

AccessAbility

Spring 2023
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Frankly Speaking

By Maria Dibble

RETIREMENT

"The key is Frank." – Bob Dylan

Four decades ago, STIC was awarded our first grant: \$100,000 from the NYS Education Department to establish an Independent Living Center in Binghamton. Frank Pennisi and I were its cofounders, writing the initial proposal and engaging in much advocacy to get the bill passed that created STIC.

Almost forty years later, Frank is retiring, his last day being April 7, and it will mark the beginning of the end of an era for STIC.

When we started STIC we were largely clueless about running an organization, but we both had common sense and a strong commitment to the mission to assist children and adults with all disabilities to live as independently as they could in their communities. It also meant advocating for change, working to close sheltered workshops and developmental centers, and ending institutionalization of people everywhere, though I don't think either one of us had any idea how difficult the task would be—and still is, though progress has been made.

While much politics was involved in STIC's establishment, little did we know

that just about any good and progressive issue we promoted would also be smothered in politics.

For example, we had this idea in our first few years to make all polling places accessible to people with disabilities, since the only way many could then vote was through absentee ballot, which was less than satisfying and certainly less than equal. We got a lot of pushback from officials, especially in Tioga County, as well as from poll workers, some of whom said, "Why can't *Those People* stay home where they belong?" and "We don't have any of those disabled people here." And they were the nicer comments.

Frank headed up the effort, working with a very supportive person from Broome County government to survey every single polling site in Broome, Chenango and Tioga Counties on primary day (because all of the voting machines would be in the same locations on election day). We recruited volunteers and created a survey. Then Frank, the woman from the county and all of the volunteers went to each of their assigned sites to assess their feasibility to be accessible. With tape measure in hand, they had to determine the widths of doorways, whether there were stairs and

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how many, what other barriers existed, what was the parking like, was there a curb cut to the entrance, and much more.

Then followed the analysis of the data. They compiled the surveys into three classifications of polling places: totally accessible; partially accessible but able to be retrofitted with minor alterations; and completely inaccessible, the site needing to be moved. But you can't just move a polling site, you have to be able to locate it within the same precinct, making the job quite difficult in some cases. After almost two years, Broome County achieved 100% polling place accessibility, the first county in the state

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Authorship

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.

to do so, and before any law existed requiring it.

Frank's diligence, persistence and dedication were definitely major factors in this accomplishment. Later he also worked to have appropriate accessible voting machines selected by the state board of elections, another task fraught with political machinations.

In the latter part of the 80s, the first iteration of the "Americans with Disabilities Act" (ADA) was proposed in Congress, and it was a bill that immediately caught our attention and strong interest. This was it! A comprehensive landmark civil rights law for people with disabilities. We were excited at the prospect and got involved to promote its passage. We initiated and also joined rallies around the state, wrote letters, met with legislators, protested in front of entities that opposed it and much more.

It passed in three years, but sad to say, I doubt that a bill of its significance and importance could be adopted today. Back then, the Republicans and Democrats worked more cordially together. Politics was still partisan, but nothing like it is in 2023. But I digress.

Frank took it upon himself to become an authority on the ADA, learning the bill in all of its various versions, until the final piece of legislation was signed into law by President George H. W. Bush on July 26, 1990, a date many of us still celebrate as Disability Independence Day. The victory was major, and I'm proud to say we did our part to promote and see it adopted.

Once the bill was signed, regulations were promulgated, and Frank commented on every set. He became STIC's ADA expert and he is respected statewide for his knowledge and expertise. I'm fond of saying that he knows more than most attorneys about that law.

To illustrate Frank's steadfast persistence and commitment to an issue, he worked for 23 years to see Title II of the ADA (addressing state and local governments) adopted into NYS law in order to guarantee those rights would continue for New Yorkers even if the Supreme Court knocked down the federal law. Other sections of the ADA had already been incorporated into NY law, but this one took much longer, and for minor and petty reasons. Colleagues thought it would never pass, but Frank, a true advocate, never gave up. Victory was ours, and that of all people with disabilities, in the end, mostly due to Frank's determination and perseverance.

I could fill the entire newsletter with all of Frank's achievements and contributions to STIC, and it wouldn't be enough space. It suffices to say that he will be very sorely missed, as a colleague, an advocate and a friend, although his legacy will live on as part of the very foundation of our organization.

Frank, may the next chapter of your life be filled with good health, peace, and happiness! And remember, if you ever wish to visit us, just clap the heels of your ruby slippers together three times and say, "There's no place like STIC!"

*Doug's
Fish Fry
at STIC!*

March 21, 2023

11:00 am - 6:00 pm



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Turnabout is Not Fair Pay!

Disability rights advocates were justly pleased last spring when Governor Hochul signed into law a state budget that established a separate, higher minimum wage for personal care workers, and dropped the state's efforts to wipe out most of the CDPA program providers, known as Fiscal Intermediaries (FIs).

So they were deeply shocked this year when her proposed 2023-24 budget eliminated the special personal care minimum wage, cut wages for many downstate personal care workers, created an incentive for Medicaid managed care organizations (MCOs) to reduce the number of FIs they contract with, and gave the state Department of Health (DOH) new authority to eliminate FIs.

At press time advocates were hoping that the governor would rescind some of the proposals in her 30-day budget amendments. In the meantime, you need to know what she was trying to do.

Last year's budget established a new, separate minimum wage for homecare workers who provide Medicaid-funded Personal Care services, including Consumer Directed Personal Assistance (CDPA). The wage was increased by two dollars per hour above the upstate minimum wage on October 1, 2022, to \$15.20/hour, and is scheduled to go up another dollar on October 1, 2023. Most importantly, the law says the personal care minimum will always be higher than the general upstate minimum wage. So when the general wage went to \$14.20/hour on December 31, 2022, the personal care wage rose to \$16.20/hour, and when the upstate minimum wage reaches \$15 (probably next December), the personal care wage will be \$18.

But if Hochul gets her way, that will be the last increase for personal care workers for a while. She wants to tie the state minimum wage to inflation, so it will go up every year—a problematic idea for several reasons—but the personal care wage wouldn't rise again until the general wage hits \$18, and there would be no effort to keep that wage higher than the general minimum.

As advocates have said repeatedly, there is a severe shortage of homecare workers in NY and around the nation, and the reason is because homecare is a minimum wage job that is much more demanding physically and emotionally than most other minimum wage jobs. The only way to ease the shortage is to pay wages well above minimum for this work. Hochul's plan will put us right back where we were last winter, with homecare a minimum wage job and people taking better-paying, easier-to-do jobs instead of providing this essential service to enable people with disabilities to live in their own homes and participate in the community. And that's not all.

Right now, there is a "wage parity" law that requires personal care workers in New York City and surrounding counties to get the local union wage for personal care whether they work for a union shop or not. Many—but not all—"traditional" personal care providers in that region are unionized, and of course CDPA is not. Hochul wants to eliminate wage parity and apply the same inflation-indexed general minimum wage to those non-union workers. That won't just mean their wages won't stay above minimum; it means they'll be cut by a significant amount. That will drive them out of the personal care workforce, exacerbating the shortage downstate.

Last year Hochul tried to make all MCOs submit requests for proposals (RFPs) to continue their contracts with the state. There could be an upside to that idea if MCOs that have a high rate of inappropriately cutting services and, therefore, losing Medicaid Fair Hearings, could be eliminated. But we doubt that's the goal. There are at least 18 MCOs in NY, most of which serve only New York City and downstate counties. Some influential public health planners believe that when it comes to provider organizations, having fewer will better hold down health costs. They forget that it is really competition among a multitude of providers that keeps costs lower. But NY's policy makers seem to be in thrall to those planners, and it's likely that the

main reason for Hochul's proposal was to have an excuse to get rid of some MCOs. Of course, the MCOs didn't like it, and the legislature opposed it, so her plan went nowhere. She's reviving it again this year with a new twist: in the scoring process for those MCO RFPs, she wants to award extra points to MCOs that have fewer contracts with homecare providers, including CDPA providers like STIC.

DOH's previous plan to eliminate CDPA FIs was not popular with legislators either, and its "Request for Offers" (RFO) process, which required FIs to compete for a sharply limited number of DOH contracts, was flawed to the point of illegal corruption in its obvious favoring of New York City-based organizations that purported to serve large portions of the state. Rather than fight with legislators, and with providers who launched a lawsuit, to preserve it, Hochul heavily modified the contract requirements to avoid excluding any existing FIs last year. But now she's back again with a proposal to completely repeal the RFO process and give DOH "emergency" regulatory authority to do whatever it pleases to eliminate hundreds of FIs once more.

STIC agrees that there are too many CDPA FIs in the state. Most are not consumer-controlled non-profits, and many violate CDPA requirements to maximize people's control of their services. DOH should have never let them get into this business in the first place. If those FIs were eliminated, that would benefit disabled New Yorkers. But again, we don't think that's the point. The goal is simply to bow to the dictum that "fewer is better" and hand CDPA over to a few very large companies headquartered downstate, without regard for real consumer direction, provider experience, or service quality. Local control and administration, adapted to local conditions in transportation, weather, and job markets, are critical to an effective CDPA program. Without them, people will face service delays and gaps that threaten their health while centralized administrators hundreds of miles away see only the "big

picture”—meaning New York City—and view problems affecting smaller numbers of people upstate as too trivial to fix.

At press time we were hearing that there is little or no enthusiasm in the legisla-

ture for any of these proposals. Some Assembly members publicly campaigned for Fair Pay for Homecare legislation to keep personal care wages at least 150% above minimum and specifically mandate

that MCOs pass 100% of that increase through to personal care providers so the workers will actually get those higher wages. Forty state senators signed on to that bill. Stay tuned.



Governor Hochul’s initial 2023-24 budget proposal sent two huge bombs hovering over personal care wages and the CDPA program, but at press time we didn’t know if they would actually drop. Advocates immediately sprang into action to try to get them revoked, or at least modified, in the 30-day amendment period, and state legislators expressed little enthusiasm for them. We’ve covered them separately (see page 3). Hochul also announced a massive upgrade to the state’s mental health services and “affordable” housing programs, which we discuss on page 6.

So what’s left?

One big potential benefit is expansion of the Medicaid Buy-In program. As we explained last time (*AccessAbility* Winter 2022-23), the Buy-In lets people with disabilities make a decent living without losing eligibility for Medicaid and the essential long-term services and supports it provides, including homecare. Right now, an individual adult aged 65 and younger can make up to \$68,988 a year in wages, and have assets worth up to \$20,000, and continue to get Medicaid. People are living longer and retiring later, and advocates have long asked for the age limit to be removed. Hochul’s proposal will do that and a lot more, though maybe also a lot less.

It’s difficult to calculate the upper income limit because Buy-In participants must go through a process that distinguishes

“earned” from “unearned” income, and it defines earned income strangely. That \$68,988 figure presumes adjusted earned income at 250% of the federal poverty level (FPL). Apparently, Hochul wants to set the limit at 2250% of FPL, which would make the maximum salary for an individual around \$300,000, and it could be much higher.

However, in return for that, there will be some new requirements. The Buy-In got its name because it lets states charge premiums for Medicaid insurance coverage on a sliding scale. NY opted not to do so, figuring that creating an office to process premium payments would probably cost more than those premiums would bring in. But Hochul would institute premiums as follows:

Individuals with incomes between 250% and 300% of FPL would pay \$347/month. Those between 300% and 400% of FPL would pay \$518/per month. For incomes between 400% and 500% of FPL, the cost would be \$779/month, and for incomes above 500% of FPL, it would be a whopping \$1449/month. Incomes would follow the same calculation formula mentioned above, so a 250% FPL income is \$68,988, and we can theoretically project that \$80,716 would equal 300%. Annual premium cost for someone between those two limits would be \$4164, which is not chump change, but would be do-able for most while providing a psychological dis-

incentive for working to others. (It’s only psychological because if you’re not in the Buy-In, your income can only be \$20,120 if you want to keep Medicaid; that’s a whole heckuva lot less than the \$64,824 you could keep after paying your Buy-In premiums.) On the other hand, it’s unusual for people with disabilities who have jobs to even reach the 250% threshold under those rules. Also, these numbers apply to households of one person; the limits, but not the premiums, go up if you’re married and/or have dependent children. And the new rules would exclude income from “responsible family members” from the eligibility calculations.

Right now a disabled worker must only put in one hour a month of work in order to qualify. Hochul would raise this to 10 hours. Some people are apparently enrolled in the Buy-In and doing the minimum allowed amount of work purely to gain eligibility for Medicaid. Why this should be necessary we don’t know unless you have a lot of valuable assets, or a “responsible relative” with a good income. Some people’s disabilities are so significant that it’s hard for them to work ten hours a month—but if they can’t, they’d have to make over \$167/hour to lose their Medicaid under the non-Buy-In rules, which doesn’t happen very often in part-time jobs.

Hochul also wants to apply a cap at 30,000 participants to the Buy-In. This doesn’t seem like a big worry because right now only about 15,000 New Yorkers participate. But we can’t find anything in the regulations that would give the state the authority to apply a cap. The Buy-In isn’t a waiver program that allows caps; it’s an entitlement for a specified eligibility group, all of whose members must receive the benefit if they ask for it.

As expected, the new, more generous calculation for the state’s global Medicaid spending cap will allow much higher increases in Medicaid spending over the next three years, which is largely what’s

paying for all of the new stuff. Hochul is not proposing any new general taxes, but she does want an additional \$1 per pack of cigarettes, and she wants to extend previously time-limited tax increases on corporations and wealthy individuals.

There was some interest in repealing the notorious “ADL minimums” that will prevent lots of new Medicaid recipients from being eligible for Personal Care services, including CDPA, when they take effect in 2024. Senator Gustavo Rivera (D-Bronx), who chairs the Senate Health Committee, introduced his repeal bill, S.328, and there was hope that Assemblywoman Amy Paulin (D-Scarsdale) will follow suit as new chair of the Assembly Health Committee. Hochul’s budget people project huge savings from the ADL changes, and while they are entirely theoretical (and idiotic, because they don’t address the spending increases that will result from people being forced into expensive institutional settings instead of remaining in their own homes with much cheaper personal care), they’ve been used in the global cap calculations. Advocates are pushing this issue hard but prospects for success are unknown.

There’s a 2.5% cost of living increase (COLA) for providers of OPWDD, OMH, and OASAS services, which should enable a small wage increase for direct service providers. With the actual cost of living rising at 6.5% annually, that’s not nearly enough to solve the worker shortage. OPWDD and its subcontractors that run residential or congregate day programs must hire a lot more people in order to comply with the federal Home and Community Based Settings Rule. The compliance date will finally arrive in March. Among other things, those programs must have enough staff so people can have their own individualized schedules for activities in community locations of their choosing. Van rides, group park visits and movie nights won’t cut it under the new rules. However, it remains to be seen whether CMS will actually punish noncompliance in a way that really hurts. Folks who use those programs should file human rights complaints if they can’t get the support they need to do what they want.

There’s also a 5% COLA for nursing facilities, intended to combat staff shortages. Those places are certainly understaffed, but

the state could save money by downsizing them and applying that 5% to personal care wages, enabling their residents to actually get enough hours of service to live in their own homes at much less cost. The nursing facilities have been crying that they are suffering while other programs get increases, but they are lying. NY State Attorney General Letitia James has been suing them for neglecting their residents while transferring millions of dollars in profits to their owners’ pockets by means of shell companies. For example, the nursing facility rents its building from a separate company that is owned by the same people, often paying well-above market rate for the space, whereas if the facility owned its building it would not have a rent expense at all and could use the money to raise wages for its employees.

Last year’s budget included expanded eligibility for NY’s Basic health insurance plan for people whose incomes don’t qualify for Medicaid, and made Medicaid available for undocumented immigrants aged 65 and older. Those changes were to begin this year, but Hochul now wants to delay them until 2024.

Hochul is proposing level funding of \$16 million total for Centers for Independent Living like STIC, which comes out to about \$390,000 per center. At a 6.5% annual inflation rate, that represents a cut in our general operating budget.

More information on Hochul’s proposals can be found in our summary of NYAIL’s annual Disability Policy and Budget Agenda, starting on page 11.

Firestorm Ignited: NYC Mayor Eric Adams and Mental Health

On November 29, 2022, New York City Mayor Eric Adams ignited a firestorm among mental health advocates that may ultimately lead to real improvement in community mental health services (see page 6). It sure didn’t look that way at the time though.

Adams announced a new directive ordering police to forcibly take people to hospitals if, in their opinion, they seem to have a mental illness that is keeping them from taking good care of themselves. This followed a “clarification” from the New York State Office of Mental Health earlier in the year that people can be taken to hospitals for “evaluation” if, due to their mental health disabilities, they are engaging in behavior that could significantly degrade their health; imminent risk of harm to themselves or others is not required for such action.

We must emphasize that when a mental health disability leads people to be homeless, or hungry, or at risk of becoming seriously physically ill, or obviously delusional even if harmless, those are good reasons to offer them ongoing services and supports, including housing, food, clothing, medication, peer counseling, and other types of assistance. STIC strongly supports efforts to ensure that all people in those situations receive those offers and can actually get those services.

But we absolutely oppose any effort to force them to accept any of those things, or to spend time in a hospital. Forced treatment is only appropriate for people who are at imminent risk of doing serious harm to themselves or others, or who are violating other people’s civil rights. We do believe that repeatedly accosting people in public violates their civil rights, and while we may part ways with some mental health advocates as a result, we don’t apologize for that position.

Adams used an alleged major crime wave in New York City to justify his directive, a crime wave that does not really exist. As we reported last time, a temporary bump in violent crime resulting from the pandemic economic downturn, followed by some high-profile attacks in the subway, scared the more comfortable inhabitants of Manhattan last spring.

Adams, a Democrat, is a socially conservative black former New York City police captain with a mixed record on police reform. He opposed the city’s longstanding “stop-and-frisk” racial



profiling program, but he tends to circle the wagons and defend law enforcement against perceived threats, as when he called for a “revival” of solitary confinement in jails and prisons after a Rikers guard was beaten by inmates. (Despite laws purporting to end the practice, solitary confinement continues mostly unabated, though under different names, in NY correctional institutions). He is also a successful professional politician who served in the NYS Senate, and later as Brooklyn Borough President, and when his approval rating dropped from 63% after his inauguration to 29% last July, he felt a strong need to be seen to be doing something about crime.

Adams also cited compassion for people who are genuinely suffering on city streets, while falsely claiming that people frequently refuse treatment. We endorse the compassion, and we agree that something more needs to be done. But people whose mental health disabilities cause misery don’t refuse treatment very often. Most of them are simply never offered it.

Adams’ plan received national attention as another example of big cities “cracking down” on homelessness, and that resulted in a flurry of protests from local and national mental health advocates. All of those advocates emphasized the need for more housing and downplayed the more immediate need for less misery, so we at STIC wrote a position paper and distributed it broadly around the state. While it supported long-term approaches, including more permanent supportive housing, and more housing that is simply affordable by people with very low incomes, it also insisted that an extraordinary effort must be made within 60 days to canvas homeless people in New York City and offer them temporary safe housing, as well as peer support and mental health treatment, if they voluntarily chose to accept it. We pointed out that vacant hotel space, recently used to isolate people with COVID-19, along with funds that Adams said would be available to support his directive, could be used for this purpose. We tried to organize the state’s disability rights advocates to unify behind this idea, but that didn’t happen.

But all this uproar seems to have motivated Governor Hochul. Her budget pro-

posal includes a massive new infusion of funds into housing and community-based mental health services (see below), some of which mirror what we proposed in our paper. It remains to be seen how much of it will be enacted this spring.

Firestorm Quenched? Governor Hochul and Mental Health

In the wake of a national furor generated by New York City Mayor Eric Adams’ order to police to round up and forcibly hospitalize people with mental health disabilities, which brought broad attention to the deficiencies of the state’s mental health service system, and under pressure from a pending lawsuit over NY’s failure to deliver mental health services to children (see *AccessAbility* Summer 2022), Governor Hochul announced a major new initiative to increase the availability of supportive housing, so-called “affordable” housing, inpatient hospital beds, and community-based services and supports for people with mental health disabilities.

As outlined in her State-of-the-State message, and fleshed out in her later \$1 billion budget proposal, the package features both an unprecedented level of promised service expansion and a striking absence of realism about what it will take to make that expansion successful.

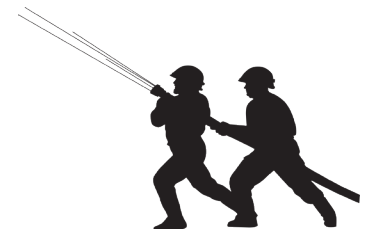
As we’ve previously reported, there is a strong link between homelessness and mental health disabilities. We emphasize that this is a cross-disability issue. Nearly all of the push-back on this point comes from a stubborn insistence that the only relevant disability is so-called “severe” or “serious” mental illness. That’s just wrong. The incidence of specific “serious mental illnesses” is quite low in American society, but mental health disabilities that contribute to homelessness also include post-traumatic stress disorder and substance use disorder. Several non-mental health disabilities, such as traumatic brain

injury, Alzheimer’s and other forms of dementia, autism, and intellectual disability are also involved. Taken together, in most parts of the country, over 50% of homeless people have disabilities that impair their ability to maintain stable housing.

There are also locations that have long-standing structural housing shortages due to a refusal to construct new housing that people with lower incomes can afford. This adds to homelessness, and while many nondisabled people can move to other places where housing is more available and less expensive, most people with disabilities don’t have incomes that can cover either moving costs or high rents. New York City is one of these locations.

Long experience has shown that the best way to address disability-related homelessness is to provide permanent housing as quickly as possible, without regard to whether the person is “in treatment” or “sober” or has a criminal record, because removing the tremendous stressor of having no place to live makes coping with everything else much easier. This is the origin of the “housing first” mantra, which calls for a massive increase in “low-threshold supportive housing.”

“Supportive housing” is a broad term. At minimum, it means housing in which tenants with low incomes get rent subsidies. It can also mean that one or more support services, like intermittent monitoring, homecare, peer support, and employment supports, are bundled in with the living space. There are lots of supportive housing programs in New York City, but many of them require tenants to be in some sort of mental health “treatment,” sober if they have substance use disorder, and free of criminal records. This last point is a big barrier for people with substance use disorder or other disabilities that led them to commit petty crimes. In November 2022, the *New York Times* reported that about 2600 of these types of supportive housing units were vacant, due to how hard it



is for people to meet the tenancy requirements. The *Times* estimated there were about 3400 people living in the streets or subway tunnels. If Mayor Adams had used those units in his plan to get homeless people off the streets (see page 5), it would have almost completely solved the problem. But he did not, likely because it's easier to order the police to pick people up and dump them in hospitals than it is to commandeer housing units that have been made useless by judgmental and bureaucratic admission policies.

You may wonder why we here in Binghamton are using so much space to talk about an issue that mostly affects New York City. The reason is because there are plenty of homeless people with mental health disabilities in Broome County and some of the other counties we serve. There is also a shortage of low-income housing, worsened by the floods of 2006 and 2011, which destroyed many affordable housing units. In Broome County, housing developers have focused on building off-campus housing for BU students whose parents can afford high rents. Further, there are almost no community-based long-term support services for people with mental health disabilities around here, which leads to an endless cycle of hospital readmissions and homelessness. Although it's obvious that Hochul undertook this initiative to try to bail Adams out of his predicament, it is a statewide project and there could be some benefit in our region.

So, what has Hochul proposed to do?

- Add “3,500 new housing units for individuals with mental illness”: This will include “500 community residence-single room occupancy units to provide housing and intensive services to individuals with serious mental illness and at the highest risk of homelessness; 900 transitional stepdown units to help individuals transitioning from various levels of care to community-based living; 600 licensed apartment units to serve individuals requiring an intermediate level of services ...; 1,500 supportive housing units ... , split between scattered-site rental units that can be opened quickly and new construction or renovated facilities completed over the next five years.” “Community residence” is a specific designation for

group homes operated or funded by the state Office of Mental Health; we don't know if that's what's being proposed here. Licensed apartments and step-down units are also OMH concepts. There's no information on how many of these units will be in New York City, and it's not clear how many would be low-threshold units. We don't know if the rules for existing vacant units will be relaxed to make them useful.

- Get unused inpatient psychiatric treatment beds back into service: During the pandemic, general hospitals were allowed to close these beds, mostly in New York City. After the pandemic ended, hospitals resisted reopening them; we don't know why but we can guess that nursing and other staff shortages are part of it. Hochul wants to bring 850 beds back online immediately, and fine hospitals \$2000 per day if they don't comply. She also wants to reopen 150 adult beds in state psychiatric hospitals, adding 100 to the 50 downstate beds that were announced last November (see *AccessAbility* Winter 2022-23). Some advocates worry that reopening beds is a step backward from an emphasis on community-based services. The thing is, we've never really taken a step forward; community-based services have always been extremely scarce. Hospital beds are needed because for many people, mental illness is cyclical; their need for intensive treatment waxes and wanes over time. There are community-based modes of intensive treatment that work, but they, like all community supports for this population, are rare, and they don't work equally well for everyone. Unlike some advocates, we don't prefer no treatment at all over voluntary time-limited inpatient treatment. Perhaps if the rest of Hochul's plan pans out and makes a lot more community-based services available, then we can reclose some beds, but some of them will always be needed. 50 of those beds will be outside of New York City, but we don't know if any will be added in our region, where the shortage of opportunities for short-term intensive treatment for people in crisis is dire.

- Policy changes and funding to require availability of treatment and supports: Hospitals will be required to “responsibly admit patients in need of care, with new

comprehensive standards for evaluation and increased state-level oversight to ensure new protocols are ... used effectively.” People who are “high-risk, high need” will be discharged to “immediately available wraparound services,” and outpatient service providers must “provide immediate and ongoing appointments for” those discharged. Fifty new “Critical Time Intervention” (CTI) teams will be created to provide the wrap-around services. CTI is just a fancy name for providing intensive supports at the beginning of a transition period and gradually fading them out after people are connected to other, ongoing supports for case management, housing, and employment. Its proponents say it is effective in preventing recurring homelessness, with research studies to prove it, but it has some pretty rigid time-limits, and can only succeed if those other long-term supports are actually available. Again, we don't know how many of these teams will be added upstate.

- More community-based services, including: 12 new CPEP programs for short-term hospital level crisis care. Our local CPEP program has a bad reputation, but it's partly due to the fact that it is tiny and must constantly reject people who really could use its services. More beds in that program would be good, but that doesn't seem to be part of the plan, and we don't know where the new programs will be located. 42 Assertive Community Treatment (ACT) teams, 20 of which will be upstate—though we don't know if any will be added here. ACT is a very good model for mobile high-intensity support services, and there has never been enough of it available. 26 new walk-in Certified Community Behavioral Health Clinics that provide both mental health and substance-use disorder services, raising the state's total to 39, serving about 200,000 people. Eight new “Safe Options Support” teams, at a cost of about \$36 million, to specifically outreach to homeless people and follow the CTI model to get them into safe permanent housing with supports; three of these will be upstate somewhere. There will also be “20 expanded-capacity Article 31 mental health clinics,” and “dozens of new care managers” will be hired to serve people with serious mental

illness via health homes. This level of expansion of community-based services and supports really is unprecedented—or it will be if it actually happens.

And finally, while not specifically aimed at people with mental health disabilities, Governor Hochul is targeting the housing shortage by proposing to “build 800,000 new homes over the next decade.” This includes “\$250 million for infrastructure upgrades and improvements to support local housing growth and development.” There is also a “New York Housing Compact,” which clears zoning rules that prevent building higher-density, lower-income housing near public transit, sets

housing targets in every community, and offers construction incentives.

This is a lot of very good stuff, but we’re skeptical about it. Almost all of it is extremely labor-intensive. To roll out these new support services, whether housing-based or not, and open more hospital beds, thousands of direct-service people must be hired. Yet there remains a critical shortage of direct service workers in medical and disability services across the state because wages have not kept up with inflation for over 15 years. Hochul, facing a 6.5% annual inflation rate, only wants a 2.5% cost-of-living adjustment for mental health service providers. That’s not going

to cut it; at that rate we’ll never be able to hire all the people we need to make those expanded services a reality. There is also a big question mark about those 800,000 housing units. \$250 million over ten years won’t fund more than a fraction of that. Hochul’s plan relies heavily on private developers biting on her new-construction incentives and ponying up billions of dollars. It also requires getting a very unpopular idea—elimination of racist, anti-poor-people zoning restrictions from our cities—through the legislature. She tried this last year and failed utterly. She’ll have to show a lot more backbone this time if this plan is going to come off.

courts watch

Baerga v City of New York: No Injunction

We reported this case last spring; Baerga and others with mental health disabilities sued New York City over its policy of sending police instead of qualified mental health crisis responders when people in crisis request help, resulting in unjustified forced hospital admissions, and sometimes, physical injuries or death.

On November 29, 2022, New York City Mayor Eric Adams announced a new directive ordering the police to seize and forcibly transport people to hospitals who, in their opinion, appear to have a mental disability because they are homeless or just don’t seem to be taking very good care of themselves (see page 5). The plaintiffs immediately filed a request for a preliminary injunction against that directive, alleging that people with mental health disabilities would be harmed by it.

Unfortunately, the judge dismissed that request on January 30, 2023. We emphasize that the case itself is going forward, but there will be no immediate court order stopping Adams’ directive.

The judge found that the plaintiffs did not have standing to request an injunction based on Adams’ order for a pretty simple reason: To qualify to request a preliminary injunction, a person “must have suffered an injury-in-fact”; it’s not enough to ar-

gue that such an injury is likely to occur in the future. The plaintiffs certainly were injured by New York City prior to Adams’ directive, but they had not been injured ***by that directive***—and they were using that directive as the reason for an injunction. That just won’t go in the courts.

The judge dismissed the case “without prejudice,” meaning the plaintiffs can come back to court to seek an injunction as soon as they are injured by the new directive. They’ll also have to show that, having been released from the hospital, they are likely to get picked up again. There should be many people in that situation by now, and hopefully we can report something next time.

Arellano v McDonough: Not Partisan

Adolfo Arellano served in the US Navy for four years, and he was on an aircraft carrier when it collided with a freighter. He was almost thrown overboard and he saw crew members being crushed to death. Allegedly as a result of this experience, he acquired post-traumatic stress disorder (PTSD), along with schizo-affective and

bipolar disorder. (We don’t have the full record of the case, so we don’t know if this claim was disputed. Schizo-affective and bipolar disorders don’t usually result from a single traumatic event, although PTSD is often misdiagnosed as bipolar disorder. Be that as it may, the Veterans Administration (VA) conceded that Arellano was seriously disabled as result of the incident.) He was honorably discharged in 1981 (apparently due to the disability) but did not file a claim for disability compensation until 2011.

The VA followed federal law and awarded the compensation, beginning in June of

that year. Arellano claimed he was retroactively entitled to compensation for damages starting on the date of his discharge because his disability prevented him from understanding that he could file a claim for 30 years, and he sued the VA in federal court. (By convention, the case is named for the current Secretary of that agency, Denis McDonough.) He lost there, and in the Court of Appeals, and now he has lost in the Supreme Court.



Some people regard this as shocking. How can it be fair (the legal term is “equitable”) for someone to be denied a retroactive claim because they genuinely didn’t know they could be compensated until after the deadline? We agree. It is shocking.

However, some people would also like to find a way to blame the right-wing judges on the Supreme Court for this. That’s hard to do, because this was a unanimous decision, with which all three liberal Justices agreed. Some people suggested that this must be because the liberals are so outnumbered and overwhelmed by the need to combat right-wing extremism in a lot of very important cases this term that they decided to “pick their battles” and cave on this one.

We don’t think so. This is about as cut-and-dried, open-and-shut a case as we will ever see.

Arellano asked the court to invoke a legal concept called “equitable tolling,” which means that deadlines can and should be ignored if they would result in serious inequities. But Supreme Court case law going back to at least the 1990s says that equitable tolling can only be applied when a law doesn’t pretty clearly prohibit it. The relevant law in this case does just that. It says you can’t collect disability **compensation** from the VA beginning on the date of discharge unless you apply for it within a year of that date. The law allows various exceptions to the rule, and it says that only those specific exceptions can result in a longer grace period. In fact, it allows exactly the sort of grace period that Arellano wants for applications for a disability **pension**.

A damage claim is different from a pension claim. Damage claims include things like lost wages and pain and suffering, and the amount may vary based on those things. A pension isn’t compensation for damages; it’s a retirement benefit for people who, due to service-related disability, couldn’t serve long enough to be eligible for the standard pension.

Congress could have applied the same rules to compensatory damages related to disability that it used for disability pensions, but it deliberately did not. The law was written by lawyers who knew all about equitable toll-

ing, and it is pretty obvious that they intended to preclude that remedy. The most liberal judge in the world could not have come to any other conclusion.

This is also nothing new; Congress has been mistreating veterans since at least the War of 1812. This isn’t a story about tensions and bargaining between liberals and conservatives in today’s newly lopsided Supreme Court. It’s just the same old disrespect for veterans on a different day.

Short Bites

FDA Unfettered

The omnibus budget bill that Congress passed and President Biden signed in December included language that allows the federal Food and Drug Administration (FDA) to ban the electric shock punishment devices used on people with disabilities at the Judge Rotenberg Center in Massachusetts. We don’t have the precise language from this law, but we previously reported that both the House and Senate had included somewhat different provisions in their bills to reauthorize the FDA prior to last year’s election. Those provisions were dropped in order to pass a “clean” bill not requiring a House/Senate conference committee to address conflicts.

Advocates called on the FDA to quickly reinstitute its ban that was quashed in federal court in 2021. An FDA spokesperson said in January that they were evaluating the omnibus bill’s language and deciding what to do next.

NY Equal Rights Amendment Passed Again

We previously reported (*AccessAbility* Fall 2022) that the NYS legislature passed an amendment to the state’s constitution that adds a lot of new items to the list of human characteristics that people can’t discriminate against, including disability. The amendment also includes a statement that being a member of a protected group (such as religion) doesn’t give a person the right to discriminate against somebody in another protected group (such as sexual orientation or gender identity). And it has wording to prevent claims that actions taken to “prevent or dismantle” discrimi-

nation against any group constitute illegal discrimination against some other group.

This would be a good thing if it actually gets into the constitution. Having passed the legislature twice, it must now go before the voters in 2024. It’s possible they will reject it, not due to the inclusion of disability, but because of those other points, which will be very controversial when voters start thinking about them, and opponents start advertising against them, next year.

It’s Mostly Over Now, Baby Blue

The Biden Administration has announced that the COVID-19 public health emergency will officially end on May 11, 2023. What that actually means is fairly complicated to explain. We don’t have space to do that in detail, but here’s a summary.

The emergency declaration, and various pieces of federal legislation that followed it, established two types of changes. One required states not to kick anybody out of Medicaid, or cut any Medicaid services for them, even if they are clearly no longer eligible for them, as a condition of receiving extra federal money to address the pandemic. This is known as “maintenance of effort,” or MOE. The other relaxed limiting regulations on public benefits, or temporarily blocked certain actions, in order to help people out during the emergency.

In its December 2022 omnibus budget bill, Congress decided to end the MOE for eligibility determinations on March 31, 2023. States will have to reassess everyone within a year of that date, and disenroll people who are no longer eligible according to the rules that existed before the emergency. There is also an MOE that applies to states that accepted enhanced Medicaid funding through the Biden Administration’s American Rescue Plan Act (ARPA); it prohibits those states from making changes to Medicaid programs that would limit eligibility or reduce the available scope of services below what was available before the emergency. This MOE will stay in effect until that extra money is spent, which NY says will be sometime in 2024.

NY has previously claimed that its ruinous new “ADL limits” on personal care eligibility were in place before the emer-

gency and therefore it should be allowed to implement them now. That claim is controversial. The ARPA rules say the cutoff date is April 1, 2020. The state enacted the new rules on that date, but they had to be approved by the federal Centers for Medicare and Medicaid Services (CMS), and they were never really put into effect. The emergency itself was actually announced in January of that year, and the first Medicaid MOE was enacted in relief legislation passed in March, before the changes were passed. The state's Department of Health (DOH) cannot produce unambiguous written proof that it received CMS approval for the ADL limits on or before April 1, 2020, and CMS apparently told them that they must not implement those changes until the ARPA money runs out.

The omnibus budget bill will also phase out other enhanced Medicaid matching funds programs by the end of 2023. However, some other forms of pandemic-related aid will be permanent. This includes expanded telehealth services, and various measures to reduce Medicaid "churn"—people who frequently lose and regain Medicaid eligibility due to factors out of their control.

Settings Rule

The long-awaited due date for full compliance with the federal Home and Community Based Services (HCBS) Settings Rule (see *AccessAbility* Fall 2016) will arrive as you are reading this, on March 17, 2023. NY, however, is woefully out of compliance. The state submitted its latest compliance plan to the feds last winter. It features such laughable items as claims that assisted living facilities and Medicaid social adult day programs are not "disability-specific programs" that must take extra steps to become integrated; that OMH supportive housing programs are not subject to the Settings Rule; and that OP-WDD's five-year plan will actually help solve the DSP shortage without raising wages. In fact, the state, which was well on its way to compliance when the deadline was first extended several years ago, and whose previously-submitted plans didn't contain such obvious nonsense, is now demanding an extension until well into 2024 due to worker shortages that it blames on the pandemic. The pre-existing

shortages, worsened by COVID-19, are mostly due to a refusal to keep the wages that direct service workers can get from not-for-profit service providers in line with inflation for nearly 15 years.

Farewell to LaTonya Reeves

LaTonya Reeves, for whom the LaTonya Reeves Freedom Act was named, died after a short illness in January 2023 at the age of 56. A black woman with a developmental disability who used a power wheelchair, Reeves "fled" a Tennessee nursing facility and moved to Colorado because she had heard about the Denver Atlantis Community, a historically important disability rights and services organization that helps people live in their own homes. She eventually went to work for the organization, helping people transition out of institutions.

The bill, successor to the Disability Integration Act, was introduced in her honor by Colorado Democratic Senator Michael Bennet in 2021. It establishes a federal civil right for people with disabilities to receive adequate supports and services so they can live outside of institutional settings in their own homes and participate in community activities, and it provides a private right of action enabling them to sue state governments that fail to provide those supports. By the end of 2022 it had 202 House sponsors, including three Republicans; in the Senate it had 22 sponsors, including 21 Democrats and Independent Bernie Sanders. It must be reintroduced in the new Congress. Prospects in the House this time may be a bit better because, with the new Republican majority, the Democratic chairman of the committee that controls the bill, who opposed it due to the influence of lobbyists for institutional programs and public employee unions, has been replaced by a Republican. Although this bill is better than its predecessor, and STIC supports its passage, it still contains an unenforceable demand that states spend their own money to massively increase the amount of accessible housing for people with low incomes. Its prospects for enactment are poor. Still, LaTonya Reeves deserves the gratitude of Americans with disabilities everywhere, and we hope that her fam-

ily and friends will take comfort from the fact that she died doing exactly what she wanted to do: fighting for her rights.

NY Bills to Watch

Keeping All New York Students Safe Act

At least one state legislator has followed through on promises to regulate the use of restraint and seclusion in NY schools, made after a series of national and local newspaper articles highlighted abuse of public school students (see *AccessAbility* Winter 2022-23). Assemblymember Michaëlle Solages (D-Valley Stream) introduced this bill as A.03311 in February.

The bill would end NY's use of physical restraints (that is, restraining a person by having other people hold onto her) in situations that don't involve immediate risk of physical harm to humans. Right now, such restraints are allowed merely to preserve the "good order" of the school. It also outlaws prone and supine physical restraints, or any other physical restraint that can restrict breathing or blood flow to the brain. Currently these techniques, which the US Department of Education says "should never be used," are permitted in NY schools. It prohibits physical restraint as a planned intervention in a student's service plan; it may only be used in emergency situations when less restrictive methods won't work, and it may only continue for as long as the immediate physical threat exists. Only personnel who have been specifically trained in acceptable methods of restraint would be permitted to carry out restraint, except in an extreme emergency when no such personnel are available.

The bill would also prohibit use of seclusion (placing a student in a room from which s/he is physically prevented from leaving by means of a locked door or other methods). It permits "time-out," which, notably, is defined as a "behavior management technique that may involve the separation of the student from the group or classroom in a non-locked setting. 'Time out' does not include seclusion or a separation of the student from which such student is physically or otherwise prohib-

ited from leaving.” This would preclude the common technique of having an employee hold an unlocked door closed by its handle to prevent exit.

The bill requires immediate verbal or electronic notification of parents of the use of physical restraint, followed by detailed written notification within 24 hours. A meeting with the parent(s), student if appropriate, employees who performed the restraint, an expert in behavioral issues, and others, must be held within 5 days to discuss the incident and ways to prevent recurrences.

This bill is remarkably well-written. All terms are very clearly defined. It applies to all public primary and secondary schools, private schools that get state funds, and Head Start programs. It provides students and parents a private right of action to sue the state if the law is violated, and it includes a waiver of the state’s “sovereign immunity” against such suits under the Eleventh Amendment of the US constitution. There is a pretty effective enforcement provision: the Commissioner of Education can revoke up to 50% of a school’s state funding if s/he finds it has willfully refused to comply with the bill’s requirements.

The one problem with the bill is that there is no requirement that schools notify a state-level authority about these incidents unless the school district is awarded a grant to do so, and even then, the district must only provide aggregated statistics about restraint and seclusion incidents as part of the grant application, and not necessarily during the three-year run of the grant. On February 6, the Albany *Times-Union* reported that Solages said she plans to add regular reporting to the state to the bill. The grant program contains a lot of good things, including funding for training of personnel, not only in acceptable restraint techniques, but matters such as federal and state civil rights laws for students with disabilities and the use of positive behavioral supports.

We don’t know what the chances are for passage. At press time there was no Senate version of the bill, though two senators, Peter Harckam (D-Westchester) and John Liu (D-New York City) have expressed interest.

Ending (most) Subminimum Wage for Disabled Workers

This ongoing project of several years’ duration for NY disability rights advocates has been reintroduced in the state legislature as an amendment to the minimum wage law. It removes language allowing payment of subminimum wage on the basis of age or disability. It permits less-than-minimum wage for jobs where a non-disabled person would get the same wage, such as stipends for interns or volunteers and payments for independent contractors such as babysitters or cab drivers. Sadly, it **may not** prohibit OPWDD’s use of subminimum wage in its prevocational services programs; it allows such wages where the recipient is a “learner” employed by an organization that exists for charitable or educational purposes.

OPWDD Reimagines Managed Care

We previously reported that OPWDD’s new five-year plan includes a project to hire a consultant to study the feasibility and appropriateness of a managed care model. Advocates, including STIC, have almost unanimously opposed this model, and have warned that when other states have tried this, it has gone badly. Some agency insiders have claimed off-the-record that managed care would never really happen, and OPWDD appeared to be listening to its critics when it announced this study. We figured if the study was done on the level, it would produce evidence supporting our position and recommend dropping the idea once and for all.

On December 28, 2022, OPWDD’s consultant, Guidehouse, issued a preliminary report with a lot of boilerplate language about how managed care could be beneficial, and very little mention of the volumes of criticism the idea has received in NY, or of the negative experiences in other states. On the whole, it does not create an appearance of objectivity on the issues.

Guidehouse says it plans to talk to various stakeholders and thoroughly review information from other states. We think that Cen-

ters for Independent Living, not-for-profit providers of community-based OPWDD-funded services, and disability-rights advocacy groups should ask to participate in that process. Final results of the report are expected in spring 2024. Stay tuned.

NYAIL Disability Rights Agenda 2023

(abridged, from NYAIL)

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL leads statewide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. Under the Hochul Administration, New York has made bold commitments to the advancement of rights and community integration for people with disabilities and older adults through the creation of the Office of the Chief Disability Officer, creation of the Master Plan on Aging and development of an Olmstead Plan. Investing in the below priorities would show real leadership from the state in advancing these critical initiatives and implementing necessary systems change. We urge the Legislature to take legislative and administrative action in the 2023-24 budget as outlined below.

NYAIL supports the following items that are discussed elsewhere in this newsletter:

- *Expanding eligibility for NY’s Medicaid Buy-In program by raising income and asset limits, while also removing the age limit, to support employment for people with disabilities. However, we object to the proposed expensive premiums and increased work requirements (page 3).*
- *Prohibit the practice of paying people with disabilities below the minimum wage in New York State. A.3103 (2022) (Steck) and S.1828 (2022) (Skoufis) (page 11).*

NYAIL opposes the following proposals that are featured elsewhere:

- *Repealing the RFO process for Fiscal Intermediaries in the CDPA program (page 3).*

- *Repealing the modest gains made in last year's budget to increase the minimum wage for home care workers, as well as repealing homecare wage parity downstate (page 3).*

Independent Living

- *Increase base funding for ILCs to \$18 million, an increase of \$2 million.*

ILCs provide critical services to people with disabilities to assist them to navigate the ever-changing service system to live independent, fully integrated lives in the community. ILCs provide a wide range of critical services based on local needs, all of which address the social determinants of health: education, employment, housing, transportation, and life skills.

ILCs also employ many people with disabilities statewide and help elevate them to positions of leadership and governance within the centers. Increased ILC funding will help continue to build future leaders and the workforce of people with disabilities. ILCs adapted quickly in the early weeks of the pandemic to meet the needs of people with disabilities. Maintaining investment in this response network is essential in being prepared for future events which disproportionately impact those we serve. Serving new populations experiencing independent living challenges can only be accomplished with renewed levels of investment, for example, assisting those with long term post-COVID disabilities and older adults who overwhelmingly want to age at home.

ILCs have been underfunded while the cost of providing services has increased dramatically, creating a crisis for centers and the people they serve. Since ILC funding is located in the State Education budget, we are left out of the cost-of-living increases provided to human service agencies. The 2.5% COLA increase proposed in the Executive Budget does not include ILCs. We are calling on our partners in state government to correct a history of inadequate support for ILCs by increasing their funding by \$2 million to \$18 million total.

Health / Medicaid

- *Address the homecare crisis by increasing wages for homecare workers to 150% of the state's regional minimum wage, as outlined in the Fair Pay for Home Care Act.*

There has long been a homecare aide shortage in parts of the state, but over the past few years, it has become an acute crisis in all parts of NY. The homecare crisis is by far the primary barrier to transitioning people from nursing homes back into the community. The state has an obligation under the 1999 Supreme Court decision, *Olmstead v L.C.*, to provide people with disabilities with supports and services in the most integrated setting, their home communities. Yet the lack of available homecare is making this impossible for many.

The 2022-23 state budget included small raises for the first time in a decade, but even after this \$3 raise, homecare workers in most of NY earn just \$16.20/hour to do the essential work of caring for our loved ones.

Now, the Executive Budget undoes this small progress by freezing wages at \$18/hour until minimum wage reaches the same rate. The issue is further accentuated for the CDPA program through the proposed repeal of Wage Parity downstate. (See page 3 for more on these issues.)

NY must include Fair Pay for Home Care in the final budget to effectively address the increasing home care crisis. Fair Pay for Home Care also ensures providers paying home care workers would get adequate reimbursement rates, which has been a challenge with last year's increase.

- *Repeal cuts to eligibility for Medicaid advanced by the Medicaid Redesign Team (MRT) II which make it more difficult for people to receive vital community-based long-term supports and services (LTSS). A.5367A (2022) (Gottfried) and S.328 (Rivera).*

NYAIL strongly supports repealing cuts to eligibility for Medicaid community-based LTSS. The MRT II was directed to achieve Medicaid savings without impacting access to services, yet they advanced proposals that make it more difficult to receive community based LTSS. The state raised the eligibility threshold for qualifying for Personal Care and CDPA. Now, people must require assistance with physical maneuvering with at least three activities of daily living (ADLs) to qualify. If they have a dementia or Alzheimer's diagnosis, they must require supervision with at least two ADLs, effectively eliminating Level

I homecare, which includes Instrumental Activities of Daily Living (IADLs), such as cooking, cleaning, and grocery shopping, things that allow people to remain in their homes. It also sets up a discriminatory standard, basing eligibility in part on diagnosis. This policy would put many people at risk of unemployment, injury, hospitalization, and institutionalization. NYAIL urges the state to repeal this policy.

- *Create a seamless comprehensive system of access to health care by passing the New York Health Act. A.6058 (2022) (Gottfried) and S.5474 (2022) (Rivera).*

People with disabilities have a right to a transparent and accountable health care system that provides accessible coverage and services based on medical necessity. The current disjointed system of Medicare, Medicaid, and private commercial coverage is difficult to navigate and fails people with disabilities. The New York Health Act would end this chaotic medical care system and simplify health care by providing New Yorkers with a comprehensive benefits package that includes everything currently covered by Medicaid, including community-based LTSS.

- *Require the Department of Health (DOH) to publish aggregate data related to homecare and CDPA on their website. A.1926 (Gonzalez-Rojas) and S.1683 (Hinchey).*

Each year, important policy decisions are made regarding homecare and CDPA, yet very little data is made publicly available, making it difficult to assess claims made by DOH. Data such as how managed care plans and counties authorize hours would provide consumers with critical information when picking a plan. The lack of available data makes it difficult to demonstrate systemic problems, such as the homecare crisis. DOH publishes similar data on their website regarding nursing homes, other Medicaid paid congregate care settings, and hospitals. This bill would direct DOH to publish similar data for homecare and CDPA on their website quarterly.

Employment

- *Waive the state's sovereign immunity to claims under the Americans with Disabilities Act (ADA) and Section 504. A.7121 (2022) (Kelles) and S.1164 (Sanders).*

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

- *Increase employment opportunities for people with disabilities by setting a 7% hiring goal for state agencies, contractors, the legislature, and the judiciary. A.3137 (2022) (Epstein) and S.1125 (Skoufis).*

One of the primary goals of the ADA was to significantly increase employment of people with disabilities. Yet their employment rate, which is roughly 34%, has not been significantly improved since the ADA became law. According to a 2019 *RespectAbility* report, NY ranks a dismal 38 among states in hiring people with disabilities. This bill seeks to change this by setting a hiring goal of 7% for the state legislature, state agencies, including SUNY and CUNY, state subcontractors earning over \$10,000, state courts and the judiciary with 50 or more employees.

Aging

- *Increase the State's funding for the Long-Term Care Ombudsman Program by \$15 million.*

The Long-Term Care Ombudsman Program (LTCOP) serves as an advocate and resource for people living in nursing facilities and other institutions. The program is intended to promote and protect residents' rights, health, and safety by receiving, investigating, and resolving complaints made by or on behalf of residents. The pandemic demonstrated people in institutions must be able to access an ombudsman when needed. LTCOP funding is insufficient to provide adequate staffing and services across NY. To address this crisis, we urge NY to increase funding to \$15 million and bring the annual investment in LTCOP to \$19.4 million, up from the current \$4.4 million. This would add staff to conduct regular and consistent visits. The Governor's 2024 budget proposal includes only a \$2.5 million increase.

Housing

- *Increase funding for Access to Home to \$10 million.*

Access to Home is an important program administered by NYS Division of Homes and Community Renewal (DHCR). It provides funding for home modifications, allowing individuals with disabilities and older New Yorkers to stay in their homes and out of costly institutions. For many, the addition of a ramp to their front door makes the difference between being able to leave the house and being homebound.

Access to Home was cut by 75% several years ago. Ever since, it has been funded at a mere \$1 million statewide, leaving many parts of the state without the program and resulting in years-long waiting lists. We urge NY to increase HCR funding to \$10 million. By investing in Access to Home, older adults and people with disabilities will remain in their homes and out of institutions. NY will more than recoup this investment in other state agency expenditure reductions.

- *Mandate annual reporting on Access to Home for transparency on how the limited funds are spent and to assess unmet needs. A.9631 (2022) (Hunter) and S.8209 (2022) (Mannion).*

Basic data is not available to assess the need for more funding. This bill would direct DHCR to collect and report program data on an annual basis and make it available to the public.

- *Create a Visitability Tax Credit to help homeowners make their homes more accessible.*

Despite strong and continued support from the legislature, the Visitability Tax Credit bill (A.3409/S.7365 of 2022) was vetoed again. This is a priority for the disability community. A tax credit would help keep people in their homes and out of institutions by assisting them with the costs of making their homes more accessible. NYAIL urges the legislature to include the \$1 million pilot program in the state budget.

- *Create minimum standards for the design and construction of new homes that receive state or federal assistance to make them more accessible. A.1625 (Simon) and S.763 (Krueger).*

Most existing housing stock was not built to meet the needs of people with disabilities, including disabilities acquired as one ages. Housing built with basic accessibility features—known as “inclusive home design” or “visitability”—can meet people's needs throughout the lifespan, allowing for visits by friends/family members with disabilities and avoiding costly renovations.

Government Operations

- *Restore the Interagency Coordinating Council for Services to Persons who are Deaf, Deafblind or Hard of Hearing within the Office of the Chief Disability Officer (CDO).*

The CDO was established to ensure a voice in state government for all people with disabilities. The state needs to better address deaf issues at the policy level, and additional resources for the CDO is the best place to do so. (*Editor's note: This is part of the governor's budget proposal.*)

Transportation

- *Require counties to expand paratransit beyond ADA minimums. A.3181A (2022) (Steck); S.5092 (2022) (Kennedy).*

The limited availability of accessible transportation services is a major barrier faced by people with disabilities, often leading to unemployment, inability to access medical care, lack of access to voting sites, and isolation from friends, family, and full community participation. The failure to provide paratransit service throughout the state is a major contributor to this problem.

The ADA requires that counties provide accessible paratransit service to disabled people who are unable to take the fixed route bus. At minimum, paratransit service must be provided to disabled people within $\frac{3}{4}$ of a mile of the closest bus stop. As fixed route bus lines are eliminated, people are being cut off from paratransit service. This leaves people stranded, without services, or the ability to work or attend houses of worship or medical appointments. NY could address this by increasing the minimum service provided to people who rely on paratransit.

Elections

- *Change local, village, county, and City of New York elections to coincide with the dates of state and federal elections. A.8560 (2022) (Paulin) and S.6197 (2022) (Skoufis).*

People with disabilities are still fighting for our right to a private, independent vote. Progress was made through the Help America Vote Act (HAVA), which mandated all polling sites to have accessible, universally

designed voting machines for all state and federal elections. Yet local elections are not held to the same standard and are often administered using paper ballots only. Paper ballots are inaccessible to many people with

disabilities. Moving these elections so they coincide with state and federal elections and are administered by the County Board of Elections will ensure they will be held in an accessible manner.



STIC NEWS



Scouts Share a Disarming Experience

By Lucas Stone

On the evening of Thursday January 26, the halls of STIC were filled with curiosity and excitement as we hosted a troop of Wolf Scouts and Webelos pursuing their Aware and Care Adventure badges.

Per the Wolf Scouts/Webelos website: "Aware and Care is one of the Webelos/Arrow of Light elective adventures. For this adventure, Webelos learn about the challenges faced by people with disabilities. By thinking about how people are different and people are alike, Webelos will appreciate that every person has strengths and weaknesses. By working together, we can help one another and make life better for all."

The roughly 20 Scouts were treated to demonstrations by Stephanie Quick, Beth Kurkoski, and Lucas Stone. Stephanie Quick, Education Advocacy Specialist, led the scouts through a communication exercise involving iPads in which they had to relay messages non-verbally to one another. Scouts problem-solved and overcame various roadblocks pertaining to speech and communication using specific programs installed on the iPads.

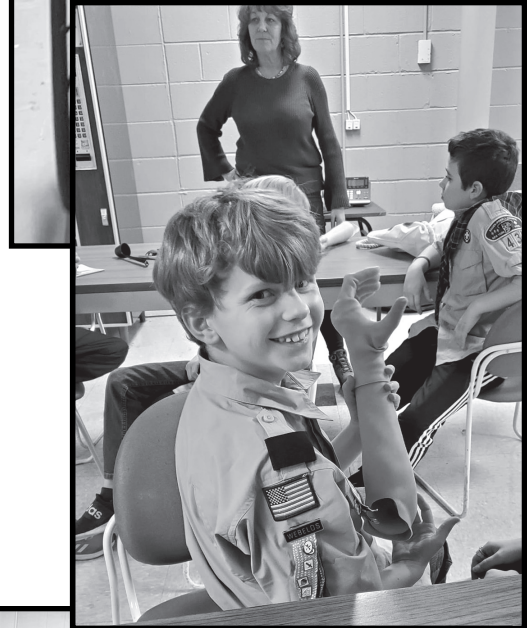
Beth Kurkoski, an Early Childhood Family and Community Engagement (EC-FACE) specialist, provided a unique experience for the scouts: letting them try to guess what her disability was! A surprise reveal confirmed one astute Scout's suspicions; that Beth had a prosthetic arm! The life-like arm was removed and inspected. Other various arms that Beth has utilized

over the years were also passed around, including a robotic arm!

Lucas Stone, Technology Related Assistance for Individuals with Disabilities (TRAID) specialist, guided the Scouts on a tour of the medical equipment loan closet. Of particular interest was a device called the Quadstick. The Quadstick controls the actions on screen via a sip/puff input which allows quadriplegics the freedom to play their favorite video games. The gamer sips and puffs on a straw in certain combinations to perform specific tasks that are programmed into the device.

The grand finale was a wheelchair race through the lower halls. Scouts were timed on a course that included turns and an incline at the very end for an added challenge. Loud sighs of relief could be heard after the final ascent to the finish line!

The demonstrations set up for the Scouts taught them a broader understanding not only of some of the challenges people with disabilities face on a daily basis but also the ways in which they're able to overcome those challenges. Stephanie, Beth, and Lucas helped to instill in the Scouts STIC's core beliefs that the world should be accessible to everyone and free of barriers to live independently!



STIC is Now in a Family Way!

By Kelsie Seyler

STIC is proud to announce our newest program: Children and Families Mental Health Counseling is now accepting referrals.

This unique program is the first of its kind in Broome County. The program is designed to provide counseling services for children ages 5-21 who have co-occurring mental health (MH) and intellectual/developmental disability (I/DD) diagnoses. This has been a significantly unmet need in our local community for many years. Dually diagnosed children rarely receive adequate and quality treatment for both disorders, and frequently are shuttled between MH programs and I/DD programs due to a failure to recognize the complexities inherent in dual diagnoses. The program goals for children are to increase emotional stability, socialization skills, enhance or maintain relationships and friendships, improve educational outcomes, develop coping mechanisms for stress and anger, and improve sense of well-being. Program activities will include one-on-one counseling, community

outreach, support groups for children, and family support/counseling. The program will serve individuals and families currently residing in Broome County.

Kelsie Seyler has a master's degree in social work and a variety of experience working with kids, adolescents, and adults in school, community, residential, and home-based settings. Most recently, she worked as a live-in coach where she provided 24/7 support to people with mental health diagnoses—focusing on creating and implementing life skills and recovery tools. Kelsie's experience in school settings includes focusing on development of skill building strategies with neurodivergent children, participating in IEP meetings, and providing mental health services, both individually and in small groups. Kelsie has also provided life skills support to individuals with intellectual/developmental disabilities in the community which included self-care tasks, general household chores, money management skills, appropriate social behaviors, safety skills, and adopting healthy lifestyles. She has also trained and mentored new staff to do the same.

Please contact Kelsie Seyler at kelsies@stic-cil.org or (607) 724-2111 ext 378.

history of her life and finding hidden secrets and gems discovered in her tomb by your archaeological team.

Xscapes is also proud to announce a partnership working with Binghamton University to have projects completed by students to help increase the tech in our rooms while challenging students to be creative thinkers. There will be six projects completed this spring for "Last Pharaoh Standing" and "Exit Protocol".

Xscapes is also preparing for a summer of great mobile escape room fun. Please consider renting one of our mobile escape rooms for school functions, corporate team building or outdoor fun of any kind. Xscapes is proud to offer "Immunity Quest" and "Black Beard's Curse" for your mobile experience. Contact us on our cell phone to discuss options and pricing.

As always, please feel free to book an escape room at www.Xscapes-STIC.com or call (607) 760-3322 for more information.



A Truly Frightening Award

By Maria Dibble

STIC is very pleased to congratulate our own Todd W. Fedyshyn for receiving a very prestigious award related to his work in the Halloween Haunt industry, and for his outstanding haunt "Reapers Revenge".

From the website of the Haunted Attraction Association: "The Haunted Attraction Association loves awarding those that the industry thinks deserves the highest recognition ... an OSCARES award! These awards are highly coveted and are the best of the best. The President's Award is given to an individual that has dedicated years of supporting / advocating for the industry and for demonstrated excellence in the haunted attractions field. One person is nominated and honored each year with this award during the OSCARES Award Banquet at the Transworld Halloween Trade Show in St. Louis."

If there is anyone who lives, breathes, thinks and dreams about Halloween, and deserves this award, it is Todd. Some of you may remember STIC's "Haunted Halls of Horror". Well Todd was one of the cofounders and scary minds behind the event. He is creative, energetic, and yes, sometimes scary. Not really, but he loves to scare people, and he'd probably haunt all year round if he could. Fortunately, he is also creative in other areas, for instance, our Xscapes rooms. You can see for yourself by checking one out sometime.

We all applaud you Todd, for your achievements, ingenuity and creativity. Knock 'em dead! (Then you can use them as a special attraction. Heheheheheh....)



Xscapes

By Todd Fedyshyn

Xscapes / STIC is proud to share our exciting new escape room "Last Pharaoh Standing: the Life and Legacy of Cleopatra". This will be our fifth game for our successful escape room fundraiser here at Southern Tier Independence Center and will open in early May 2023. Cleopatra was queen of the Ptolemaic Kingdom of Egypt from 51 to 30 BC and was the last active ruler of the Egyptian Empire. She was a member of the Ptolemaic dynasty, and a descendant of its founder Ptolemy, a Macedonian Greek general and companion of the amazing Alexander the Great. Your journey will involve learning the



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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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