

# AccessAbility

Winter 2021-22  
Number 145



We are in the midst of our holiday season, and there is so much to be thankful for, but sometimes we tend to get so bogged down by the minutia of life (home or at work) that we let ourselves be buried by those things instead of rejoicing at another year lived and another year of successes as well.

This time of COVID-19 has weighed upon all of us in different, but equally stressful ways over the last almost two years, so much so that we've forgotten how to celebrate our joys.

The smell of a Christmas tree; the sparkle of light from a menorah burning in a window; the sound of a child's laughter; the smell of the Thanksgiving turkey cooking in the oven; the aroma of baking cookies; the scent of freshly-cut grass, the sound of your favorite tune; the beauty of a flower; the recitation of a poem and so much more.

We but need to rest and think a minute to bring happy and pleasant memories to our minds and hearts. We can reminisce with our families about fun childhood adventures and adult vacations. We can remember our first romance or our first dance. We can sing our favorite holiday song (even if it is off-key). We can revel in giving to and sharing with others instead of focusing on ourselves.

2022 is just over the horizon, another opportunity for reflection and renewal. We should celebrate our inner strength, our personal power and our spiritual fortitude. Instead of berating the virus and all of its effects, things we don't have much control over, we should view this time period as a learning experience, a chance for growth, a well-spring of blessings and good memories as we perhaps connected more with family members, got involved more in our commu-

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nities (even if it was virtual), and had an opportunity to spend some time exploring and revitalizing our inner selves. Yes we went through some trials and tribulations, but we have come through it stronger and more able to cope. I hope and believe that we all have the capacity to reach out to help another in need, to hug a child and tell them you love them, hold your partner in an extra-long embrace, and all the other things that truly matter, and in the end, perhaps the only things that make a difference.

So, please join me in making a difference this holiday season and the year to come. The world will be a better place for it. Happy Holidays, good health, and much sharing.

# AccessAbility

December 2021

EDITOR IN CHIEF: MARIA DIBBLE  
MANAGING EDITOR: KEN DIBBLE  
EDITOR: ELIZABETH SIGNOROTTI  
LAYOUT: RUSSELL RICHARDSON

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*AccessAbility*

Southern Tier Independence Center  
135 E. Frederick Street  
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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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# CDPA Events Calendar

There's been some confusion about if or when various changes to New York State's Personal Care Services (PCS) program will take effect. We've been reporting on several such changes that were enacted into state law in April 2020 as part of that year's state budget process.

Many of the most important changes have not taken effect because they conflict with "maintenance of effort" (MOE) requirements that were part of the federal Families First Coronavirus Response Act of March 2020.

On November 1, 2021, the state Department of Health (DOH) issued a helpful letter explaining what has really changed and what has not. We'll summarize the highlights here; you can read all about it yourself on the DOH website at: [https://www.health.ny.gov/health\\_care/medicaid/redesign/mrt2\\_recommends/pcs-cdpas\\_reg\\_chg.htm](https://www.health.ny.gov/health_care/medicaid/redesign/mrt2_recommends/pcs-cdpas_reg_chg.htm).

## What's NOT Happening Right Now

- The requirement that the medical practitioner who orders your Personal Care or CDPA services cannot be your attending physician
- The requirement for a state contractor to carry out an "independent needs assessment" of persons seeking PCS or CDPA. Note that this assessment will be an "advisory" tool, to be considered, but not necessarily agreed with, by the Managed Care Organization (MCO) or Department of Social Services (DSS, for fee-for-service situations). The MCO or DSS makes

the final decision on how many hours of service to approve.

- The requirement for a second-level "independent medical review" if the MCO or DSS thinks you need more than 12 hours of service per day on average. The results of such a review also appear to be "advisory"; if the reviewers think you don't really need 12 hours of service, the MCO or DSS may still approve them—but don't count on it.
- New eligibility restrictions based on how many "Activities of Daily Living" (ADLs, such as mobility, bathing, using the toilet, eating, and others) you need assistance with; the new rules require most people to need "at least limited assistance with physical maneuvering" for at least three ADLs; those with Alzheimer's or other forms of dementia will need "at least supervision" for at least two ADLs. Note that this rule, when it takes effect, will not apply to anyone who is or has been already authorized to receive PCS or CDPA; it only affects new people.
- The requirement that CDPA Fiscal Intermediaries (FIs) must have a contract with DOH rather than with a county DSS. This is kind of a sleeper; it would seem to mean that DOH can't carry out its project to destroy most of the FIs in the state, because that process hinges on only permitting FIs that receive a state contract to operate.

## What IS Happening

A few of the regulatory changes took ef-

# BAD WEATHER?

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

fect on November 8, 2021. These are a mixed bag of mostly harmless, mildly harmful, and beneficial.

- Nurse practitioners and/or physicians' assistants can now sign some DOH forms, along with physicians.
- Services can now be authorized for 12 months at a time, instead of 6 months.
- County DSS are no longer required to notify people annually of the availability of the CDPA program.
- A requirement for "LDSSs or MMCOs to document in the notice and plan of care the factors and clinical rationale specific to the client that went into the medical necessity determination that PCS or CDPAS should be denied, reduced, or discontinued."

### What have the Feds Approved?

We had previously reported that we didn't think DOH had submitted a Medicaid State Plan Amendment to the federal Centers for Medicare and Medicaid Services (CMS) to get the required approvals for these changes. That was incorrect (and thanks to long-time advocate Trina Rose for the correction, and for additional re-

porting). It was submitted on September 29, 2020.

However, DOH's claim that CMS approved these changes is debatable. They don't appear to have done so on the record. DOH's submission was SPA 20-41, and it contained all of the nasty PCS/CDPA changes we've been discussing. CMS responded on April 15, 2021, to say that SPA 20-41 was approved on April 8, effective April 1, 2021. However, that approval letter only covered the state's Electronic Visit Verification (EVV) compliance plan and some technical changes to CDPA definitions. It did NOT address the big PCS service changes at all.

There's a rumor that CMS told DOH verbally that they could go ahead with those changes as long as they do not impose a "hard cap" on service hours. The question is, do they? There is certainly a hard cap of 0 hours for anybody who doesn't meet the new ADL requirements here.

So we can't say for sure whether these changes would have taken effect if the COVID-19 pandemic had not intervened. What we can say is that the state legislature has another opportunity to

repeal them, and a different governor to try it with. Although Governor Hochul has made a big show of "cleaning house" to get rid of many of Andrew Cuomo's appointees, including his DOH Commissioner, she chose to retain his budget director, Robert Mujica. Mujica is said to have been a major force behind the "Medicaid Redesign Team" and its efforts to cut Medicaid services and spending, which included the Personal Care/CDPA changes. This does not bode well for the upcoming budget process.

On November 2, Assemblyman Richard Gottfried (D-Manhattan), Chair of the Assembly Health Committee, and 32 other Assembly members sent a letter to Hochul urging her to either drop the plan to decimate CDPA FIs entirely or delay it until after the pandemic ends. Two of our local members, Republicans Christopher Friend and Joe Angelino, signed the letter. Donna Lupardo, a Democrat, did not. Senator Simcha Felder (D-Brooklyn) sent a similar letter to the Governor. At press time in late November we had not heard any response from Hochul.

## A Jim Dandy Rescue Plan

Biden's American Rescue Plan offered a temporary ten percentage-point increase to the federal share of a state's Medicaid expenses that are used for Home and Community Based Services (HCBS) between April 1, 2021 and March 31, 2022, with the resulting extra money to be used to "enhance, expand, or strengthen" HCBS, broadly speaking. In order to get this money, New York had to submit a plan to the federal Centers for Medicare and Medicaid Services (CMS).

Last time we reported that it appeared that CMS had not approved New York's plan, and that it was being reworked by the Division of the Budget for resubmission.

What actually happened is that on August 25, CMS sent a letter to the NYS Department of Health (DOH) announcing that they had partially approved the plan. This letter wasn't made public until after our Fall issue went to press.

Several proposals in the plan were approved, but CMS had questions about some of the most important ones and declined to approve them until it got answers. Some of those questions focused on the proposals that advocates had identified as most problematic.

Concerning a proposal to spend over \$55 million to train nursing facility employees to better recognize residents who were able to move to more integrated community settings: The advocates argued that nursing facilities are not HCBS settings and are already required to ask residents if they'd like to leave, and if so, refer them to the Open Doors program operated by Centers for Independent Living like STIC, suggesting that these funds would be better spent by that program. CMS merely asked DOH to say whether the funds would be used for existing training programs or to create new ones, and if the former, to ex-

plain how this would enhance, expand, or strengthen HCBS. DOH said this would be a new training program. As for the second question, the response was, "This would be a training program that has not existed previously and thus would enhance, expand, and strengthen the ability of these providers to transition individuals to home and community-based settings." In other words, its newness meets the criteria for an expansion or enhancement, regardless of whether it is demonstrated to be needed.

The biggest concern was the proposal to pass much of the money earmarked for provider organizations through managed care companies. Advocates were concerned that these companies would not actually pass the money on, because they have a history of failing to do so with things like recruitment and retention payments that were supposed to increase

wages for direct service workers. CMS asked DOH how it would ensure that these funds would be passed through and used for their intended purposes. DOH responded that it planned to modify the state’s managed care contracts to specify timeframes and reporting on how funds were spent, as well as outcome measurements for how workforce recruitment and retention were improved. Crucially, though, DOH’s response didn’t state these timeframes or when these reports would be due.

Another contentious issue was whether DOH should be allowed to use these funds to support “natural growth” in the Medicaid program. Some advocates objected to this concept, arguing that “natural growth” in an existing program isn’t an expansion or enhancement. CMS’s questions were very much on point here: By “natural growth” does the state mean just an increase in Medicaid expenditures resulting from things like an aging population or an economic downturn? Or does it mean growth that results from other state activities that are intended to expand or enhance HCBS, such as removing roadblocks that prevent people from getting enough hours of service? If it’s the latter, CMS wanted DOH to explain how it will project those expenditures. If not, then CMS wanted to know how just paying for increased use enhances or expands HCBS. This might theoretically affect whether NY can collect a “second match” on the expenditure of these funds prior to March 31, 2022. DOH responded that it needs to think about it and will get back to them.

On October 18, DOH released its first quarterly report on this project. Not surprisingly, it showed little progress. It did indicate that DOH was following CMS instructions to prepare various state plan and waiver amendment proposals to implement rate changes and direct payments to providers through MCOs. Interestingly,

the report indicated that DOH was working on several “Attachment K” waiver amendments, which are “emergency” amendments to get already-expended funds approved.

This report follows a repetitive format; DOH must address the same points for each of the many separate proposals in its spending plan. One of these points is an explanation of how the activity will be sustainable after the extra funding goes away. Most of DOH’s responses in this category follow a standard template: “[Activity x] will have long-lasting impacts on [some good thing].”

We don’t have any information on this later than DOH’s October 18 report. However, we can anticipate that CMS will eventually approve almost everything in DOH’s plan with the exception of a proposal to expand availability of integrated housing by means of rent subsidies (a form of “room and board” that CMS stubbornly insists is not fundable in HCBS programs, even though it is part and parcel of segregated services). It’s been said that CMS did not expect the heavy workload in terms of reviewing and responding to state proposals that resulted from the law, which has led to delays in processing. It is probable that the agency will end up taking the states’ word for it on a lot of this stuff, and will depend on state Medicaid authorities to monitor and enforce the rules. In NY, based on past history, that means there will be very little scrutiny or accountability for the life of the program (which ends March 31, 2024), although at some point in the future some federal auditor may have a “lasting impact” on NY’s finances when it finds money has been wrongly spent. And the outlook doesn’t seem very promising for New York’s hope to expend a big portion of these funds before next April, thereby getting the prized “double match” from the feds—though there are those K attachments, not yet approved by CMS, which aim to recoup already-spent money.

Finally, we can be confident that tracking what happens with this, and whether it actually helps anyone, is going to continue to be a hard slog through the deep weeds. Stay tuned, policy geeks.

## Bed Sores and Broken Promises

In October, the Long Term Care Community Coalition (LTCCC), a not-for-profit advocacy organization with headquarters, and two long-term care ombudsman programs, in New York State, released a report on nursing facilities and the failure of governments to monitor them effectively called *Broken Promises: An Assessment of Federal Data on Nursing Home Oversight*.

The report points out that laws and regulations governing nursing facilities are strong; they demand high-quality care to ensure that residents “attain, and maintain, their highest practicable physical, emotional, and social well-being.” But there is a “systemic acceptance of subpar care” by the government agencies that oversee them, and by our elected officials, who refuse to confront the issue by demanding—and providing the money to pay for—better enforcement.

The report found that New York has the lowest rate of nursing facility deficiency citations in the country—one per 50 residents per year, on average. That does not mean that nursing facilities in NY are better than those in other states; it likely means that the state’s Department of Health (DOH) inspectors have been lax in carrying out inspections and in citing problems.

Also, NY has a poor history of identifying the problems it does find as serious. You’ll recall our editorial in the Summer 2021 issue, where we described a nursing facility near Syracuse in which a woman who could not walk on her own died while trying to get to a bathroom with nobody to help her. She slipped and fell and accidentally hanged herself when her nightgown got caught on a doorknob. DOH inspectors cited the facility for the incident, but ruled that it involved “No actual harm or immediate jeopardy, but has the potential to cause more than minimal harm.”

Over-drugging of nursing facility residents with anti-psychotic medications is a longstanding problem, and it has been on the rise in recent years, as reported by the *New York Times* in September 2021. The *Times* said that at least 21% of nursing facility residents

STIC’s offices will be closed for the holidays,  
**December 24 through January 2.**  
We will re-open on January 3.  
*Happy Holidays!*

are on these medications. The incidence of mental diseases for which these drugs are intended to be used in the United States is less than 0.01%, according to the National Institute of Mental Health. Nursing facilities typically use these drugs at high dosages to keep residents quiet so their needs won't burden the scarce staff, not to provide treatment for actual mental illnesses. Use of "chemical restraints" has been prohibited in nursing facilities for about 30 years, but these drugs can be prescribed to treat genuine psychiatric conditions in those places. The problem is, it looks like nursing facility doctors are resorting to issuing bogus psychiatric diagnoses to justify the use of these drugs, especially on people of color. In September 2021, the *Journal of the American Geriatrics Society* reported a rise in diagnoses of schizophrenia among black nursing facility residents with Alzheimer's disease that is disproportionate to the incidence of that disease among black people overall. Further, the more black residents a state has, the more frequently its nursing facilities are cited for over-drugging. However, how seriously states take this is another matter. The LTCCC found that although New York and New Jersey inspectors cited instances of misuse of these medications, they "*never* identified inappropriate drugging as harmful to residents."

Lousy infection control in nursing facilities has been highlighted during the pandemic, but it has been a widespread problem in these places for years. Nationwide, there are about 1.4 million people in nursing facilities. According to the Centers for Disease Control and Prevention (CDC), before the pandemic began, on average about 70% of nursing facility residents experienced a serious infection *between one and three times every year*, and up to 380,000 residents died from those infections each year. The General Accounting Office reported that about 82% of nursing facilities were cited for poor infection control practices between 2013 and 2017, and about half of those places received multiple citations for ongoing problems. According to the LTCCC report, only 3.2% of these citations identified the problems as causing harm or putting residents "in immediate jeopardy." We'll say that again: in normal times, when there's no infectious disease pandemic happen-

ing, on average, 70% of nursing facility residents experience a serious infection at least once, and up to three times, every year, and those infections kill around a third of those residents every year, but state inspectors rarely identify infection control deficiencies as a serious threat. New York and New Jersey, again, are near the bottom when it comes to states that even cite infection control deficiencies.

Pressure ulcers, or "bed sores," are a problem for people who spend most of their time lying or sitting in one place without moving, and this is especially true for people in nursing facilities, of whom about 7.25% have unhealed pressure ulcers. These are wounds, and if not properly managed, can become very large, very deep, open holes in a person's body, penetrating to the bone. Most of these can be prevented by having staff frequently change the position of people who can't do so themselves, and most sores that appear can be effectively treated if addressed quickly and aggressively. States like NY and NJ under-cite these conditions, and when they do flag them, they usually do not report them as causing harm. You may ask yourself, how can an open, stubbornly not-healing wound not be considered harmful to a human being? The answer, apparently, is that it can be if the affected human is stuck in a nursing facility.

A 2014 study of people who enter nursing facilities to receive short-term rehabilitation funded by Medicare found that about a third of them are harmed within 15.5 days of their admission, and almost 60% of these injuries were "clearly or likely preventable." Staff ratios in these places are a huge problem; most nursing facilities don't have enough staff to provide minimally adequate care (defined as at least 4.1 hours of care per day). The operators like to complain that this is because they aren't adequately reimbursed, but most of these are for-profit businesses that make enough money to show a good profit every year. Further, even nursing facility operators agree that Medicare reimbursement for short-term stays is quite generous, so what explains their failure to prevent those residents from being harmed at an extremely high rate?

Who's responsible for all this?

1. The nursing facility operators, who have been aware of the current quality and safety requirements since they were enacted in 1987.

2. CMS, whose regional offices are supposed to keep state monitors, including DOH, on track. Instead, "CMS and the state agencies treat the industry as their client and prioritize the industry's interests over those of the residents, their families, and taxpayers," as the LTCCC report puts it.

3. State agencies like DOH, which only inspect every facility once every 9 to 18 months, have a poor track record of verifying that deficiencies have been corrected, and have a lackadaisical attitude about how unpleasant and dangerous these places are for the people who live in them.

You can read the LTCCC report here: <https://nursinghome411.org/news-reports/reports/survey-enforcement/survey-data-report/?emci=5aacd373-2d38-ec11-9820-c896653b26c8&emdi=a7c0eb54-d638-ec11-9820-c896653b26c8&ceid=2329222>

In related news, the LTCCC recently reported that one out of six nursing homes in the United States is a "problem facility." Within STIC's service area, Vestal Park; Beechtree, Oak Hill, and Cayuga in Ithaca; and Chestnut Park in Oneonta are on that list. You can learn more about that here: <https://nursinghome411.org/data/problem-facilities/?emci=4bb492d3-c71b-ec11-981f-501ac57ba3ed&emdi=b5514bae-cb21-ec11-981f-501ac510a405&ceid=2330111>

## Cheesy Rotenbergers

Back in September media outlets began reporting complaints from parents that the state's Office of People with Developmental Disabilities (OPWDD) was telling them that they had to bring their children back into the state from residential facilities in other states if they wanted OPWDD to continue paying for their services, and if they didn't want to take them home they would be placed in one of New York's two remaining developmental centers—Sunmount, in Tupper Lake.

The parents were very upset and got their state legislators involved. Their chief

complaints were that OPWDD planned to place their children in the “most secure” area of Sunmount—the area reserved for people accused of serious crimes—and that in some cases, OPWDD seemed to be callously taking advantage of a loophole in a 2014 law that gave parents “due process rights” when the state wants to change or terminate their services, but those rights only kick in after the child “ages out” of school-based services when s/he turns 21. They were issuing these notices to families shortly before their children “aged out,” when the families had no right to object.

Many parents contrasted the home-like atmosphere of their children’s current placements with the prison-like setting at Sunmount and were horrified.

It quickly emerged that a lot of these people were inmates of the Judge Rotenberg Center in Massachusetts, which is notorious for torturing people with developmental disabilities with electric shocks (see page 10). This might lead some in the disability community to have little sympathy for these families, but it isn’t quite that simple.

The Rotenberg “Center” is not just one building; it is a service system that operates a variety of residential and non-residential programs, including group “homes” and family care homes. Unlike similar programs in New York, though, Rotenberg uses “aversive conditioning,” including but not limited to electric shock, to modify some people’s behavior.

In behavior-modification terms, an “aversive stimulus” is the same as a “punishment”; both terms mean something that causes an unwanted behavior to decrease. However, in practice, “aversives” is usually used to mean unpleasant physical stimuli, such as a spray in the face with water or lemon juice, withholding food or limiting food to bad-tasting items, corporal punishment, or other pain-inducing measures like electric shock. There is a broad consensus in the psychiatric profession that aversives are less effective than their opposite, rewards for good behavior, in getting long-lasting results. This system, known as “positive behavioral supports,” which involves giving people something meaningful and enjoyable to do that occupies their full attention and makes use of

their talents and abilities, and rewarding them for doing those things, is effective in mitigating harmful behavior patterns and is considered a best practice.

Some families insist that before their children began receiving aversive conditioning, including in some cases shocks, “nothing else worked” to get their children to stop hurting themselves or others. However, positive behavioral supports nearly always work well, when done correctly. It’s likely that whatever was done with these children that didn’t work simply wasn’t done correctly. In extreme cases drugs can also be effective, but some of these families have a strong distaste for medication, noting unpleasant side effects. There have been cases of doping people up to the point that they become dysfunctional or develop extrapyramidal symptoms (repetitive twitches, hand movements, etc.), but that’s just another example of doing things incorrectly. Medication is intended to be used sparingly, to blunt the worst behaviors, while applying positive supports to gain long-term improvement. Even so, it’s difficult to be sympathetic to people who would rather see their children tortured than have them mildly sedated, if that’s what’s actually necessary.

Both OPWDD and the State Education Department (SED) banned all forms of aversive conditioning in NY many years ago. SED also stopped paying for its use in out-of-state programs, except for a small number of students who had aversives in their Individual Education Plans prior to July 1, 2009, and whose plans, updated annually, continued to require it.

Some state legislators wrote a letter to then-Governor Cuomo about this fiasco, and OPWDD withdrew its demands that these families take their children home or send them to Sunmount.

Ultimately this situation is the result of OPWDD’s failure to take proactive measures to put in place appropriate supports for people after they age out of SED-funded school-based services. With proper planning and adequate funding, they could be assisted to find integrated homes in the community, or at worst, group “home” placements, if their families were unable or unwilling to take them in. In November of 2017, Disability

Rights New York, the state’s federally-funded Protection & Advocacy program, sued OPWDD over this issue (see *AccessAbility* Spring 2018). There still has been no decision in that case.

## **Kastner Oil, Unavoidable Delaneys, and Smearred Mascari**

Care Coordination Organizations (CCOs) are the agencies that took over service coordination for people eligible for services from the NYS Office of People with Developmental Disabilities (OPWDD). This change occurred several years ago as OPWDD’s response to a demand from the federal Centers for Medicare and Medicaid Services (CMS) that it eliminate certain types of conflicts of interest from its system.

Those conflicts were real. Service coordinators working at various agencies that also provided direct services, including OPWDD itself, were frequently ordered by their bosses to ensure that nobody on their case loads was referred to competing agencies for any type of service. This often meant that people with disabilities and their families never learned about services that would have enabled them to have more integrated and productive lives in the community, and this led them to be needlessly confined to segregated settings.

But CMS’s and OPWDD’s interest in avoiding conflicts of interest only went so far. OPWDD encouraged service coordination agencies to band together to form consortiums to own and operate CCOs, ignoring the conflicts of interest inherent in such schemes. They deliberately ignored the potential for these consortiums to prevent service coordinators from referring people to agencies that were not members. However, CCOs were forced on STIC and other service coordination providers; we were prohibited from offering that service after a certain date.

So STIC joined several other agencies in the Southern Tier and central NY to form PrimeCare, a for-profit CCO. We remained involved as long as we could to try to ensure that service coordinators who had worked for us, and the people they served, were treated fairly by the new company. However, eventually the largest agency in PrimeC-

are's ownership consortium exercised its overwhelming influence in the company to buy out the other partners, including STIC. We no longer have any involvement with PrimeCare.

We continue to hear reports that OPWDD service coordination, now called "care management," has lost its old focus on intensive individualized and personal support for people with developmental disabilities and has reverted to a paperwork-oriented medical model. We can't fault specific care managers at PrimeCare for this, but it does appear that the company isn't doing much better than the other CCOs around the state in this area. Those people, like others in NY, are being forced to focus on paperwork and medical health-related records tracking. They have been given higher caseloads and are being discouraged from extending themselves to provide real day-to-day help to the people they serve.

We did not realize that OPWDD's former Commissioner Theodore Kastner, who resigned this fall, also had serious concerns about the CCOs, though for very different reasons. In September 2020, he filed a complaint with the NYS Inspector General (IG) alleging that his predecessor, Kerry Delaney, along with Governor Cuomo's Deputy Secretary for Health and Human Services, Paul Francis, and Delaney's assistant Michael Mascari had engaged in corrupt practices and favoritism in awarding CCO contracts and setting their reimbursement rates.

The IG issued a report on September 29, 2021, that largely dismissed Kastner's charges as unfounded. However, some of those charges were unfounded only because NY has a lax legal framework for managing conflicts of interest, and the IG recommended that this be addressed.

This was a very tangled web indeed and would take more space than it warrants to fully explain here. The basics are these:

Mascari worked part-time as a consultant/assistant for Delaney (formerly a DOH lawyer) during the development of and bidding for the CCOs. At the time he was also the Chairman of the Board of PHP (Partners Health Plan, a not-for-profit health insurance company).

During the CCO development and bidding process, Kastner and Mascari were,

in a sense, competitors seeking CCO contracts. Kastner, as a consultant, was helping Montefiore Medical Center prepare its bid, while PHP, under Mascari's chairmanship, was partnering with some other agencies to establish a CCO called Care Design. (Actually, a holding company called Partnerships did the partnering; Partnerships owns PHP, and Partnerships' only corporate member was a company called PHSI, of which Mascari was a director.)

Mascari was simultaneously working for Delaney as a consultant to the Transformation Panel she formed to develop plans to move the agency to a managed care model. CCOs were designed as a first step in that direction. Under his guidance, OPWDD chose some organizations as "emerging CCOs" and provided extra help and technical assistance to them. Care Design was deemed an "emerging CCO"; Montefiore was not. Kastner complained to OPWDD about this at the time but was brushed off.

This was an obvious conflict of interest, but it was deemed by the IG as only an "appearance of conflict" because Mascari's job was to review documents and "assist OPWDD in assessing managed care readiness," and no witnesses could be found who said he made any final decisions. However, the IG did find that OPWDD did not make an adequate effort, under state law, to formally recognize this conflict and take steps to mitigate it, such as by requiring Mascari to sign an agreement to recuse himself from involvement in any matters pertaining to PHP or Care Design while working for Delaney. Mascari testified that he recused himself. Roger Bearden, then the General Counsel for OPWDD, claimed that he advised Mascari to resign from PHP when he took the OPWDD job, but Mascari insisted that Bearden never told him any such thing.

When Delaney left OPWDD she had a job waiting for her as CEO at PHP, which had been arranged for her by Mascari (there is no dispute about his role in that). Kastner alleged that this was a *quid pro quo* in return for Delaney granting a CCO contract to Care Design. The IG didn't find any evidence of "complicity" or malfeasance in this hiring. However, it did find that it violated the New York State Public Officers Law, which "prohibits State employees from accepting or receiving gifts, including offers of employment, when it could reason-

ably be inferred or expected the gift would influence the employee in the performance of his/her official duties or was intended as a reward for his/her official action."

Delaney claimed she recused herself from decisions involving PHP once the job offer was made, but the IG found evidence that this was a lie. She continued to work with Mascari for about six months after the job offer was made in February 2018, and she approved the CCO designation letters on June 29, 2018. It wasn't until August 22, 2018, that she sent a draft memorandum to Francis describing a partial recusal, planning to continue "her oversight of the implementation of CCO/HHs, which included the CCO Care Design." However, the IG's report suggests that New York State no longer has any "jurisdiction" over Delaney to take action against her.

Delaney was probably qualified, as a lawyer involved with both DOH and OPWDD, and an administrator of the latter, to run a health insurance company. It's not about whether she got a job that her experience and skills did not merit. It's about whether she got it as a reward for ensuring that Mascari got his CCO.

What our leaders need to understand is that nobody who works in government should be permitted to gain any sort of benefit from that employment other than the wages and fringe benefits that come directly from the job. Did Delaney get the PHP job as a reward for taking specific actions to help Care Design get its contract? We don't know. Would Delaney have gotten the PHP job if she had not been OPWDD Commissioner and working with Mascari on a regular basis for over two years? That seems unlikely.

It's the "revolving door" that exists between government and the private industries that government exists to regulate that is the problem. There is no amount of formal "recusals" or "firewalls" that can ensure that government workers will not be inappropriately influenced to support the interests of people who have been their friends and colleagues in private industry, or that corporate officials will not be able to trade on the good will of their former buddies now working for the government. It's laughable to believe otherwise. And it has to stop.

# courts watch

## *Winegard v Newsday LLC*: Oh what a tangled web...

We've been covering the battle in the courts over whether the Americans with Disabilities Act (ADA) requires websites to be accessible to people with disabilities for several years, most recently this past summer, when we discussed *Gil v Winn-Dixie Stores, Inc.* That 11th. Circuit Court of Appeals ruling stated that websites are not "places of public accommodation" that the ADA requires to be accessible.

The Second Circuit court, which covers New York, has previously decided that websites *are* places of public accommodation. Nevertheless, on August 16, 2021, a lower court within the 2nd. Circuit's orbit, the federal District Court for the Eastern District of New York, essentially sided with the 11th. Circuit on this issue. The judge who wrote this opinion is Eric Komitee.

Winegard is a Deaf person who apparently has a sideline of filing ADA lawsuits; he's filed 44 such suits in the Eastern District alone. In this case he complained that the website of *Newsday*, a Long Island newspaper, featured videos that were not captioned and thus not accessible to him.

Unlike the supermarket in the *Winn-Dixie* case, it's pretty clear that a newspaper is not a "place" of public accommodation. It has no physical location that is open to the public for the purpose of obtaining goods or services. Therefore, it's tough to argue that *Newsday's* website is an ancillary function that helps people use a physical location—there is no "nexus" to a physical location on which other judges have based their decisions.

The case is interesting for disability rights advocates because it sheds light on how difficult it can be for courts to interpret legal language that is not perfectly plain and clear on its face. Judge Komitee discussed two Latin legal maxims in his decision: *ejusdem generis* and *noscitur a sociis*. *Ejusdem generis* means "of the same kind," and the principle here is that if a

law contains a list of specific things (like "car, train, bicycle"), followed by a more general description ("and other forms of transportation"), then that description should be read to only include items of the same kind as those in the list (only ground transportation, not including airplanes or sailboats). Notice it's possible to argue about what the "same kind" here really is. One judge may believe that "transportation" in this example only includes things that run on dry land, while another judge may believe that it includes anything that does not fly, and would therefore let you add sailboats to the list. *Noscitur a sociis* means "he is known by his associates." If you're having trouble understanding the meaning of a particular word, you should consider how it is used in the immediate context. For example, as we discussed in a report on *Winn-Dixie* in *AccessAbility* Winter 2017-18, the US Department of Justice (DOJ) guidance on "public accommodation" describes a public accommodation as a "facility" that falls into any of twelve categories of physical places. The dictionary definition of "facility" includes things that are not physical places, but it's possible to argue that the immediate context in which DOJ used that word, next to a list of types of physical places, indicates that those other definitions are not applicable.

The intent of Congress in writing a law is also very important. In our transportation example, Congress would likely have known that there were other ways to get from here to there besides those in that list, and courts can be justified in assuming that if Congress intended to *include* boats it would have added "boat" to the list and leave consideration of whether sailboats or speedboats can be included to the phrase "other forms of transportation." Courts can also assume that if Congress intended to *exclude* boats it would have added "ground" to the general phrase.

Finally, the US Supreme Court is supreme for a reason. Regardless of how lower federal courts interpret a statute, if

those courts don't agree with each other, then usually the Supreme Court decides, and thereafter all federal judges are supposed to tailor their reasoning to match. One may think this principle would provide pretty clear guidance, but if one did, one would be wrong. For example, there's a 1991 Supreme Court decision that says that *ejusdem generis* can be ignored "when the whole context dictates a different conclusion."

Oh boy, now we have to figure out what "whole context" means. It might be that, taking everything into consideration in 2022, when nearly everything operates to a great extent by means of websites, the law should obviously be extended to cover websites as places of public accommodation. On the other hand, there's that pesky old Congressional intent thing. Some decisions supporting covering websites under the ADA rely on the notion that the web really wasn't a thing when the ADA was written in the late 1980s (it passed into law on July 26, 1990). Komitee claims this is not true, but he's wrong. The *internet* existed prior to the ADA, and the basic concept of the web was invented in the late 1980s, and some people in Congress were discussing its potential for growth at that time, but the first actual public websites only appeared in 1990. The web didn't really begin to exist in anything like its current form until 1993, and it took a lot longer for streaming video like that on *Newsday's* website to become practical. But that's less important for our purposes than the fact that there were other commonly used ways to purchase goods and services besides at physical locations in 1990, such as the very popular Sears catalog. Catalogs were not given as examples of public accommodations in the law, so one can argue that Congress did not intend to require that they be made accessible. (Too bad for blind people.) Even if they overlooked it then, our elected representatives had an opportunity to correct this when they passed amendments to the ADA in 2008,

by which time web accessibility had been broadly discussed in public and addressed by some federal courts. Yet they did not.

So what will the Supremes say, when this issue eventually reaches them? Well, the answer is that it may not—or at least, not any time soon. They refused to take up a similar case in 2019, leaving intact the 9th. Circuit’s ruling that websites with a “nexus” to a physical place of accommodation *are* covered by the ADA. That’s pretty unusual when different circuit courts disagree on something. But in this case it may only be because the district court did not fully decide the case on the merits, and the circuit court sent the case back to that judge for reconsideration, so the Supremes may not want to touch it until all that is resolved.

The point to take home from all this blather is that it is, indeed, just blather. Komitee, a conservative recent Trump appointee to the bench, has good logical arguments on his side. Liberal judges often use equally good reasoning to arrive at completely different conclusions. And unfortunately, if our elected representatives do not write laws clearly, plainly, and precisely, when those laws go before judges the result is a total crapshoot.

When disability rights advocates are given an opportunity to help draft laws, they really, really *really* need to demand that the language should be clear, simple, and plain. Above all, they should never accept some lawyer’s claim that “oh, that’s okay, it really means something other than it appears to say.” The truth is, if a legislator won’t agree to plain clear language in a bill, it means that s/he is trying to hide something—and most likely that something is that s/he doesn’t really want to do what we want them to do, but s/he wants to get credit for doing it anyway. In such cases it would be better to find another legislator who actually wants to do what we want. I hope that’s plain enough for everybody to understand.

### ***Cardew, et. al. v NYS Department of Corrections: Make them crawl!***

The plaintiffs in this case allege that New York State’s Five Points Correctional Facility in the Finger Lakes mistreats people with physical disabilities who use mobility devices.

When prisoners arrive at Five Points, the guards take away their wheelchairs, walkers, and canes and won’t let them have them to get around in or near their cells. They aren’t returned to them until they meet with a medical provider for an evaluation, which can take weeks or months to arrange. This happens even if those devices were given to them by other prisons from which they transferred. Often, wheelchairs are only allowed for long-distance travel, and are stored at considerable distance from prisoners’ cells. The guards either refuse to retrieve them even when needed to travel a long distance, or they take so long to bring them that whatever event the prisoner was going to (such as a meal or medical appointment) is over by the time they get them. Prisoners are allowed to crawl down the hall or sidle along the wall to get them, but again, this often takes too long to be practical. Not to mention that it’s risky to their health in many cases, and abusively cruel in all cases. When people who didn’t come with wheelchairs develop a need for them, it can take a year or more to get them. When provided, the wheelchairs are often in such bad condition that they cannot be used safely. Only manual wheelchairs are allowed, not motorized ones, so when prisoners who can’t wheel themselves need to get around, they have to request a “pusher,” another prisoner who does this as a job. Pushers are frequently not available and either don’t arrive at all or come too late to be useful. Prisoners who shouldn’t try to wheel themselves sometimes do it anyway, and then they get injured.

This is a class action civil rights lawsuit that alleges violations of Title II of the Americans with Disabilities Act (ADA) and Section 504 of the federal Rehabilitation Act. Both of those laws require Five Points, a public entity under the ADA that receives federal funds covered by Section 504, not to discriminate against prisoners because they have disabilities, and to provide reasonable accommodations and/or alternate means of access while in prison. It should be a no-brainer: wheelchairs are as necessary for healthy functioning for those who use them as are food and water. They cannot be denied. We’re surprised that the Eighth Amendment of the US Constitution, forbidding “cruel and un-

usual punishment,” was not invoked here, as it has been in other prison accessibility cases, including *United States v Georgia*. The plaintiff in that case, who had paraplegia, alleged that he was subjected to cruel and unusual punishment because the prison he was confined to was inaccessible: he couldn’t move his wheelchair around in his little cell, and the guards would not help him get in and out of bed or to use the toilet, so he was left sitting in his own waste most of the time. It’s not a far cry from that to being forced to crawl down the hall or to risk a heart attack when trying to wheel oneself around.

This case is just getting started; we’ll let you know what happens.

### ***Doe v CVS: Drugstore Cowboys***

“Doe” is a pseudonym used by several employees of the CVS drugstore chain who were HIV-positive. Originally, under the terms of the medical insurance provided by their employer, “the Does” could go to a pharmacy to get their prescriptions filled and covered by insurance. The medication regimens needed by people with HIV can be very complex, and those people may need to rely on the ability to interact directly with pharmacists to prevent dangerous drug interactions, side-effects, and adjust dosages.

CVS changed its insurance plan to require people who use HIV meds, deemed “specialty medications,” to get them through a mail-order pharmacy, Caremark, but Caremark could not be used for ordinary medications. Now these employees couldn’t communicate directly with the pharmacist, nor was there a single pharmacist who was aware of all the specialty and non-specialty meds each person was getting from various doctors, and therefore there was no one who could monitor for potential dangerous drug interactions.

The Does sued CVS under a convoluted argument whose details we don’t need to relate here. Ultimately, the federal Rehabilitation Act governs this case. The Rehab Act, as amended by the Americans with Disabilities Act (ADA), has been held to cover medical insurance because insurance companies receive federal Medicare and Medicaid money. The Rehab Act/ADA definition of “disability” doesn’t necessarily cover people who are

HIV-positive but asymptomatic because one has to have significant functional limitations to meet that definition. However, it also applies when people are discriminated against because they are believed to have disabilities—and that’s a pretty common thing when it comes to HIV.

CVS argued that its plan didn’t only apply to employees with disabilities as defined by the ADA. It just required anybody who used certain classes of medications to get them through the mail-order pharmacy. They said they had no intent to discriminate, and if discrimination occurred, it was an unintentional byproduct of its new rules.

The Does argued that intent doesn’t matter. Rehab Act case law, in the form of the US Supreme Court’s 1985 *Alexander v Choate* decision, has firmly established that Congress did not intend to require discriminatory intent to prove violations of the law; it is enough that a policy or practice has a “disparate impact” on people with disabilities that it does not have on nondisabled people.

The case went through federal district court and a court of appeals, and the Does were winning when CVS brought it to the US Supreme Court. CVS’s argument directly challenged the *Choate* decision. This was extremely dangerous because subsequent decisions by a much more right-wing Supreme Court required deliberate discriminatory intent to be proved to win civil rights cases related to race or ethnicity. It was possible, if not likely, that the 6-3 right-wing majority on today’s Court would rule against the Does, and thereby, the entire disabled community.

The reason why that may not be likely is that the history and language of the Rehab Act and the ADA contain much more support for the notion that Congress intended to prohibit unintentional disparate impact than do other anti-discrimination laws. The *Choate* opinion made this clear: “much of the conduct that Congress sought to alter in passing the Rehabilitation Act would be difficult if not impossible to reach were the Act construed to proscribe only conduct fueled by a discriminatory intent.”

But that’s all moot now. The disability community organized in force on this.

They submitted “friend of the court” briefs to the Supremes, and they also pleaded with CVS to drop the case because of the potential damage it could do to 35 years of legal precedents. And ... CVS did!

There followed much beneficial publicity for the drugstore chain, along with promises to continue collaborating with disability activists on a number of issues. This was certainly a win for people with disabilities, though CVS may have had a bigger win with all the positive strokes they’re now receiving from our people. It’s also worth noting that CVS recently announced it would close about 900 pharmacies across the country—which will likely once again make it harder for people who need to consult directly with a pharmacist to do so.

### **Rotenberg v FDA: Ban the Ban on the Ban**

Last time (*AccessAbility* Fall 2021) we reported that the federal Circuit Court of Appeals had ruled in favor of the Judge Rotenberg Center’s request to overturn the federal Food and Drug Administration’s rule banning the use of the Center’s electric shock device.

In September, the FDA, with federal Department of Justice backing, asked the full DC Circuit to review that 3-judge-panel decision. We can’t find a copy of the FDA’s brief, but *Disability Scoop* quotes it here:

“A divided panel of this court held that if a medical device has multiple uses, FDA lacks statutory authority to ban a device for a particular intended use because that would impermissibly regulate the practice of medicine. That holding erroneously limits FDA’s authority to prevent the sale and distribution of medical devices intended for uses that pose unjustifiable risks of pain, injury, and psychological trauma.”

This sounds like the FDA is hoping the full court will embrace the dissenting opinion authored by one of those three judges.

On October 25, seven Democratic Senators sent a brief letter to FDA Acting Commissioner Janet Woodcock, thanking her for the FDA’s efforts and urging her to “continue to take every step necessary to protect children and adults with

disabilities.” We can only echo that sentiment here.

However, there’s another twist to this story (see page 5).

### **USA v Uber: Wait wait, don’t tell me...**

Beginning in 2016, Uber, the on-demand transportation company, began charging a “wait fee” to any passenger who takes more than two minutes to get into an Uber vehicle. The clock starts ticking when the Uber app determines, by means of GPS, that the vehicle has arrived at the pick-up point. Apparently, the timer stops when the vehicle’s GPS location changes—when the car starts moving. This is all automatic, and the driver doesn’t have the ability to waive the fee.

We all know about people who call for a ride and then diddle around getting out of the building and don’t actually get to the vehicle for several minutes. That’s not what this is about.

The federal Department of Justice (DOJ) has received numerous complaints from people who use wheelchairs that the unavoidable amount of time it takes for someone to transfer from the wheelchair to the car seat, and then get the chair folded and stowed by either a personal assistant or the driver (typically five minutes or more) is triggering these wait fees. These people only request the Uber ride when they are at the door of the building and ready to come out.

DOJ sued Uber over this in federal district court in northern California on November 10, 2021. This is an obvious violation of Title III (public accommodations) of the Americans with Disabilities Act (ADA), which covers transportation services.

Uber will likely respond, as it has in the past, that it is not a transportation service; it’s a software app with no responsibility to comply with the ADA. This is, of course, bogus, as we’ve reported in articles concerning other lawsuits against the company. We’ll let you know what happens.

### **James v United Healthcare: Your check’s in the mail**

This case blew by us pretty quickly; it was filed on August 11, 2021, and settled the same day. But it relates to an ongoing

ing problem with insurance coverage for mental health and substance abuse services that we've covered before (see *Accessibility* Summer 2019).

United Healthcare (UHC) is the nation's largest medical insurance company. It owns and operates affiliate companies and insurance plans across the country, including in New York.

NY Attorney General Letitia James alleged that the company's practices violate both New York's 2006 "Timothy's Law," and the 2008 federal Mental Health Parity and Addiction Equity Act, which was expanded by ObamaCare to include small group and individual insurance plans. There are some differences between these laws but both of them require at least some level of "parity" in coverage when plans cover both physical and mental health services. This usually means that coverage limits or payment rates must be comparable. For example, if the plan does not limit the number of doctor visits for a physical condition, it should not limit the number of such visits for a mental condition.

UHC's companies and plans serving New Yorkers violated these laws in two ways:

They applied a utilization review process to out-of-network outpatient psychotherapy that they do not use for out-of-network physical medical services. This process required both patients and providers to resubmit a justification for continued services to the company if the patient received more than 20 therapy sessions within six months.

They also paid lower fees to out-of-network psychotherapy providers who are not physicians than they paid to out-of-network non-doctor physical medicine practitioners.

It is more likely for psychotherapy providers, such as psychologists and masters-level social workers, to hold non-physician degrees and not participate in insurance company networks than it is for physical medicine practitioners. This amounts to wholesale discrimination against one of the most common services needed by people with mental health or substance abuse disabilities.

James sued UHC in federal district court for the Eastern Division of NY. Quite apparently, the settlement was negoti-

ated prior to her filing the papers; both documents are 29 pages each and such lengthy documents, like Rome, are not built in a day.

In the settlement, UHC agreed to stop these discriminatory practices—but only temporarily. For some reason the agreement permits the company to resume similar practices after two years. Meanwhile, according to James's press release, UHC "will pay approximately \$14.3 million in restitution to consumers affected by the policies, including \$9 million to more than 20,000 New Yorkers with behavioral health conditions who received denials or reductions in reimbursement."

We don't have any information on how any of those New Yorkers can claim reimbursement.

### ***Taej'on Vega v Broome County: Unconscionable—Again!***

This is yet another case about a person with a disability who was mistreated in the Broome County Jail.

Vega, a black Latino man with diagnoses of bipolar disorder and other mental health disabilities, was about 18 years old when he was sent to the Broome County Jail in October 2019. He was being held before trial; we don't know what crime(s) he was charged with.

On February 20, 2020, the jail guards conducted a random search of Vega's housing unit (known as a "pod"). They ordered all the prisoners in the pod to lie down on the ground, a standard procedure. Vega complied and lay down on his stomach. As some guards passed him, he asked them how their day was going.

One of the guards said, "Oh, you think this is a joke?" What followed was described in the complaint filed by Vega's lawyers.

"Before he could respond [a guard] thrust his knee on the back of Mr. Vega's neck and pressed his thumb into his mandibular nerve on his neck. [Another guard] then ordered [the first guard and a third guard] to take [him] to his cell, [and to] search [the] cell and perform a visual body cavity search. He did this to punish Mr. Vega for what he viewed as disruptive behavior."

The complaint continues to detail the assault, which we summarize here: the

guards handcuffed Vega, dragged him to his cell, and threw him down on the bed and held him there. The first guard hit him with closed fist several times on the side of his body and lower back, and with an open hand several times in the face. Vega was held down and struck in the head and body while the guards repeatedly used the "n word" and made other humiliating comments.

Vega was then un-cuffed and ordered to "Strip n-word." The first guard "open-hand slapped him across the face, grabbed him by throat so tight he couldn't breathe, shook him twice, and said 'do what you're told [n-word].'"

After Vega was completely naked, the first guard conducted a visual body cavity search, ordering him "to manipulate his genitals and bend over to expose his anus." The third guard threw Vega's commissary and personal items on the floor and crumbled up pictures of his daughter that were hung on the cell wall. The corrections officers then stuffed his bed sheets into his cell's toilet, flushing it repeatedly until the sheets were soaked with toilet water.

Vega was then left in his cell naked and traumatized. He began to cough up blood and suffer "extreme pain in his chest and abdomen." He used the jail video-call system to call his mother, who took "screen shots of ... bruises all across his body and face." Those pictures, which have been made public, clearly show injuries in the areas where Vega said the guards struck him.

He filed a grievance with the jail administrators; predictably, it was denied. He continues to experience nightmares and severe anxiety as a result of the event. As the complaint noted, "The beating took a piece of Mr. Vega. He was not his usual cheerful self, and was left constantly looking over his shoulders, paranoid about the next beating."

Other guards witnessed the beginning of these events and they did not report seeing any violent or defiant behavior from Vega before the guards pounced on him and hauled him to his cell.

Even if Vega had used a sarcastic or mocking tone when he asked the guards how their day was going (and we don't know

that he did), his remark did not justify what they did to him.

This is just one of many reasons why bail reform has since been enacted in this state—to ensure that people who are merely accused of non-violent crimes are not locked up and exposed to sadistic prison guards.

## Say Goodbye to Lou Brown

Some of you will remember Lou Brown, the Wisconsin Professor of Special Education who spoke at conferences hosted by STIC some decades ago. Lou was well-known for his insistence that any person, no matter how disabled, can do useful paid work if given the proper support. His philosophy was simple: Don't teach disabled kids "dumb stuff". An example was a child who had been con-

tinuously trying to learn how to tie his shoes for several years. Lou said, just give the kid a pair of slip-ons and move on. He said, if it's true that people with intellectual disabilities learn more slowly, then schools need to focus all of their time on individually teaching them only the things that they, personally, will find essential to enable them to maximize their independence and productivity.

Lou was an advocate for age-appropriate activities for people with intellectual disabilities. He told a story of a disabled boy named Aaron, who, one Thanksgiving when he was three years old, and attending what used to be called "nursery school", painted a "hand-print turkey" that Lou called "adorable." But when Aaron, at age 25 and in a day program, came home with another hand-print turkey, Lou said he was "livid. Kill the turkeys!"

Lou was also famous for saying "'Pre-' means 'Never.'" This referred to the common practice of continually "preparing" people with intellectual disabilities to do things, and have lives, that they were never actually permitted to experience. He believed that people with disabilities should just be immersed in real life settings, with as much support provided as necessary at the beginning, some of which might be faded out later as the person adjusted and learned.

Lou Brown was an early pioneer in the movement to close all forms of segregated residential and day settings for people with disabilities, a force of nature who responded to people who said "it can't be done" with examples of how it was being done.

Lou Brown died on May 1, 2021. He will be missed.



# STIC NEWS



## STIC's Pioneering History with Self Determination

By Rhonda White

It has been a while since we have said hello from the STIC Self-Direction Program. "HELLO!" If you recall, the Self-Direction Program is the newest to the STIC family, but we are not new to the Self-Direction world.

I recently had an interaction that resulted in a person stating, **"Why would you pick STIC? They are new to Self-Direction and even with years of experience my FI doesn't have answers, so why trust your child's future with someone new?"**

It's a very serious statement; I get it! As parents we advocate for only the best for our children. When our children become adults we hope they advocate for the very best for themselves. That is what STIC is: **ADVOCATE – KNOWLEDGE – EXPERIENCE.** So I would like to share some of the experience behind the STIC Self-Direction program so that you can advo-

cate and share your knowledge about us to others.

STIC has been involved with self direction since the concept was first discussed. We sat on project-design committees organized by OPWDD to suggest the best ways to organize the program to make it as simple as possible for consumers. We held focus groups with consumers and their families to get feedback on what was being developed, and shared the results with OPWDD. When the program was implemented (a lot differently than initially proposed) one of our Medicaid Service Coordinators (MSCs) was very active in continuing to monitor developments, provide feedback, and help people through the paperwork-heavy process. The first version of "self-direction" was known as Consolidated Supports and Services (CSS) and began as a pilot. We worked with two families in that pilot in 2011.

Subsequently it became so popular and in-demand that in 2014, it became clear that the program was too big to track without some added regulations. Even though more regulations were added, taking

away some choice, the program was still directed by the people themselves, hence Self-Direction became the name of the new program that was offered to everyone served by OPWDD if they chose to try it.

STIC continued our involvement, our staff went through the new training, and we began to explore becoming a Fiscal Intermediary, or a broker under the new requirements. We decided initially not to do so due to a variety of regulatory reasons, but MSCs nevertheless remained active in providing services and we kept up with the information being provided by OPWDD.

So as you can see, STIC not only has knowledge of the OPWDD Self-Direction program going back as far as its inception, but we played a role in seeing it get off the ground. Self-direction reflects the core of the Independent Living philosophy under which, as an agency, we operate, so this was a perfect fit for us and why we've been so involved for the last 20+ years.

As an FI, we also have extensive experience, not through OPWDD, but through the Department of Health. We've been

operating as a Fiscal Intermediary for the Consumer Directed Personal Assistance (CDPA) program since 1999, and we're extremely experienced with the approach and regulations behind it. Although the regulations under OPWDD for FIs are a bit different, the core concepts are the same as for CDPA and we are thoroughly familiar and experienced with them.

Another service, more unique to STIC, is that we are strong advocates. We know your rights and will ensure that they are never infringed upon. We will help you to navigate the system every step of the way and will support your best interests. If we see something in the program that isn't working as it should or could, we will advocate to change it.

So the answer to, **"Why would you pick STIC? They are new to Self-Direction and even with years of experience my FI doesn't have answers, so why trust my child's future with someone new?"** is simple. STIC as an agency is not new to the Self-Direction world. Our Executive Director and one of our Policy Analysts have been involved since before the program was implemented. Our individual employees have knowledge and experience with the processes, procedures and regulations that govern the program.

If you are qualified for OPWDD services and interested in the Self-Direction program, give us a call. If you know of others who are deciding right now on a new FI, please share your new understanding of STIC's experience and knowledge. We can assist people and their families to build the best budget/plan for success and independence by choosing their own staff

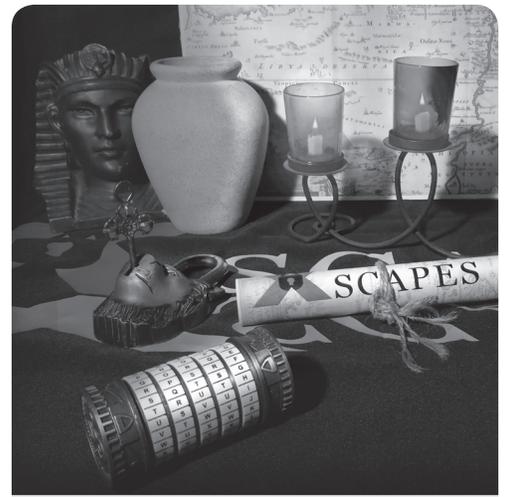
and services. Our experience in all of the components that assist you and your community supports, along with our teamwork and one-on-one approach, will make the Self-Direction experience one of growth and happiness without added stress.

Call Rhonda White at 724-2111 ext. 386 for more information. We are looking forward to meeting you.

## Online Talk Show Coming in 2022

By Todd Fedyshyn

STIC is proud to share an exciting new idea for 2022 to have a monthly online talk show. Our staff and people from our community will be interviewed to share information in reference to our mission statement. This show will air on Facebook and YouTube and will have many different topics related to changes we're seeing in the programs we administer. We're working out the details for this project currently and plan to launch sometime this spring. The show will include an intro segment, quick minute from our Executive Director Maria Dibble, breaking news, action alerts, Barrier Busters, STIC service spotlight, TRAIID Talk on assistive technology, Xscapes updates and final thoughts to close the show. We also plan to discuss and include upcoming events and other state or national topics of concern. Please stay tuned for this new show and contact us with any ideas you might want to see discussed in future episodes.



# Xscape for the Holidays!

It's that time of year again. Give the gift of entertainment and excitement, while helping STIC / Xscapes raise money to support independence in our community with the individuals we serve. Purchase your Xscapes bucks by calling (607) 760-3322 and we will mail your gift out immediately to your loved ones in time for the upcoming holidays. Xscapes bucks come in 5 / 10 / 20 / 50 / 100 and can be used to book any of our premiere escape rooms located at STIC. Your family will not be disappointed with this Xscapes Bucks gift.



## Book Reviews

### Blinded by the Light

It's a cold, blustery snow storm late at night on the Harpur College campus, sometime in the mid-1970s. A tall, thin long-haired, bearded blind hippie freak stumbles off the edge of the Library Building's loading dock and tumbles into the soft deep snow. He gathers himself, brushing the snow off his overcoat as well as his ruffled dignity, and creeps around the side of the build-

ing, his white cane plunging into and out of the snow drifts, his hand following the brick wall.

Eventually he arrives at the main entrance, and with the doors behind him, he heads off in what he thinks must be the right direction to reach his dorm in Hinman College. But after a while he realizes he is off course, unsure of where to go, and growing colder by the minute. Suddenly, he hears a tiny, tinny

jingling sound in the distance... and rescue is at hand.

This is just one of many engaging stories in Bob Gumson's memoir, *In Blind Sight*.

Some of our readers will know Bob from his time as Director of the Independent Living Unit at ACCES-VR, the state bureaucracy that is responsible for administering the miniscule general operating grants that the NYS legislature provides to Centers for Independent Living like

STIC. A rather smaller number will remember Bob personally.

I know Bob because he was a great friend of my wife, STIC's Executive Director Maria Dibble, during and after their time together at Harpur College, the liberal arts school at what was then called SUNY Binghamton and is now known as Binghamton University.

I transferred to Binghamton from SUNY Geneseo in my junior year, after Bob had moved on to graduate school in Boston, so I was not part of the core group of friends that Bob writes about in this book. I came to know several of them later though, and I can testify that Bob's portraits of them ring true.

That's not to say that everything in this book is true. Like Mark Twain's novel *Tom Sawyer* as described by his character Huck Finn, Bob's book is mostly true, but he told some real stretchers in there. Bob says a memoir doesn't necessarily have to be literally true, and he admits to some "exaggeration". Actually, some of these stories are closer to complete fantasy, but that's perfectly okay. Because this man *can write!*

It's a cliché of course, but I had trouble putting this book down. I lost a lot of sleep reading it deep into the night. Some of that, I suppose, was due to my anxiousness to find out if I was mentioned (I was, not by name but by reference, once), and to find out what he had to say about my wife. Bob doesn't tell all of the stories that I know about, and that's probably a good thing. But it wasn't just those things that kept me reading.

You might ask whether you would really find this book interesting if you didn't know Bob and his friends. I think you absolutely would.

Most of his stories convey a deep warm-hearted nostalgia and love for his friends and the times they shared. But there's more than that here.

Bob began to lose his sight as a child, due to an undiagnosed degenerative eye disease. It took years for him to become completely blind. Many of the early stories vividly describe his struggles and triumphs in adjusting to this disease process and its steady progression of losses. He

was on heavy doses of steroids as a treatment for years and experienced "roid rage" that made his behavior unpredictable and troublesome at times. He loved athletic pursuits and was good at them, but eventually was no longer able to play his beloved stickball. One truly memorable story describes his terror and panic-stricken attempts to escape when they came to his hospital room to take him away for his first of many surgeries.

You'll read about Bob's earliest fumbling romantic escapades and his later string of dozens of more or less casual girlfriends before he met and married the love of his life, Pat—who was STIC's head injury services coordinator before she took on the job of running the Traumatic Brain Injury waiver program for the NYS Department of Health in Albany. He'll tell you how he managed to attend a birthday party for the Grateful Dead's bandleader Jerry Garcia. There's a wild description of an acid trip that is very engrossing and quite realistic (don't ask me how I know that). There's also a tale of how his decades-long friendship with an obsessive-compulsive research psychologist ended when the man finally exceeded Bob's tolerance level.

Through it all runs a steady stream of music. Many of Bob's friends were musicians, including a former housemate of Maria's who became a Grammy-winning violinist, and he came to embrace a broad range of styles, from Frank Zappa to bluegrass to Yes to Billy Cobham and Pat Metheny's jazz to classical. Near the end of the book, in a striking and moving vignette, Bob speaks from his middle daughter's point of view, describing how she might cope, after his death, with the need to do something with his huge accumulation of vinyl records, cassette tapes and CDs.

The stories also gradually carry us along Bob's meandering route to rediscovering his Jewish spirituality, and leave him in his retirement in a very accepting and thoughtful space.

I wouldn't be me if I didn't point out that this book is not flawless. His use of "Ebonics"-like dialect when recounting the speech of black people is jarring and off-putting. Bob grew up in the New York City neighborhood of Canarsie, where

people speak with a very thick Brooklyn accent, but he doesn't use that dialect when relating the remarks of his white childhood friends. And although Bob had the services of a professional editor to help him with the book, there are spots where more editorial attention should have been applied; there are occasional sentences that are so garbled that it's difficult to understand what he was trying to say.

But those are very minor quibbles. At its best, the descriptive and emotional quality of Bob's prose is as high as any you may have read by any famous and revered author. One wonders what he might have accomplished if he had pursued a literary career. Instead, his professional life was focused on supporting people with all types of disabilities in pursuing their efforts to have real jobs and participate in integrated community living. He is still passionate about that, and especially about the use of braille. He quotes a startling statistic in the book: Only about 30% of blind people are employed, but 85% of those who do have jobs know how to read braille. He laments the fact that schools are not required to teach braille to blind children, and many do not.

I wholeheartedly recommend *In Blind Sight*, not only for its blind insights and its tales that will bring back familiar memories for a few of us, but for the strongly conveyed humanity of its colorful characters and their often amazing stories.

## Words of Mouth

Not long after Pat Green became STIC's Head Injury Services Coordinator back in 1988, she began getting phone calls from a "crazy woman" in Rochester who told a horrendous tale of being locked up in a so-called brain injury rehabilitation facility in Cortland, where she was abused and neglected, and witnessed her roommate being repeatedly raped by a staffer, before finally escaping with the help of a friend. The woman wanted Pat's help to get the facility shut down and its parent company, NewMedico, investigated.

Yours truly, at the time Pat's office-mate, took an interest in the woman's story, and began following news reports on the company.

The woman, Lucy Gwin, had been talking to more people than just Pat. She and a group of her friends had already managed to turn a media spotlight on NewMedico and its claims to provide specialized, intensive rehabilitation services that were effective in helping people recover from getting hit on the head. In reality, NewMedico's facilities were, on the inside, just nursing "homes", where nothing special was being done. In fact, the residents were given as little therapy as possible, while the company collected inflated fees for as long as those residents' private medical insurance lasted.

As a result of Gwin's tireless efforts, the FBI investigated the company, lawsuits were filed, and eventually NewMedico was dismantled and sold its facilities to other nursing "home" operators.

I summarized the media reports of this saga here in *AccessAbility*, while at the same time running full-page advertisements for NewMedico. Or at least, I did until company officials started actually reading what I was printing. Then the ads stopped. But the coverage didn't.

Meanwhile Gwin had become aware of the disability rights movement and decided to make it her life's work. She began by printing a magazine called *This Brain Has a Mouth* on a more-or-less bi-monthly basis. Once her efforts had succeeded in demolishing the brain injury rehabilitation industry, she shifted her focus to other disabilities and renamed the publication *Mouth Magazine*. In doing so she became one of the most unique and well-respected voices of the disability rights movement.

Lucy Gwin was a very difficult person. Until James M. Odatto, a former Binghamton *Press & Sun-Bulletin* reporter who later broke the famous Keith Raniere-NXIVM sexual abuse story while working for the Albany *Times-Union*, wrote his biography, *This Brain Had a Mouth: Lucy Gwin and the Voice of Disability Nation*, many of us didn't know that it wasn't her brain injury that made her "crazy".

Gwin, born in 1943, grew up with her sister Bridget and parents who were distracted, neglectful and/or absent. Bridget died in 1968, after jumping out a window while tripping on acid that Lucy likely

gave her. Odatto describes this incident as a suicide, though it's really not clear that Bridget understood what she was doing when she ran toward the window and then through it. What is clear is that this incident broke something deep within Lucy—something that had already been damaged by her possibly sexually-abusive, as well as absent, father.

Nevertheless, Lucy became a highly talented and reasonably successful ad writer in Chicago, working on campaigns for products such as Virginia Slims cigarettes and Mr. Clean. Disturbed by the essential dishonesty of the ad business, she dropped out and moved to Rochester to study Zen Buddhism. She started a pretty popular restaurant known as Hoosier Bill's in that city, but when it ran into the ground she went to work as a cook on ships that transported workers to and from oil rigs in the Gulf of Mexico, where she was mistreated and, perhaps, raped by the rough men who worked in that industry. She wrote a feminist memoir about those experiences, *Going Overboard*, published in 1982. Needing money, she returned to the advertising world and was working for an agency in Rochester and driving to meet a man for a date on June 14, 1989, when a car rammed her Toyota Celica and introduced her to the disabled community.

Gwin made excellent use of the skills she learned in the ad game when designing the layout of her magazines, putting together advocacy information kits, and creating the distinctive logo for Diane Coleman's anti-assisted-suicide organization, Not Dead Yet. Her magazines were pretty widely circulated in the disability rights community, but that doesn't mean they had a large number of paid subscribers. The operation was always short of money. Gwin didn't take a salary, and most of her writers weren't paid for their work, including me.

Lucy published three of my articles: a story explaining the meaning of the ADA's "reasonable accommodation" concept, using as examples Deaf actress Marlee Matlin and Mark Harmon, her co-star in an early-90s TV show called *Reasonable Doubts*; a very long piece called "Sweat and Heavy Breathing in the State Capital", written in the style of

"gonzo journalist" Hunter S. Thompson, which concerned my trip to a conference on "Choice" put on by the NYS Commission on Quality of Care for the Mentally Disabled and its Chairman, Clarence Sundram; and an article about the differences between Centers for Independent Living that were funded with 100% federal money and those that only receive New York State money.

Many people stepped up to respond to Gwin's repeated requests for donations to keep the magazine going, including internationally known activists Justin Dart, and Evan and Janine Bertram Kemp, all of whom had worked for Republican presidents on disability issues.

But Lucy couldn't hold onto friends, lovers, children or husbands for long (she was married at least twice, perhaps three times, though that's not clear, and she had two daughters from her first marriage, from whom she was usually, though not always, estranged). Invariably she would fight with them and banish them from her life. It didn't help that sometimes these fights turned physical. Again, one might attribute her occasional violence to brain damage, but she was hitting people who pissed her off long before her car accident.

Lucy Gwin died at the age of 71 in October 2014. She left behind boxes of papers, which have been housed in the University of Massachusetts archives, where Odatto was able to access them. They are online, including most, if not all, issues of *This Brain Has a Mouth* and *Mouth Magazine*, here:

<https://credo.library.umass.edu/view/collection/mums822>

Odatto's book reads much like one imagines Lucy's mind might have operated—disjointed, out of chronological order, events dimly sketched rather than vividly remembered; a portrait of brain injury in print. It is of tremendous interest to those of us who have been influenced by her, and whose lives and work have been enriched by what she managed to accomplish. It's not a page-turner; it is, rather, a painful journey illuminated by flashes of Lucy's rage and brilliance, and the hopes and tears of the people who cared about her. It is compelling, and comes highly recommended.



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