

AccessAbility

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NO HARM????!!!!



By Maria Dibble

On December 13, 2020, Barbara Jarvis, aged 84, who lived in a nursing facility near Syracuse, NY, was found dead. She could not walk without assistance, and the staff were supposed to help her go to and from the bathroom, according to her care plan. They didn't help her, because they hadn't read the plan. She tried to go on her own, slipped and fell, and hanged herself when her nightgown caught on a door-knob. She had only lived there for three months, during which she lost 27 pounds.

This facility—Van Duyn Center for Rehabilitation and Nursing—had been cited numerous times over the past decade for deficiencies, including failing to provide 18 residents with their medications on a single day because no nurse was assigned to the job, and keeping a rotting body in its morgue at a temperature between 80 and 90 degrees. In fact, the facility had three times the New York State average number of deficiencies over a period of four years, and it was sued for malpractice or negligence 20 times since 2016. Although the COVID-19 pandemic contributed to staff shortages in nursing facilities, inadequate staffing was a longstanding problem at Van Duyn, which was cited in 2017 for not having enough nurses or aides.

Who issued all these citations over all these years? The New York State Department of Health (DOH). After Jarvis died, DOH reached yet another agreement with Van Duyn on yet another “plan of corrective action” on January 16, 2021, and the facility promised, for the umpteenth time, to make things better. Citations and demands for plans of corrective action are not the only options DOH has when a facility shows a pattern of severe neglect or abuse. They can revoke the facility's operating certificate, and they can deny Medicaid funds. They can close it down, and that's what they should have done, years ago. But there is something very wrong with the way DOH's inspectors handled Barbara Jarvis's case. They ruled that Van Duyn's failure to help her walk to the bathroom resulted in “No actual harm or immediate jeopardy, but has the potential to cause more than minimal harm.”

So if we multiply Barbara Jarvis' death times the 15,500 New York nursing home residents who died of COVID-19 (as of April 28, 2021), should we give DOH a gold medal for their stellar performance in meeting the needs of elderly and disabled residents? Should we reward them for ridding us of the cost of serving all of

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those people? How should someone feel after reading such a callous assessment of a human being dying?

My response was outrage, disgust and despair. I think I yelled, “NO HARM!?” Have we become so jaded as a society that we can say, “No harm done,” when a human being dies due to careless disregard for her wellbeing and her very life? Nursing facilities have a culture rife with neglect and abuse. Like Van Duyn, many are cited repeatedly by DOH, but suffer no real consequences for their actions. In my book, the death of this woman should be considered criminal, and the owners should be held accountable.

We've all been horrified by the massive wave of nursing-home related deaths during the pandemic. Terrible as that has been, it was to be expected, because

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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.

nursing facilities bunch people with weak immune systems together in settings that have constantly poor—and constantly cited—infection control procedures. But it took this catastrophe to get people talking about the deeper problems with nursing facilities, the ways that their residents like Barbara Jarvis die, and have been dying, for decades.

Lots of people are talking about it now—including our state legislators, some of whom have been quite eloquent in their spoken outrage. But even as the Governor's cover-up of nursing home deaths collapsed and its motivations were revealed to be, in part, to protect sales of his self-laudatory book, what have they actually done?

Really, very little. For example, they passed a bill that requires nursing facilities to provide an average of 3.5 hours of "nursing care" daily to each resident. Failure to comply will result in a "civil penalty". That sounds like something, doesn't it? But the current average for nursing facilities today is already 3.4 hours. The bill doesn't set the penalty at any particular amount—and it exempts facilities from compliance during emergencies like the pandemic!

What all of this really does is obscure the pandemic's real message. It's not just New York; nationwide, about 30% of those who have died of COVID-19 were residents of nursing facilities or other congregate care settings. Most of them were people of color with low incomes whose services were paid for by Medicaid. When nursing homes make a profit off the people they warehouse, with government footing the bill, nothing will ever truly change. The profit is the goal, not good and decent care.

The best answer to the deaths during COVID isn't more staffing, though it is desirable and necessary for humane care. The solution is homecare, personal care, Consumer Directed Personal Assistance. These programs have one thing in common, they are provided in the person's home—real home I mean, not the nursing "home". And guess what, these programs didn't see anything like 30% of the people they served dying of the virus. Sure,

some of them died, but not nearly as many as did in the nursing facilities. And the 15,500 deaths doesn't include people who died in other congregate segregated care facilities like group "homes" for those with developmental disabilities. People with developmental disabilities who live in group homes and contract COVID-19 are three times as likely to die from it as ordinary New Yorkers, according to Disability Rights New York, the state's Protection & Advocacy watchdog.

The one lesson I'd hope NYS government would have learned from this pandemic is that people are safer, more comfortable, better cared for and happier in their own homes, with control over their services, and of those with whom they have contact.

We fought for that recognition and understanding during the legislative budget process, educating lawmakers on the need for people to be informed about home-based care when considering nursing facility placement. Over and over we've heard that families didn't know about homecare services so they thought the nursing home was their only choice. This could easily be remedied.

We also fought for higher wages for home care workers. There is a critical shortage of aides outside of the state's largest cities, because the usual starting pay is, for most of the state, the minimum wage of \$12.50 an hour, and it is impossible to support oneself, never mind a family on such an income. (It's \$15/hour in New York City and surrounding counties, which is not enough to live on there either.)

On July 1, minimum wage for fast food workers in upstate NY will go up to \$15.00 an hour, and I'm truly glad for them. But, at the same time, homecare and personal care workers are left behind at \$12.50 an hour. This will only make the shortage even more dire.

Personal care is not an easy job. Sometimes it's a dirty job, with unpleasant tasks to perform, but they are essential, critically important jobs. What kind of a state do we live in where our leaders value and reward cooking and selling burgers over caring for another human being?

I know that some of the legislators support the need for higher wages and homecare as opposed to nursing homes, and they fought hard for the issue, but many others seemed to be so focused on New York City and its suburbs that they didn't even know that the upstate minimum wage is only \$12.50 an hour. In the end, with our style of governing, where three downstate residents decide the direction of programs and services, we lost the battle. Governor Cuomo and Speaker Heastie both did not

support raising wages for this essential profession, though many of their own rank and file, as well as their constituents, did.

How do we prove that homecare is more desirable and better? We've shown the cost is less; you'd have thought that would do the trick. We've seen that people die at a much higher rate in nursing facilities when a pandemic hits. The message is so loud and clear that even my dog probably gets it, so why don't they?

Ah, I can only guess that it all gets back to those donations they get from nursing homes. The Governor and many legislators receive such campaign support, making their work on the issues mentioned here highly conflicted at best.

I'm saddened for the family of Barbara Jarvis, when all that could be said about her senseless and unnecessary death is "No harm done."

Budget Outcomes: Homecare Shafted Again

Despite a major influx of money to the state, the final New York State 2021-22 budget continues the Cuomo Administration's austerity approach to supports and services for people with disabilities.

The state was awarded around \$12.7 billion in "direct aid" from Joe Biden's American Rescue Act. Billions more—some reports say as much as \$100 billion total—will potentially come into NY from that law for special purposes such as COVID-related support for schools and a higher federal matching share of Medicaid for home and community based services. This last item is quite slippery though; see below.

The legislature also enacted state income tax increases for the wealthiest New Yorkers: The marginal tax rate for incomes between \$1 million and \$5 million was increased from 8.82% to 9.65%. Two new tax brackets were added: income between \$5 million and \$25 million is taxed at 10.3%, and the rate above \$25 million will be 10.9%. "Marginal tax rate" means that those percentages only apply to the portion of income that falls into those brackets, so if, for example, you make \$30 million, various portions of the first \$999,999 are taxed at rates lower than 9.65%, the next \$5 million at 9.65%, then the next \$20 million at 10.3%, and the final \$5 million at 10.9%. These increases are projected to bring in another \$4 billion to the state treasury.

There is also a new sports gambling program that is expected to raise another \$500 million.

You may remember that the state had borrowed at least \$4.5 billion to cover anticipated tax revenue losses during the pandemic (*AccessAbility* Winter 2020-21). Of course, that needs to be paid back. That would eat up the entire \$4.5 billion in new revenue from those tax increases and sports betting, which may be what the budget negotiators were thinking—except that it doesn't appear that the state lost anywhere near that much in actual income and sales tax receipts, so much of it should be repayable without touching the new money.

Whether that turns out to be true or not, time will tell. In the meantime, Cuomo's precious "Global Cap" on Medicaid spending was retained. The cap is equal to the ten-year rolling average of the medical portion of the national Consumer Price Index. It is thus not a fixed number, but the ten-year average means it does not fairly represent the actual increase in the cost of medical services from year to year. It also completely ignores the annual increase in the number of people who use Medicaid services—growth that is inevitable and unstoppable due to the aging of the population, and exacerbated by economic downturns when people who lose their jobs become eligible for Medicaid. And the way it's implemented is fundamentally unfair to poor people of color, seniors, and people with non-developmental disabilities. It's exacerbating the problem that poor nondisabled people have always had with finding medical providers who accept Medicaid in NY, and it's

the main reason why personal care services are being squeezed year after year. There was a remarkably strong push among many state legislators, urged on by some very knowledgeable advocates, to put an end to the cap this year, and that effort did have some effect. Cuomo wanted to extend it for two years; in the end he got one year.

Cuomo's proposed 1% "across the board" cut in Medicaid rates was rejected this year. However, the 1.5% cut imposed last year remains in effect. Again, "across the board" is not a factual description of the cut. It doesn't apply to Medicaid waiver services except those subject to managed care, for example, and it does apply to the non-managed versions of so-called "state plan" community based long-term care services, such as personal care. This has resulted in pressure on managed care plans to reduce the rates paid for those services, with the primary effect being to drive down wages at a time when low wages are creating a serious shortage of workers in most regions of the state.

To address that shortage a large coalition of advocates organized FairPay4HomeCare, a campaign to raise homecare worker wages to 150% of the minimum wage. "Wow," you may say, "that seems like a lot!" Not really. In upstate NY the minimum wage for homecare workers is \$12.50/hour, so 150% of that would be \$18.75, or \$39,000 a year if the person worked 40 hours a week. Upstate homecare workers rarely work a full week—not because there isn't a need for it, but be-

cause the realities of scheduling and travel time between multiple clients make it difficult to achieve. The minimum wage for fast-food workers upstate is \$15/hour, and homecare is a much more difficult job in many respects than flipping burgers. Many homecare workers are single mothers, for whom child care is a big expense. Plus, homecare services (Personal Care and CDPA) have to compete for workers with OPWDD's Community Habilitation program, which pays significantly higher wages, especially for unionized state employees.

Again, there was significant support among rank-and-file legislators for increasing wages for homecare workers, but Cuomo and Assembly Speaker Carl Heastie (D-Bronx) were not enthused. Instead, Cuomo's proposal to cut the state's supplemental "recruitment and retention" program for direct-service workers by 25% was not passed (though the previous year's 50% cut to that program remains in effect), and \$5.1 million was allocated to (partially) cover the cost of the latest annual increase in the state minimum wage.

There is also a 1% cost-of-living increase for workers in programs operated or funded by OPWDD, OMH, and OASAS. That's not much to begin with, and the restrictions on its allocation will result in average hourly wage increases of mere pennies for many such workers.

There are some additional small increases in the budget: For example, funding for mental health Crisis Intervention Teams was increased by \$1 million statewide. This will be used to roll out the program in additional locations, but the program will continue to refuse to serve people with co-occurring developmental disabilities, even though 40% of people with DD also have mental health diagnoses. The mental health Crisis Stabilization Centers program was enacted. The good news about this program is that anyone who is experiencing a mental health crisis can simply walk into these centers, or be referred to them by almost anyone, including law enforcement or family members, and allegedly get pretty quick service from a range of experts as well as peer support. People can stay in these centers while those ex-

perts put together ongoing supports to enable them to have safe and secure housing and access to continuing services. The bad news is that some of these places will be located in un-used nursing facility space, where there will be a high risk of infectious disease, including COVID-19. It's also not clear that they will serve people with DD. We should note that failure of some CPEP ("psychiatric emergency room") programs (Binghamton General Hospital, are you listening?) to adequately serve people with DD is not a problem with the CPEP concept or its actual rules; it's entirely about the lack of adequate training and funding, and competent oversight for the program in specific localities. We don't know if there are any plans to add a Crisis Stabilization Center in the Greater Binghamton Region, but doing so would be a good idea.

The 45+ Centers for Independent Living (CILs) like STIC got a total funding increase in our general operating contracts of \$500,000, on top of the half-million they got last year. So over two years STIC got less than \$20,000, which doesn't even cover the increased cost of medical insurance during those years for the employees that contract pays for.

The usual attempt to put an end to "prescriber prevails" in the Medicaid prescription drug benefit was again beaten back.

The Traumatic Brain Injury and Nursing Home Transition and Diversion Medicaid waivers are carved out of managed care for another four years, a very good thing.

Then there are some more questionable measures: people in New York's "Basic Plan" health insurance program (typically nondisabled people whose incomes are too high to qualify for ordinary Medicaid) no longer have to pay a premium for coverage, and the plan now covers dental and vision treatment. And there's \$2.1 billion for a new "excluded workers fund," which will make cash payments to undocumented workers, among others, who can show they lost income due to the pandemic. The Basic Plan improvements are a good thing, but we question why that was considered a priority when existing services, including homecare, are still not adequately funded. And we frankly ques-

tion the appropriateness of making cash payments to undocumented workers at all. Apparently, a lot of them are homecare workers (19,800, according to the Center for Migration Studies, as reported by the CityLimits.org website), but it is illegal in New York for anyone to hire an immigrant who can't produce a green card or other proof of documented status for any kind of job. We don't know who is hiring them, but at STIC we would never do so and we would never permit a CDPA participant to do so.

Now let's get to all of that federal aid that supposedly could have kept the state from having to make any cuts, and might even have paid for increased wages for homecare workers. In many cases the state has to show that the money will be spent to address problems specifically caused by the COVID-19 pandemic. But even when that's not the case, as with some of the options for enhancing Medicaid home and community-based services (HCBS), the problem is that it's temporary, and some of it is only available for the current fiscal year. There are strict and complex regulations on how the HCBS money can be used; it's not clear that much of it will be of practical benefit. Even if it is, you can't expand services or raise wages with temporary money if you don't have a way to keep paying for those increases in later years. We think there's still an argument that the income tax increases passed this year are the solution to that problem, but we would bet that Cuomo is hoping to cancel those increases during his 2022 election campaign. It is a sad fact that a lot of voters love tax cuts, even when they don't benefit them personally at all.

Sham Nursing Facility Reforms

As of May 23, 2021, 52,591 New Yorkers have died from COVID-19. On April 28, 2021, the *New York Times* reported that over 15,500 of those people had been nursing facility residents. That's about 30%, but the difference in reporting dates is probably depressing the percentage a bit.

As we said in our editorial, the sheer numbers weren't enough to spark legislative

action; it took a public scandal over Governor Cuomo's cover-up of the numbers that erupted in February 2021, allegedly motivated by concern over sales of his self-promoting book, published in October 2020, to do that. Several so-called "nursing home reform" measures were proposed and enacted this spring as part of the annual budget process. However, none of these measures is likely to have a significant effect on the behavior of nursing facility operators.

Repeal of Liability Limitation

During the 2020 budget process, our legislators approved, and the Governor signed, legislation that sharply limited nursing facilities' and hospitals' legal liability for damages for anything unpleasant that happened in those places during the COVID-19 "emergency." It didn't just apply to people with that disease or to services or treatment provided to them; it applied to everything and everybody in every facility that worked with as few as one COVID-19 patient. Liability was limited, essentially, to deliberate, intentional acts of harm or neglect—things that would also likely be prosecutable crimes. This law was cited by some as the inspiration for then US Senate Majority Leader Mitch McConnell's (ultimately unsuccessful) demand for a blanket waiver of liability in return for agreeing to more COVID relief funding later that year.

There was an uproar about this almost immediately in New York, and some legislators claimed they didn't know it was in the budget bill they passed; they said it was inserted "just hours before" passage by the Governor's staff. However, the Greater New York Hospital Association (GNYHA), a lobbying group that represents both hospitals and nursing facilities and which has given some \$2 million to Cuomo's campaigns, issued a press release soon after the budget passed which claimed the organization "drafted and aggressively advocated" for the bill. The stench this raised over Albany caused the legislature to roll back the provisions applying to non-COVID patients later that summer. But the rest of the law remained in place until this spring (although the GNYHA press release mysteriously disappeared from the organization's website).

Then, on March 18 of this year, *The City*, a digital news website that covers New York City, reported that the FBI was interviewing Cuomo's aides and other state officials about the provision, trying to find out "how it got in the state budget." The story was picked up by *The Guardian* the following day, and, sure enough, the rest of the law was repealed as part of this year's state budget. Cuomo by this time had no political cover left, so he signed the repeal bill.

This sounds like a big deal, but it just restored matters to where they were before the pandemic, a time during which some 20 lawsuits for negligence couldn't get the Van Duyn nursing facility in Syracuse closed (see page 1).

Reduction of Cuomo's Emergency Powers

All New York governors have had the power to suspend state laws during an emergency. What's different in the pandemic is that the legislature gave Cuomo the power to essentially make new laws by decree. That's why he was able to issue the "mask mandate," close down businesses, and require nursing facilities to admit COVID-positive people while forbidding them to test those people for the disease.

When things went sour with the nursing facilities, many legislators began calling for Cuomo to be stripped of these new powers. Finally, in early March of this year, a bill was passed, and Cuomo signed it. Legislators claimed this was a "repeal" of Cuomo's emergency powers, but it's important to read the fine print.

First, only the governor's power to issue new mandates by decree was removed; he can still suspend existing state law for emergency reasons. Second, if the legislature had done nothing at all on this, all of Cuomo's new powers and mandates would have expired on April 30. In fact, while the legislature took away his power to issue new mandates, they allowed him to continue to extend or modify his existing mandates for as long as the federal COVID emergency continues. Those Cuomo wants to keep must be renewed every 30 days, with the legislature allowed 5 days

after each extension to give "feedback"—which Cuomo can ignore.

Nursing Facility Direct Service Funding Mandates

As part of the budget agreement, nursing facilities in New York will be required to spend at least 70% of their revenue on "direct resident care," including 40% for "direct resident-facing staffing," beginning in January 2022.

Nursing facilities often claim they don't get enough money from Medicaid or Medicare to cover their costs. Meanwhile, nursing facility critics often point out that for-profit nursing facility operators often divert revenue into shell corporations and other accounting dodges in order to pay themselves huge salaries and provide themselves with valuable perks. These facts would seem to be contradictory. Why would that be?

Nursing facilities across the United States are routinely cited for inadequate staffing—a factor that correlates strongly with high COVID death rates, according to the NYS Attorney General. At the same time, most of them pay their most numerous, least-skilled tier of aides little more than minimum wage, which makes recruiting staff more difficult. Not all nursing facilities are run by for-profit companies, but when they are, the companies seem to be quite healthy and make plenty of profits. In New York State, about half of all nursing facility residents are short-termers, in for post-acute rehabilitation, mostly paid for by private health insurance or Medicare, both of which tend to pay much higher rates than Medicaid. And nursing homes are allowed to keep short-stay residents, and bill them, up to and through the last possible day of the scheduled stay, whether they need the services or not, and they do it routinely without even blushing.

So how effective will this new law be at forcing nursing facilities to beef up direct care?

Well, first of all, the law exempts facilities—or wings thereof—that serve people with the highest level of needs: "medically fragile children, people with HIV/AIDS, persons requiring behavioral in-

tervention or neurodegenerative services, or other specialized populations that the Department [of Health] may designate.” “Neurodegenerative” conditions include Alzheimer’s and other forms of dementia, which is one of the most common diagnoses among long-term nursing facility residents. Facilities that serve these groups are paid the highest Medicaid rates precisely because their residents need more care; those high rates would also seem to be the most fruitful funding source for increasing direct services, would they not?

“Direct resident care” includes stuff like laundry, housekeeping, kitchen, and building maintenance, as well as things like physical therapy, “adult day health care,” and “nursing administration.” This last item can be misleading. “Nurse administrators” in nursing facilities have very little to do with direct resident care. Most of them are either supervisors or they are involved in documenting and billing for services.

Direct resident-facing staffing is anything else done by someone with “nurse” in their title, including Registered Nurses, Licensed Practical Nurses, and Nurse Aides, whether certified or not.

It’s been claimed that the bill also limits nursing facility “profits” to 5%. That’s not actually true. What the law says is that if a facility’s operating revenues exceed its total operating and non-operating expenses by more than 5%, it must pay the amount in excess of 5% back to the state. “Operating revenues” means the money it gets as payment for providing services. It doesn’t include money it gets for capital development from the state, or any other money, such as dividends or profits from investment. And as far as we can tell, it doesn’t prevent the facilities from using shell corporations or other legal fictions to hide revenue.

Our bet is that this law will be found to affect only a minority of nursing facility “beds”—those mostly used for temporary admissions for relatively low-needs residents.

The “Safe Staffing” Act

As mentioned in our editorial, this bill, also part of the budget agreement, requires nursing facilities to provide, on average,

3.5 daily hours of “nursing care” daily to each resident. “Nursing care” can be provided by registered or licensed practical nurses, by certified nurse aides, or by people the facility calls “nurse aides,” who are “not yet” certified. The bill takes effect in January 2022, and slightly increases the required skill ratio of actual nurse hours in 2023. This accomplishes virtually nothing because the average is already 3.4 hours per day.

The bill does require the Department of Health (DOH) to establish “penalties” for failure to comply, but what “penalty” means is left up to that agency, which might impose no penalty if there are “extraordinary circumstances facing the facility, including, but not limited to, whether the facility has suffered through a natural disaster or other catastrophic event, an officially declared national emergency, or state or municipal emergency ... which has been initially declared subsequent to the effective date of this section, or other such conditions or unforeseen circumstances as determined by the commissioner.” Notice how that lets the “commissioner” (of DOH) decide that an emergency that was declared before the law took effect, such as the COVID pandemic, might also be a reason to avoid issuing any penalties?

Nursing facilities can’t be held responsible for failure to comply if there is an “acute labor supply shortage within a specific region” either. The bill does say that failure to “prudently plan for” things like staff absences due to vacations or sick leave is not an excuse—but it does not address the fact that low wages tend to create “acute labor supply shortages” that miraculously disappear when better wages are offered.

All of these things are half-measures, at best. Overall, the legislature could have done so much more for the quality of life of people who end up in nursing facilities if they’d just agreed to make use of the bounty they’ve received from this year’s income tax increase to support higher wages for homecare workers (see page 3). It kind of sets things into perspective, doesn’t it? Typically the three reasons homecare gets short shrift in New York State are: 1) Cost. 2) Nursing facility lobbyists don’t like it because it competes with them. 3) Certain influential unions don’t like it because they’ve had difficulty organizing homecare workers. If cost is not an issue—and it wasn’t, this year—then that makes it pretty clear who was driving the boat in Albany this spring.

Was DOH’s CDPA Selection Process Merely Incompetent, or was It Biased?

As most of you have heard by now, STIC did not receive approval from the Department of Health (DOH) for our application to remain a provider of Fiscal Intermediary (FI) services for the Consumer Directed Personal Assistance program (CDPA).

We want to emphasize that nothing is changing right now, and this battle is not over.

Before DOH issued its “Request for Offers,” there were over 600 FI providers in the state. 373 organizations applied in this competition. DOH only approved 68 applicants. Among those approved were or-

ganizations that don’t seem to actually exist, and organizations that were the subject of investigations for Medicaid or other forms of financial fraud.

STIC, which has one of the oldest CDPA programs in the state, was not approved because our application was, allegedly, mediocre; we were rated 134 out of 373. The application required us to respond to a series of requests for descriptions of our operations. Each response was rated on a scale of 1 to 5. The only 5’s we got were on questions where the written instructions on the rating forms specifically told

raters to score us a 5. STIC has been a successful CDPA provider since 1999. The state audits CDPA programs frequently; our audits are routinely completely clean, without even minor mistakes. But our description of our “plan to maintain financial records that facilitate fiscal monitoring and audits” scored a 2.7, and our “plan to maintain written fiscal procedures that comply with generally accepted accounting principles and Medicaid rules and regulations, including internal control procedures” only got a 3. Our organizational chart got a 3. Perhaps it wasn’t graphically interesting enough? Despite our extremely high rate of consumer satisfaction, our description of how we “will use any creative approaches in delivering high quality FI services that best meet the needs of consumers” only scored 3. STIC is an Independent Living Center (ILC); we follow a peer approach in everything we do to the greatest extent possible, and we provide a lot of information, training and advice to CDPA participants to help them understand and carry out their responsibilities as employers of the people who serve them. Guess what we got on our description of how we provide “high quality FI services that best meet the needs of consumers including peer supports, peer mentoring and counseling for consumers and their families to assist in navigating their employer responsibilities”? You guessed it. 3.

Only one of the awardees for Broome County has an actual presence in the county. Most of the awardees are headquartered in New York City or surrounding communities.

The people who reviewed these applications were given almost no instructions on how to review them, aside from the rating forms—at least, no instructions that DOH will admit to. We can’t claim we were singled out because of our advocacy, because the very active and militant Center for Disability Rights in Rochester (CDR) got an award. Independent Living Centers, many of which have CDPA programs, and were among the earliest such programs in the state, seem to have done poorly overall; although CDR is such a Center, only four Centers got awards.

There was so much uproar over these awards that the NYS legislature negotiated provisions in the state budget this spring to expand the list. The new language requires DOH to make at least one award to an organization that is located in any county with a population of 200,000 or more. That could bring a lot more ILCs back in, but Broome County, where STIC is located, has a population of about 188,000. This provision seemed intended to benefit the Centers that had active CDPA programs, so our advocates pointed out to its authors that this language would exclude STIC. For some reason that has never been explained, they refused to lower the number to something more inclusive, such as 175,000. They also added language requiring DOH to make at least one award to a CDPA program that has experience in providing a range of services to people with developmental disabilities. STIC qualifies for that, and we’ve applied for it, but other CDPA programs also meet that qualification, so if DOH and some legislators are determined to exclude us for some hidden reason, this language certainly will not prevent it.

If we don’t get an award on the DD services basis, we still have other avenues to pursue. DOH’s award process violated several provisions of New York State contracting and procurement law, and the Comptroller has yet to rule on our challenge—and those of many other programs that were denied awards—on that basis. There are also options we could pursue in the courts if the Comptroller does not help us. We don’t intend to give up.

Civil Rights? Show Me the Money

For decades, disability rights advocates have decried the “institutional bias” in Medicaid and sought ways to remove it. Their efforts have generally followed one of two approaches: increasing financial incentives for states to voluntarily provide integrated “community based” services, and establishing provision of such services as a federal civil right. So far, neither route has been successful, and the institutional bias remains.

We’ve put scare quotes around two terms here, so let’s define them:

“Institutional bias” means that federal Medicaid law requires state Medicaid programs to pay for nursing facility placement, but does not require states to provide an adequate level of integrated services and supports to ensure that all people with disabilities can reliably and safely remain in their own homes and participate fully in community life. Medicaid does require states to offer “home health services,” but this service is similar to *Medicare* Home Health Services, in that it cannot be provided 24/7 and is not available to people who regularly leave their homes to work or participate in integrated community activities. More integrated and flexible categories of homecare, such as Personal Care (which includes CDPA), are optional for states; they can choose to provide it in limited amounts, or not at all. Therefore state Medicaid plans have often given short shrift to truly integrated long-term services and supports, sometimes claiming the need to save money, and state planners regard the guaranteed availability of nursing facilities as a “back up plan” that justifies their failure to do more.

History also plays a role in this. When Medicaid was created at the same time as Medicare, in the mid-1960s, virtually no one thought that anybody other than old people would need federally-guaranteed long-term care; people with disabilities were largely invisible to the politicians and medical bureaucrats who cooked up these programs. A few years later advocates for people with developmental disabilities got into the mix and the “intermediate care facility” (ICF) was born. “ICF” is a Medicaid program; if your residential setting, whether large like a developmental center or small like a group “home,” complies with its rules, it can get ICF funding. However, unlike nursing facilities, Medicaid state plans are not required to support ICFs. And people with mental health disabilities have never had the kind of successful advocacy that seniors and people with DD have benefited from, so programs for that group have not been supported by Medicaid much at all. Psychiatric centers have largely been 100% state funded,

and, of course, cannot be mandated by Medicaid. So “institutional bias” is not just an artifact of Medicaid law and regulations; it comes from the early thinking of the people who first created long-term care services, going all the way back to Dorothea Dix. It just never occurred to them to do it any other way. However, when people talk about *Medicaid’s* institutional bias, they are talking about the federal rules for that program, and the money that follows them.

“Community based” is a term of art that doesn’t mean what a lot of us think it should mean. It also comes out of the history of Medicaid and Medicare long-term care. Way back in the Reagan Administration, a child named Katie Beckett was kept in a hospital because there was no effective way for her family to care for her at home. She got encephalitis at the age of four months, and experienced brain damage and partial paralysis. She required a ventilator and skilled “nursing” care (yes, more scare quotes; in those days only nurses were allowed to do a lot of things that home health aides and personal care assistants can do today). As long as she stayed in the hospital, she qualified for Medicaid despite her parents’ income, and Medicaid was paying about \$12,000 a month—in 1978 dollars, which is roughly \$50,000 today—to keep her there. Medicaid home health care, limited though it was, would have been much less expensive, but if Katie came home she would

There is now an unprecedented effort to directly tackle Medicaid’s institutional bias by making a new kind of HCBS program mandatory for all states

no longer be eligible for Medicaid due to her parents’ income, and her parents, while not poor, certainly could not afford to pay for the amount of homecare she needed. This became a big public issue and resulted in the first Medicaid waiver program—the so-called “Katie Beckett Waiver”—which allows the income of the families of children with significant disabilities to be waived when determining Medicaid eligibility for those children. This was also the first “Home and Community Based Services” (HCBS)

waiver. It was granted on a case-by-case basis for a long time, but in 1991 Congress gave states the option of creating programs that waived income eligibility, or other Medicaid rules requiring services to be offered statewide, or to all people who qualified for Medicaid, in order to serve people with various disabilities. The rules for these waivers defined “community based” as any place that was not a hospital, a nursing facility, an ICF, or an “institution for mental disease.” This initially gave rise to a sort of “Gulag Archipelago” of small(ish) group “homes” and “day programs” that were just as segregated and restrictive as any of those other places, but they met (and still meet) the definition of “community based.” “Assisted Living Programs” (segregated residential settings for people with disabilities—typically seniors—who need fewer than four hours of unskilled support services a day) are also considered “community based,” even though, when funded by Medicaid, they are physically akin to nursing facilities, but with fewer safety rules and even less staffing.

There are other problems with HCBS waivers: states can set them up with a limited number of “slots” for participants, resulting in long waiting lists, or they can only offer them to people with certain types of disabilities.

Over the years advocates have hung around Congress, incessantly pointing out the flaws in the HCBS program, and the result has been a

series of “innovations” that offer additional federal funds to encourage, but not require, states to expand the availability of the services. Examples include “Money Follows the Person” and “Community First Choice,” as well as various pots of money that were included in several of the federal pandemic relief bills. This has had limited success in either increasing the availability of fully integrated services and supports in people’s own homes as opposed to group “homes,” or in reducing waiting lists in states that have them.

On a parallel track with this process, advocates have also called for establishing the provision of fully integrated long term services and supports as a federal civil right for people with disabilities. This has had even less success than the fiscal incentive approach, since it’s all-or-nothing: Either it’s a civil right available to everyone, or it’s not, and nothing at all changes. While the latest effort, the Disability Integration Act (DIA), initially appeared to have some bipartisan support after its introduction in 2016, it never got past the committee stage, and that support seems largely to have evaporated in 2021. (You can read the Senate’s version here, from two years ago: <https://www.congress.gov/bill/116th-congress/senate-bill/117/text>. It’s being revised, but the revisions haven’t been made public yet.)

On the other hand, there is now an unprecedented effort to directly tackle Medicaid’s institutional bias by making a new kind of HCBS program mandatory for all states: The HCBS Access Act (HCB-SAA). In early March 2021, a so-called “discussion draft” was issued by three Democratic Senators and one Democratic Congressperson. Comments were requested, and many were submitted, including by STIC. (You can read the draft we saw here: https://debbiedingell.house.gov/uploadedfiles/hcbs_access_act.pdf)

Meanwhile, a brouhaha was underway in the national disability rights community over how DIA advocacy was being handled, and it got worse when people appeared to be squaring off to support that bill or HCB-SAA. The truth is, while both bills contain some good ideas, they are also both flawed, and while DIA is probably dead, it’s not at all clear that HCB-SAA could pass the closely-divided Congress.

The issues dividing DIA advocates seem to be at least as much about personality conflicts and longstanding grudges as about the substance of the bill or advocacy strategies. Lately they have taken to using “woke” language to call each other out—but it’s still more personal than political. Sadly, the disability rights community has a decades-long history of engaging in this kind of petty feuding. Only when we were united have we ever succeeded

in getting anything important done—as we were during the fight to get Rehabilitation Act regulations released in the late 1970s, and during the campaign to pass the Americans with Disabilities Act (the story is told as well as it ever has been by the documentary film *Crip Camp*, airing on Netflix).

What we really need is both approaches, working together. And we need more inclusive visions for both. In other words, we need something that most people will feel is worth uniting around.

HCBSAA, as originally written, is far too limited. Although it requires a long list of services to be provided, those services are rigidly defined, and either leave out, or don't clearly include, important things like assistance with medication administration and care of children or pets. Its functional eligibility requirements are also too narrow: only people who need assistance with at least two types of activities—whether Activities of Daily Living (ADLs) such as bathing, eating, or using the toilet, or Instrumental Activities of Daily Living (IADLs) such as cooking or cleaning—are covered. In New York State, people with fewer needs than that are admitted to nursing facilities every day. To defeat institutional bias, anybody and everybody who is eligible for a nursing facility must be equally eligible for HCBS services. The bill also relies on the old-school Medicaid definition of “community-based,” meaning it covers group “homes” and assisted living facilities, and thus is not a clear alternative to institutionalization. Although it requires person centered planning, its limited definition of that concept does not maximize the role of the person with the disability in controlling the planning process, and it does not clearly state that people cannot be forced to rely on unpaid supports. Although it contains language requiring states to show how they can address the universal shortage of homecare workers when developing their implementation plans, it doesn't contain any enforcement mechanisms. Nursing facilities have staff shortages too—much in the news lately—but they are always open, and someone is always

there to provide some semblance of minimum service. Homecare doesn't work that way; if you can't recruit a worker, or s/he doesn't show up, you're up the creek, and potentially drowning in it. Homecare staffing has to be rock-solid reliable in a way that nursing facility staffing, sadly, doesn't. If the bill doesn't include penalties for failure to ensure adequate availability of the service, then even though the service is “mandatory” in the same way that nursing facilities are, it won't be provided with the same reliability. And that is crucial.

DIA, on the other hand, doesn't ensure that any services will be provided to anyone at all; it only expresses a hope that they will be, in the same way that other civil rights laws do not guarantee that people of color and women will actually have better lives. It has a more inclusive list of services, but it still relies on old-school concepts of “institution” and “community based,” which means states could comply by continuing to emphasize the use of group “homes,” special “day programs,” and assisted living centers, without significantly expanding *real* integrated services and supports. It does contain strict enforcement provisions, including punitive damages for people who win lawsuits. But people of color have been winning civil rights lawsuits and collecting damages for decades—and overall they are still experiencing lower incomes and relatively poorer health compared to white people, and frequent mistreatment. The US Supreme Court declared that “separate is not equal” in public education in 1954—a major civil rights victory—and yet most public schools in the United States are still segregated by race 67 years later. The Americans with Disabilities Act, passed in 1990, is a civil rights law that prohibits discrimination against people with disabilities in employment, but the unemployment rate among disabled

people is still where it was 31 years ago. From time to time the federal government has been interested in spending money to assist disadvantaged minorities—and the extent to which it does so has played a big role in how much improvement they gain. Without a mandate to spend money, DIA alone cannot bring about real change. DIA only acts on state and local governments; it does not regulate the Medicaid program or federal spending. But the money to make this work has to be federal, because states have budgetary sovereignty; they cannot be compelled by the feds to raise taxes, borrow, or spend money they

don't have and choose not to collect. HCB-SAA provides 100% of the funds for its new HCBS service out of the federal treasury; states would not need to spend any of their own money to comply.

There are good ideas in both bills, but what we really still need is a much better idea.

That idea should start with redefining “institutional setting” in

an unambiguous way that CMS cannot dilute with weak regulations. Here's the one we've suggested to the authors of both bills:

Although HCBSAA requires a long list of services to be provided, those services are rigidly defined, and either leave out, or don't clearly include, important things like assistance with medication administration and care of children or pets.

“An ‘institution’ or ‘institutional setting’ is any place or program, whether residential, employment, or ‘day program’, that groups people with disabilities together, and which is not: the individual's own home or that of their family; or a residence that is substantially controlled by the individual in all respects; or is not an ordinary, generic location in the individual's community. ‘Ordinary generic community location’ means a place in the individual's community that is not designed primarily to house, employ, provide services to, or otherwise benefit, people with disabilities.”

The DIA includes requirements for states to massively expand the availability of integrated, affordable housing that is not tied to support services. This requires most

states to spend money they don't—and never will—have, so it cannot succeed. But existing HCBS programs pay for housing for people who don't own their own homes. We suggest that, for purposes of this new HCBS program, “a residence that is substantially controlled by the individual in all respects,” which may be paid for with Medicaid funds, would include four or fewer unrelated adult residents, would not require residents to accept any services as a condition of residence, may have “house rules” only if they are set by the residents themselves, and would ensure that the residents make hiring decisions for house staff whom they directly supervise. (Adults who are adjudicated by a court to need legal guardians would have their guardians handle these matters for them as determined by the scope of guardianship.) The term “Adults” is used deliberately. Children must not live in homes other than those of their families, whether natural or foster.

This new mandatory HCBS program would only provide services in non-institutional settings as defined above, only to people who also live in such settings.

The next big new idea would be to define functional eligibility without reference to the concept of “institution” or to strict categories of needs for assistance. Here's how that would look:

An eligible person with a disability would be any person who, due to his or her disability, needs any type of ongoing assistance, including but not limited to supervision, reminders, training, physical prompting, partial or full assistance, and/or assistive technology or home modifications, to carry out at least one task in

order to ensure that s/he can live securely and maintain his/her health in his/her own home, or that of her family, or in a residence that s/he substantially controls in all respects; exercise maximum personal autonomy; and participate to the full extent of his or her wishes in employment, social activity, commerce, parenting and/or caring for family members or pets, recreation, and any other type of activity at home or in any generic community setting. “Ongoing assistance” would mean any form of assistance whatsoever, whether the level of the assistance needed changes over time or remains constant.

The third big idea would be to expand on previous concepts of enforcement. Failure by the federal, state or local government, as applicable, to provide or adequately pay for all needed HCBS services as defined above, including backup services, in a prompt manner that ensures fully reliable service provision, would violate the service recipient's civil rights. Failure to notify all eligible individuals of the availability of these services would also be a civil rights violation. Individuals may sue individually, or as a class, for injunctive relief, compensatory, and punitive damages for these violations. Also, failure by a state or local government that participates in the Medicaid program to do any of those things as long as federal funds are available to pay for them would be a violation of federal law that must be investigated by federal authorities and prosecuted in either civil or criminal court, with fines or other suitable penalties available. This would put an end to the problem of staffing shortages, as states would have to provide wages and benefits adequate to recruit enough workers, and would get all the federal money they need to do so, and if they still perversely insisted on not paying enough, they would be punished.

Could any of these new ideas pass Congress? Probably not today. Those opposed to both bills tend to be operators of segregated congregate programs and some unions that have not succeeded in organizing

homecare workers. They claim that both bills would result in closure of existing institutional settings. They're probably right to some extent, but not because either bill outlaws or defunds those programs. They simply level the competitive playing field for fully integrated alternatives. Our new ideas would do the same. Progressives would have to win more seats in both houses to overcome the well-funded and highly organized opposition to those ideas. But that would probably also be necessary to pass either the HCBSAA or DIA as written today. And disability activists would have to present a united front to overcome what can only be described as the strong distaste that some members of Congress have developed for their squabbling.

There are rumors that Congressional Democrats will tack the HCBSAA onto one of Biden's recently-proposed “infrastructure” bills and ram it through both houses using the Democrats-only “reconciliation” mechanism, but we haven't seen any evidence that this is happening so far.

We at STIC support both of those bills, and we would also support better versions of both, along the lines described here, with more enthusiasm.

We will never get everything we want, all at once. Disability rights activists have limited resources and limited time. Getting anything passed will require an enormous, sustained, investment of both. Remember, people occupied the San Francisco office of the federal Department of Health, Education and Welfare for 28 days—at times involving up to 200 people living, eating, and sleeping there—as part of the campaign to get the Rehab Act regulations issued in 1977, and there was a lot more arduous and risky activity leading up to, during, and following that event before the battle was won. That sort of thing is what it takes to make real change. It's up to us to decide what ideas are really worth fighting for now—what fights we have a realistic chance to win and what should be set aside for another day. If we can't pull it together to do that, then we can't win anything at all.





Halts on HALT Act Halted

Prison reform activists have worked for many years to end the use of solitary confinement in New York State. Solitary confinement for long periods of time is now well-understood to damage people's mental health, and periods longer than 15 days are considered by the United Nations to be a form of torture.

This spring, after nearly half a decade of advocacy and argument, the New York State legislature passed, and Governor Cuomo signed, the Humane Alternatives to Long-Term (HALT) Solitary Confinement Act. The law purports to "ban" the use of solitary confinement for periods longer than 15 days, or more than 20 days within any 60-day period, but that is not strictly true. There are various loopholes that permit prison officials to extend solitary confinement stays beyond 15 days, though it is hoped that the special requirements for this will be so difficult to meet as to discourage it from happening frequently.

Some of the bill's terms are confusing. We'll try to sort them out:

In New York state prisons, cells used for solitary confinement are called "special housing units," or SHUs. They are very small single-person cells. Sometimes the term "keeplock" is used for the same thing, but in some prisons or county jails, "keeplock" can mean confining a person to his or her usual cell, sometimes to provide so-called "protective custody" because other prisoners may try to harm them, not because they have committed any infractions of the rules themselves. In both cases, the prisoner is typically only released from the cell for one hour out of 24, for "recreation." It is this kind of confinement that is considered harmful.

HALT adds the concept of "segregated confinement," which includes SHUs or

keeplock, as well as "residential rehabilitation units."

HALT defines a "secure residential rehabilitation unit" (RRU) as a segregated cell in a separate area of a prison that provides at least six daily hours of therapy or other programs, plus one hour of recreation, outside the cell.

HALT has been said to absolutely forbid the placement of "special populations" of prisoners in any form of segregated confinement, but that's not really true either.

"Special populations" include anyone under the age of 22 or over the age of 54, anyone with a physical, mental or "medical" disability, pregnant women or new mothers whose babies are in prison with them, and anyone who is "perceived to be" LGBTQ. However, members of this group can be kept in keeplock for up to 48 hours before a disciplinary hearing has to be held to consider their behavior and its consequences. They can then be moved to an RRU, but there are additional requirements to place people with mental health disabilities in special mental health treatment units.

People determined by a hearing to have committed serious, but still relatively minor rules infractions can be placed in keeplock for no more than three days per incident. Only those found to have committed or threatened to commit violent acts, or to have procured weapons, started a riot, or engaged in other really bad behavior, can be held in keeplock for 15 consecutive days. If they are to be in

segregated confinement for longer than that, they must be moved to an RRU.

After nearly half a decade of advocacy and argument, the NY State legislature passed, and Governor Cuomo signed, the HALT Solitary Confinement Act.

Historically, solitary confinement has been used to punish prisoners for trivial misbehaviors such as wearing a hat when told not to, or having reading material in their cells, or for having personality conflicts with guards. The punishment was sometimes supplemented by "special diets" (dry tasteless

loaves of a vegetable bread-like substance), or withholding of bedding or clothing. The new law forbids this sort of thing and the use of keeplock for protective custody.

This is certainly an improvement over previous practices in New York's prisons and jails, though perhaps not as big an improvement as some of the law's advocates claim. Several years ago legislation required some reforms along these lines in the state, though they were not fully implemented and prison officials tended to try to work around them. The HALT act makes such work-arounds harder but will not prevent them if officials are determined to minimize their compliance.



courts watch

***Gil v Winn-Dixie Stores, Inc.*: Dixie Wins, Judicial Objectivity Loses**

This case dates back to 2016, when Juan Carlos Gil, a blind man, sued the Winn-Dixie supermarket chain for violating the Americans with Disabilities Act (ADA) because its website was incompatible with the computer screen-reading software he used. At that time the website did not provide online shopping; its only features were an online prescription-renewal tool, a tool to electronically link coupons to a customer discount card, and a store locator. A federal district court judge ruled in favor of Gil and ordered the chain to make its website accessible to blind customers. Winn-Dixie appealed to the Eleventh Circuit Court of Appeals. That court got around to issuing a 3-judge panel decision on April 7, 2021. (The website has many more features today; in fact, it may now work better with screen readers—which also work better now than they did five years ago—but the appeals court could only consider the matter as it stood when Gil first filed his suit.) The appeals judges ruled against Gil, 2 to 1.

The ADA prohibits discrimination on the basis of disability by “places of public accommodation,” a broad category that includes not-for-profit agencies and nearly all types of private businesses with which customers interact. Much of the case law so far has found that a “place of public accommodation” has to be a physical

“place” (an issue we discussed thoroughly in *AccessAbility* Winter 2017-18, when we last reported on this case). Cases involving accessibility of websites always raise the question of whether a website is a “public accommodation” if it is not a physical “place.”

In this case the district judge determined that s/he didn’t need to answer that question, because supermarkets are physical places, and the Winn-Dixie website was a feature of a supermarket that makes the supermarket easier and more convenient to use.

The ADA says one form of illegal discrimination by public accommodations is “a failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden.”

If nondisabled people could use Winn-Dixie’s 2016 website successfully to order prescription refills or apply coupons to their discount card, and Gil could not because of his blindness, then Winn-Dixie was treating Gil differently due to his disability. That would seem to be clearly illegal, and that’s what the original district judge found. But when it comes to laws and courts, almost nothing is ever that simple.

The judge who wrote the majority opinion for the circuit court first troubled himself to consider whether the website is a public accommodation, and he said it is not because it is not a physical place. This raises the question of whether he needed to do that in order to decide the case. There’s a lot of fun geeky legalese associated with that question,

but it boils down to being a matter of opinion. The majority judges structured their decision to force consideration of the issue and give them a platform to declare, once and for all, that websites are not public accommodations. That’s probably because other circuit courts have ruled that they are, so this may eventually require the Supreme Court to resolve the dispute.

The fact remains that there’s nothing wrong with the original reasoning in the district judge’s decision. But after unnecessarily disposing of the public accommodation question, the appeals judges questioned the practicality of that ADA phrase “otherwise treated differently.” Bear in mind that there was no dispute as to whether the website could be considered an “auxiliary aid or service” (it can be), and also no claim by Winn-Dixie that fixing its website would be a fundamental alteration or even an undue burden (although they claimed, at the time, it would cost about \$250,000 to fix). The judge effectively said that we can’t really take “otherwise treated differently” literally because that could mean that even the tiniest difference in the experiences that disabled and nondisabled customers had would become grounds for a lawsuit.

You know, we really wish that wasn’t true. But it likely is. There’s been a long trend in ADA jurisprudence of foolish lawyers trying to push the law too far, with the result being that some federal judge issues a ruling that destroys some previously useful part of the law’s language.

So now we have to get into whether the harm Gil said he suffered as a result of this experience was important enough to justify his suit. Gil had no trouble using the store locator; that part of the website worked for him. He said that the online coupon redemption tool was faster than waiting to have coupons processed manually in the store. How he could know that, we can’t imagine, since he was never able to use the feature, but the district



judge found Gil credible, so nobody argued with him on that point. We can't let that pass without noting that, in general, unless a website is extremely simple, it takes blind people using screen readers a lot more time to do something useful on it than it does for sighted people. However, Gil also said that to redeem coupons he needed to sometimes have store employees read them to him, and sometimes they would get annoyed and give him a hard time. That's a much more clear-cut case of genuine significant harm, and it's one that's very familiar to people with disabilities, who frequently need to rely on people who are not their friends or family, or paid specifically to help them because of their disabilities. It's a personal, emotional experience that's probably pretty close to what people of color experience when they are treated rudely or ignored in public accommodations. Gil's other complaint was that he was concerned about privacy with regard to his prescription refills; if he had to order them in the store he never knew who might be standing nearby and would overhear him. That on the surface seems like a significant harm, especially since there are various legal protections in place for the privacy of people's medical records. However, we can't let that pass either, because there's just too much paranoia about medical privacy in the modern world. The store employee who processes the

refill *has* to know what drug it's for, and any stranger standing near enough to hear the conversation could not possibly harm Gil if s/he learned what the drug was. Unfortunately, there was nothing in the trial record as to whether customers could call the store on the phone to get a prescription refilled, but we would bet they could; it's been a very common feature of pharmacies for a long time. Doing so would have been just as private as the website tool, and probably easier and faster than trying to use a screen reader to do it—even if the screen reader ultimately worked. The relevant point is that the ADA also requires public accommodations to offer “alternate methods” to do something if removal of an access barrier (such as an inaccessible website) is not “readily achievable,” and a phone-based system has long been considered an acceptable alternative to a website in ADA case law.

We spent all this time describing and editorializing on these points because, crucially, the majority opinion made no mention of the fact that store employees mistreated Gil when they were asked to help him; we only find out about that in the dissenting judge's opinion. This is a clear indication that the majority dishonestly manipulated the facts to reach their conclusion.

So yes, it would be ridiculous to take “otherwise treated differently” completely literally; the ADA itself does not consider “alternate methods”—which in at least some sense involve different treatment—to be illegal discrimination. And also yes, the fact that Gil was sometimes mistreated by store employees was easily reason enough for the majority on the panel to have taken his complaint much more seriously than they did.

The question of whether the ADA requires websites to be accessible is extremely important, and it is sad that the Trump Administration derailed the federal Department of Justice's plans to issue regulations on the topic. Perhaps the Biden team will revive that project. But if we want the courts to make the determination, we need to bring some much more clear-cut cases of how inaccessible websites really harm people than this one.

The next step in a case where a three-judge appeals court panel issues a decision would be to request the full circuit court to reconsider the case “*en banc*.” We don't know if that's being planned. We also don't know if the Supremes have any plans to get involved, but that seems inevitable, eventually. If we hear more about this, we'll let you know.



STIC NEWS



Update on COVID

By Maria Dibble

The last 15 months have been difficult for all of us, but we are finally seeing the light at the end of the tunnel. STIC has operated continuously throughout the pandemic, mostly via phone, Zoom or other remote means (except for two weeks to evaluate our options and set new policies for employees and the agency).

Now things are beginning to move quickly, with the CDC and then Governor Cuomo

announcing that fully vaccinated people can go into most settings without wearing masks. While we've all been eagerly awaiting this day, still it has thrown many into shock, STIC being no different. We need to review all of our policies and procedures and then make decisions on how we will implement the newest changes.

What we do know is that STIC will start to bring people back into the office (most have been working from home) beginning with supervisors on July 12. We'll allow about eight people to return each week,

until all of the supervisors are once again working out of our offices.

The next phase will be to bring all of the rest of our employees back, in small groups, beginning after Labor Day, and continuing until all of us are once again working out of STIC's building. My hope is that long before the end of 2021, things will be back to normal, the normal that was taken for granted before COVID-19 invaded our world.

We welcome consumers back to STIC as well, by appointment only, to ensure that

the person the consumer wants to see is here, and to minimize any health risks.

Given the pronouncement by Governor Cuomo, which just happened yesterday as I write this update, more will likely have changed by the time you are reading this, but be assured that STIC will continue to comply with state and federal policies and procedures, and will operate with the health and safety of our employees, consumers and others with whom we have contact, upper most in our plans. Please always call ahead if you plan to come to STIC, so that we can advise you of our latest procedures and practices.

I obviously can't predict the future, so I don't know where we will be by the time the fall issue of this newsletter comes out, but I fervently hope we will all be back to the "old normal", because I don't particularly like all that the "new normal" has brought us.

I wish everyone well, and I urge those who can to get vaccinated.

Direct Pandemic-Related Help for Younger People with Disabilities

By Eileen O'Brien

The New York State Office for the Aging (NYSOFA) was awarded a discretionary grant from the federal Administration for Community Living (ACL) to support Aging and Disability Resource Centers/No Wrong Door Systems (ADRC/NWD) to prevent, prepare for, and respond to COVID-19. The purpose for this funding is to enable the NY Connects NWD system to respond to the emergent and critical needs of its target populations, including young-

er individuals with disabilities, resulting from the COVID-19 pandemic. The use of these funds is to be in association with NY Connects, a service provided in part by STIC. Service units are to be recorded as part of NY Connects ILC.

There is a grant amount of \$8,394.72 available immediately for meeting needs in the community where there may be gaps. There is no income threshold or other requirements besides otherwise unmet needs. Assistance will be available in the form of gift cards, gas cards or direct purchase of needed item for clients (only for shut-in's or no travel supports, please). These funds can be accessed for caregiver supports as well as utility/rent assistance. Other examples may include: needed clothing (shoes, boots, coats), items not covered by SNAP (paper goods, cleaners, personal hygiene, etc.). The cap is \$100, although higher amounts can be submitted for approval through RCIL. ***There will be no direct cash payments for any reason.***

I do ask, as is always the policy, to be certain there are no other avenues to meet client needs before sending them along to me. Use your judgment for client need when making referrals and I will do all I can to help. ***They MUST be willing to provide basic demographics for tracking purposes.*** I also expect turn-around time to be fairly quick once a request is made; I just have to go through Fiscal at STIC to access resources. In the interest of streamlining please have callers contact me directly at: 607-724-2111 ext. 314 or email me at eileeno@stic-cil.org.

Thanks! I am looking forward to being part of the solution for those who are struggling in Broome County.

Charlie Says Goodbye

By Charlie Kramer

Dear friends and fellow travelers in the Disability Rights Movement, and my wonder-filled friends at STIC:

August 16 is my retirement date. Thirty-five years to the day I started. I can not express how grateful I am to Maria and Frank who brought me on. There were only eight of us. I will not forget the day Frank and Connie Head came to my office to check out the accessibility and talk.

This is a difficult time for me, saying goodbye to this portion of my life. It has been an honor to work with so many individuals who have taught me as we walked the road of life together. Sometimes it was short; some have been with me for many years. I am richer for it.

We have seen so many things over that span of time. The ADA, curb cuts, full access to buildings, accessible bathrooms, Interpreters for the Deaf, at events and on TV, closed captioning, the right to stay out, and get out, of institutions, and so much more. There is still more to be done to work with all disabilities and to maintain what we have accomplished together.

You may see me around until the next person steps into my role, as I will be doing supervision for our continued contracts.

Nevertheless this is a goodbye. I hold each one dear to my heart, and hope the energy and the love of this work carry on as I pass the torch.

With Sadness and Love,

Charlie





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Xscapes: The Southern Tier's Premier Escape Rooms

By Todd Fedyshyn & Maria Dibble

Craving some adventure after our long isolation due to the pandemic? Looking for an exciting family-friendly way to spend an hour or two? Do you enjoy solving puzzles, exploring for clues, uncovering secrets? STIC's Xscapes is the answer to your search for adventure and excitement. Xscapes is STIC's fundraiser that provides nonstop thrilling entertainment for all ages while raising money to support our mission of promoting independence for all people with disabilities in our community.

"Valley of the Kings" is an exotic quest to solve puzzles and find the tomb of the Egyptian pharaoh, expose the treasure and beauty to the world.

"Twilight Zone / Binghamton's Rod Serling Experience" provides players an opportunity to learn about Rod Serling's accomplishments and get inside his unusual mind, thus the Twilight Zone. Be prepared to enter dimensions of Sight, Sound, and Mind.

"Wizard and Dragon" is an exciting journey to Iceland where your team's challenge is to return the Dragon's eggs that were stolen by the evil wizard. This high-paced game will get your heart beating with the thrill of the hunt, and joy of discovery.

"Exit Protocol" is a spine-tingling adventure that requires players to access the under-cover secret spy location, download encrypted spy data and eradicate the location before it falls into the enemies' hands.

Valley of the Kings or Exit Protocol
(60-minute games)

Private bookings up to eight people cost \$200.00 (reserves the room for your group only). Non-private bookings are \$25.00 per person, minimum of four, with the understanding that the four empty slots may be filled by other players.

Twilight Zone or Wizard and Dragon
(90-minute games)

Private bookings up to eight people are \$240.00 (reserves the room for your group only). Non-private bookings are \$30.00 per person, minimum of four, with the understanding that the four empty slots may be filled by other players.

Xscapes is also proud to offer our Kids' Escape Games for ages 7-12. This one hour

of entertaining fun includes two 30-minute escape room experiences, **Immunity Quest** and **Wizard Academy**. Reserve an hour of adventure and excitement for a flat rate of \$200.00 for up to 12 kids and 2 adults.

To book an escape room or for other information, please visit our website: www.xscapes-stic.com. Or call: (607) 760-3322

Please also check our website for COVID Protocols.

We promise that you will have an enjoyable time in a safe and clean environment, and be challenged by our unique escape rooms, while supporting STIC's mission and services.





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

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

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

THANK YOU!

Southern Tier Independence Center

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