter just as much.

Self Direction at STIC is Now in Full Swing

By Rhonda White

Last quarter STIC became a Fiscal Intermediary (FI) under the OPWDD Waiver (not to be confused with STIC's CDPA FI program). We've worked diligently to put together a Self Direction FI program for you the consumer, and your employees, with the STIC mission that you all have come to know and love. Our mission is to "shape a world in which people with disabilities are empowered to live fully integrated lives in their communities". We offer many programs to assist with independence and self-advocacy, so it is a natural fit for STIC to venture into Self Direction FI services to assist you and your employees.

That's right, I said your employees. You are the co-employer of record. When you are approved by OPWDD to start Self-Directed Services you will pick your FI and Broker. As you work with the Broker, Care Manager and FI to put together your budget, you'll be interviewing and hiring your own Community Habilitation, Hourly Respite and Supported Employment providers. These are your employees. You'll be guided by a STIC FI Specialist to learn your employer responsibilities. We'll help you understand what the line items in the budget mean and what will best help you to be more independent. Let's start with your employees. You are their co-employer. You'll hire who you feel is a good fit for you. This can be a friend, a neighbor or someone you just met. The only restrictions are they can't be a parent/legal guardian or anyone who lives with you, and must be 18 and have a driver's license. You will pick their pay rate, once you understand the fringe rate and the caps that STIC has established. You'll set your employees' hours. You decide if there is extra training needed beyond the required new employee training. The FI handles the Human Resource responsibilities and completes the billing and reimbursement process. In other words, we complete the hiring process, including and not limited to, finger printing and background checks, W-2 forms, training and other tedious paperwork, and we bill Medicaid. We'll continue to guide you to be the best employer you can be. A good employer finds and keeps the happiest—which usually means the best—employees.

Self Direction does not stop there. I said earlier you would develop your budget. So let's learn a little bit about that. The first thing to understand is that everyone gets a Personal Resource Account (PRA). This is the amount of money that is set aside for your services. It is determined by those pesky DDP2 forms or CAS assessments and other questions that you may dread every year. Whether you choose traditional services and live in an IRA, live with your parent or independently, attend a day program and on and on; the point is, everyone has a PRA attached to their name. In the traditional services, the PRA number and services are monitored by the provider agencies and someone on the third floor of the DDRO. Self Direction takes the PRA and puts it into your control with your team of FI, Broker and Care Manager to assist you. Who knows better what you need for continued independence than YOU?

The Self Directed team led by you will discuss what things you need. One area of the budget is Individual Directed Goods and Services. Just like it says, there are many things to choose from. Most common are gym memberships and community classes. Maybe you have a personal outcome for "community integration"; a class that is open to everyone in the community might be good for you. Now you pick what is fun for you or something you have always wanted to try. Maybe a yoga class or a painting class, maybe a writing class at our community college or maybe an archery team interests you. If you will meet many new people at the class, this would be put in your budget. You and your broker will go down the entire list and pick what works for you. You will see as you are filling in the categories, your PRA number is getting smaller. This is because you are spending the money set aside in the PRA.

If you live in your own apartment or want to try living independently there are categories just for you. There is the housing subsidy that assists you to pay your rent. There is the paid neighbor and live-in caregiver—people you pick to increase your independence. After discussion and contracts are signed with you, the providers of these two services and the FI, they will become part of your budget to assure your continued independence and safety.

If you are the designee of a child or someone who may not be ready to live independently there are Family Support Services built into the budget. You won't lose those supports; they are now just calculated into your PRA budget. And don't fret, the FI communicates with you and the agency that provides these services to monitor how much of the assigned units are being used. Family Reimbursed Respite is in the budget also. You can assign up to $3,000 annually for this category. Again, the FI will keep track and monitor the usage and how much you have left throughout the year.

So what if you think, "OK, I want to try this," but are unsure of being able to self-direct some services? Seriously, some categories can be difficult. Let's use Supported Employment ("SEMP") as an example. You don't know anyone trained in this category. You're stressed, thinking "what should I do?" Well, you pick Direct Provider Purchased Services. This means you pay an agency for SEMP. It can be expensive, but well worth it in this situation and the FI must keep track with the other agency how much you use monthly, because it is in your budget and takes away from the annual PRA. Another example is respite houses. Maybe you'd like to attend for a week or so. Your parent/guardian may be on vacation. The respite house is a Direct Provider Purchase and the FI will continue to make sure that you do not go over your allotted units. This is also reflected in the budget and is taken from your PRA as you use the service.

The last section of the budget is Other Than Personal Services (OTPS). It is a smaller category of no more than $3,000 annually. One of the more used items is staff activity fees. This is an amount set in your budget to pay fees your staff might be charged while assisting you with your Life Plan goals. Another OTPS item is staff advertising/recruitment costs. If you need it, your broker or FI can help you advertise in different places to find new employees. That cost can be reimbursed to you and deducted from your budget PRA.

That is just a quick explanation of Self Directed Services and what STIC as the FI can do with you to gain more independence, your way. We're bringing in brokers and receiving referrals now. The process is going smoothly. Currently we are using a paper system, but we should have an electronic system by mid-year or so.

Does this sound interesting? If you have any questions, please reach out to STIC FI Specialist Rhonda White at (607) 724-2111 x386, or send an email to SDS@sticcil.org.

IT'S THAT TIME AGAIN!

Over the next few months the US Census Bureau is going to contact you.

Please remember:

1. Census results help fund important local programs and services.
2. By law, your answers to the Census are kept confidential.
3. There are three easy ways to respond: Online, Phone, or a Paper Form. It does not matter which one you use, just be sure to do your part!

To Learn More Visit 2020census.gov

Fill out your Census, it is important for our community.

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THANK YOU!

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