

# AccessAbility

Spring 2022  
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## Happy Valentine's Day!

*By Maria Dibble*

In all of my 38 years as Executive Director of Southern Tier Independence Center (STIC), I have never been able to write an editorial or an article that thanked a governor for giving Independent Living Centers a budget increase.

Until Now! Governor Hochul provided a \$2.6 million increase for ILCs around the state. There are 41 centers, and as long as the funding remains in the budget, we'd receive a \$63,000+ increase in the ILC contract through ACCES-VR. You may think that it doesn't sound like a lot of money, and compared to our overall budget it is not, but the point is that this governor chose to recognize the work of the ILCs, and for the first time in my long history, has given an increase, instead of us having to get the legislature to do so. Considering that we went almost 15 years with only two tiny cost-of-living increases, you can see why this has made me so enthusiastic.

Governor Cuomo, over his long 12-year tenure, systematically vetoed every disability-related budget bill supported by the ILCs, and he never offered us a funding increase. He decimated the Consumer-Directed Personal Assistance Program by cutting eligibility and limiting the people

that could qualify for the service. The impact of those changes hasn't been noticed yet because they haven't gone into effect due to COVID.

In addition to a funding increase, on Valentine's Day, February 14, 2022, Governor Hochul signed the bill reinstating the NYS Office of the Advocate for People with Disabilities, (renamed the Office of the Chief Disability Officer) a bill that Cuomo vetoed even though his father originated the office. I'm not so naïve as to think that the governor will support all of our initiatives, but at least she's listening to our concerns. It has been a long time since anyone in her position has done so, and we appreciate it.

As we thank the governor and are grateful for her support, we also strongly urge her to consider the dire crisis we are facing in the field of home care, where there is a chronic deficit of workers due to poor wages. The Fair Pay for Home Care bill, which has bi-partisan support in the legislature, would correct the problem and pay a living wage that recognizes the importance of their work, work that keeps people with disabilities at home, independent, and alive. What could be more important than that?

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An overwhelming majority of home care workers make so little that they have to access benefits like SNAP ("food stamps") and Medicaid. If they were paid sufficiently, they would no longer need government assistance to live. This would save money for NY, and the extra spending the workers would engage in would boost our economy. No matter how you parse it, the Fair Pay for Home Care bill makes good sense.

We are happy that our relationship with Governor Hochul's office has begun on such a positive footing, and we look forward to working with her throughout the legislative cycle.

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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.

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# Hochul's First Budget: What's Not to Like?

Governor Hochul's first proposed state budget is a massive, COVID-relief-fueled down payment on a restoration of sanity to New York's disability services system. That being said, there are still big pockets of irrationality that haven't been touched.

Advocates had been wondering what was going to happen to all of the Biden Administration's American Rescue Plan Medicaid money. It appears that after the first couple of rounds of public paperwork exchanges (see *AccessAbility* Winter 2021-22), the feds at the Centers for Medicare and Medicaid Services (CMS) and officials at NY's Department of Health (DOH) got down to brass tacks in private and hammered out a plan to let NY's budget process determine how most of the money will be spent. Also, state tax receipts came in at about three times higher than projected. As a result, the state has a budget surplus of about \$5 billion this year, which is expected to grow to about \$6.4 billion next year, and surpluses are projected through at least 2026.

So how are we all gonna get rich?

Hochul has proposed a whopping 5.4% cost-of-living adjustment (COLA) for organizations that provide various state-agency-funded services. The agencies include the Office for People with Developmental Disabilities (OPWDD), the Office of Mental Health (OMH), the Office of Addiction Services and Supports (OASAS), and others. But if you work for those agencies, don't get too excited yet. The providers get to decide how to allocate that money; it may go to wages, but it also may go to infrastructure. Not-for-profit providers have been squeezed by year after year of cuts to their contracts; most of them will need to make up for those losses, and inflation is currently running at around 7%, with medical inflation much higher. Agencies like STIC will need to use some of this money to address rising health benefit costs as well as increases in things like the costs for heat and electricity, internet and cybersecurity services, and more.

Hochul is also offering one-time retention bonuses to people who work for those providers, and to homecare workers funded through DOH. Here's what we know: To get a bonus, you would need to have worked in one of these types of jobs for at least six months beginning before March 31, 2023, and your annual salary must not be above \$100,000. The bonuses will be paid for each of two such six-month periods. The amount you'd get each time depends on your average weekly hours: If you average 20-30 hours per week, you'll get \$500; for 30-39 hours a week, it's \$1000; and an average of 40 hours a week will get \$1500. The maximum any person can receive will be \$3000. We don't yet know when these payments will start.

Hochul wants to restore the previously-enacted 1.5% "across the board" cut to Medicaid programs (as we've said, not really across the board, but applied to most fee-for-service and managed care rates), and she wants to increase those rates by another 1%. We don't know if "restore" means we'll get back pay or if it just refers to payments going forward. Again, how providers use this money will be up to them.

There is also about \$40 million in the proposed budget to support previously-scheduled minimum wage increases. Upstate the non-fast-food minimum wage is currently \$13.20/hour; it will rise again on January 1, 2023, though we don't know by how much.

As mentioned in our editorial, Hochul is the first NY governor who has proposed to increase funding for Centers for Independent Living like STIC in living memory. Her plan would provide \$2.6 million for the 41 centers, or about \$63,000 each. That's not chump change, but it's not a lot either, considering what inflation has done over the past decades, and especially this year at 7%.

There's a pretty big proposed win on the hated Global Medicaid Spending Cap. This cap on the rate of spending increases was a bogus marketing tool for the Cuomo



Administration; when he wanted to cut something, like homecare, Cuomo cited the need to avoid exceeding the cap. But when he wanted to give money to his cronies in the nursing home and hospital industries, an “exception” was made while he continued to tout his success at “bending the cost curve.” Cuomo’s cap was often cited as 2% per year, but that’s not accurate. It was whatever percentage the 10-year rolling average of the medical portion of the federal Consumer Price Index worked out to be. Hochul wants to change the formula to the 5-year rolling average of CMS’s National Health Expenditure projections, and she wants it to continue through 2024. That number accounts for growth in the number of people who receive Medicaid, as well as the increasing needs of our aging population. It should make a big difference in how year-to-year Medicaid rate increases are calculated, though advocates still want the cap to be eliminated completely.

Another big win is a proposal to increase income eligibility for seniors and people with disabilities who want Medicaid to the same level that applies to nondisabled people (138% of the federal poverty level), and also get rid of the asset limit for those two groups.

Hochul would like to expand income eligibility for the state’s “Essential Plan” (health insurance for low-income people) from 200% to 250% of the federal poverty level, and increase that plan’s coverage of long-term services and supports.

Most of these Medicaid expansions will require CMS approval, so don’t look for much to happen before the end of calendar year 2022, even if all of these changes are passed by the legislature.

Hochul’s proposed budget contains \$25 billion over five years for housing, though most of it would pay for supportive housing. The devil’s in the details on how good that is. We keep reminding advocates that simple rent subsidies are included in the definition of “supportive housing,” so this doesn’t necessarily apply only to programs that require residents to accept social services. But we don’t know for sure how the money will be divided up.

A few years back the feds enacted a program to designate 988 as the nationwide

telephone hotline number for people who are experiencing a mental health crisis (this is often called the “suicide prevention hotline,” but that’s not the only thing it can be used for). This is supposed to take effect in July of this year. Most states have not gotten this set up yet, including NY, but Hochul is proposing \$35 million for fiscal year 2022-23, which begins April 1, and \$60 million for 23-24. Again, the devil’s in the details, but this could be designed to ensure that 988 calls for help would only dispatch actual mental health peer and professional support people, and not armed police looking for a fight. Also, advocates would prefer permanent funding through a tax on phone service so this doesn’t have to be made a part of the budget every year.

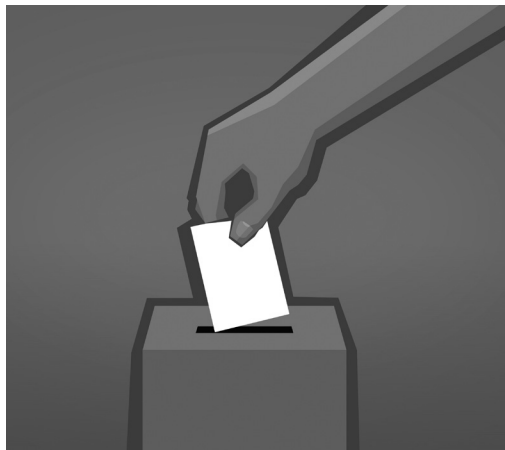
So what could possibly be wrong with all this largesse?

There is no significant wage increase for homecare workers. There is a retention bonus, but it only applies to people who are already working in those jobs. It won’t help people who can’t get personal assistance services because there aren’t enough workers to go around. There are funds that help raise those wages, but the way it looks right now, it’s not nearly enough. In upstate NY we have to compete with fast food workers, who are guaranteed at least \$15/hour. These changes may keep some current workers from quitting for another year, but that’s about it. Homecare is a much more demanding job than flipping burgers, and we need to make the wage scale more attractive than what McDonald’s offers if we are going to put a real dent in NY’s homec-

are shortage, which is the worst in the nation, according to a report by major health insurance benefits provider Mercer Global. As we went to press, advocates were still pushing very hard for the “Fair Pay for Home Care” plan to increase personal assistant wages to 150% of the minimum wage. This year there is a huge amount of support in both houses of the legislature to enact some version of that plan—and that includes some Republicans, like our region’s Senator Fred Akshar. Hochul’s budget director Robert Mujica, a Cuomo hold-over, said that the \$40 million for planned minimum wage increases should be enough to address the problem. That’s just wrong. The state’s Medicaid Director, Brett Friedman, claimed that DOH couldn’t guarantee that money allocated for wage increases would actually reach workers because it passes through service providers who could hold onto it. That’s ridiculous. It’s true that managed care plans have done such things, but it’s only because DOH refuses to carefully monitor what those plans do. And the Fair Pay bill contains explicit language requiring homecare providers to raise those wages.

Finally, on the red-herring front, Hochul, like Cuomo before her, wants to eliminate the “prescriber prevails” rule for Medicaid-funded prescriptions. This rule allows doctors to override Medicaid drug formulary exclusions of specific medications when medically necessary. This gets proposed every year and defeated every year, and we hope the same happens this year.





# *Vote!* It's Already Easy, and May Get Easier

2022 will be another critically important year for voters. We've all heard a lot about how various states have passed laws to make it harder for people to vote. That didn't happen in NY, although the voters failed to approve some initiatives that would have made things easier here. We need to remember that despite all this, *it's still pretty darn easy to vote*, compared to the many really hard things that most people have to deal with on a regular basis. The main thing that's required is for people to make the effort.

We also know that many polls have consistently shown that most Americans support a broad range of progressive ideas. No matter what right-wingers say or do, all we have to do to get those ideas enacted is show up at the polls in our huge majority numbers and vote for them. In 2020, over 66% of eligible voters cast a vote. That's a pretty high number historically for the United States. But if, say, 85% voted, not just for president but in EVERY election, we would be virtually guaranteed of passing a progressive agenda.

So we're going to push voting, starting now. The NY State primary election will take place on June 28. It's time to get registered to vote, if you aren't already. **Please:** register, and vote. Do it even if it's inconvenient. Do it even if you're blind and you have to get somebody to help you and that makes you mad. Do it even if you have to take unpaid time off from work. Do it even

if you have to get "on the grid." Do it even if you have to dig up some documents to prove that you are eligible. Do it even if you have pay cab fare to get to the polls. Do it, NO MATTER WHAT.

This year Governor Hochul is trying to make it easier to register to vote. She has proposed to set the deadline to register at 10 days before election day for hand-delivered forms, and 15 days for postmarked mailed forms. That's an improvement over the current 25-day rule, but we don't know if it will pass, so don't procrastinate. If you aren't registered yet, please get on it right way.

Hochul also wants to require at least one polling site on or near any college campus with at least 300 students. That should also help younger voters, who usually have a low turnout rate. But again, don't wait for this change to pass, and don't refuse to travel a bit to vote if it doesn't pass.

VOTE, no matter what it takes. It is the single easiest and most effective thing you can do as a citizen to make things better.

## Is Repeal More Appealing?

There have been a few developments in the personal care saga since our last issue. As we've reported (see *AccessAbility* Winter 2021-22), most of the really damaging changes to personal care eligibility have been on hold to comply with the federal "maintenance of effort" (MOE) requirements for states to receive COVID-related Medicaid funds. Those requirements will now be in place until at least April 16 of this year, following another extension of the official federal pandemic health emergency.

One of those changes, the so-called "Independent Assessor" who would determine whether a person needs personal care, was projected to take effect in March but is now delayed until at least May 1. The state's Department of Health (DOH) has acknowledged that the designated assessor, MAXIMUS, is not likely to have enough workers to handle the massive influx of new work before then, and maybe not even after then. There are, conservatively speaking, several hundred thousand people who receive personal care whose needs must be assessed

each year. Currently various county social services departments and managed care companies assess a few thousand of them each. That's huge amount of work to suddenly move into one location.

Assemblyman Richard Gottfried (D-Manhattan), the chair of the Assembly Health Committee, introduced a bill to repeal the Independent Assessor and substitute a person-centered planning process. Upon first review, it looks promising. It's Assembly bill A.9023.

There is, again this year, a bill in both houses of the state legislature to repeal the worst eligibility changes. In the Senate, it's bill number S.5028; in the Assembly it's A.5367. It would restore personal care eligibility rules to what they were before April 2020. That would mean the return of the availability of stand-alone Level 1 "housekeeping" personal assistance services for people who are found to need them, regardless of whether they also need more intensive help with so-called "Activities of Daily Living" such as mobility or using the toilet. It might also mean the Independent Assessor would be gone, as well as the new prohibition on having your own doctor order homecare services for you. We don't know how much support this bill will get this year, though our own Assemblywoman Donna Lupardo has signed on, and Senator Gustavo Rivera (D-Bronx) told a Staten Island news website that it will be part of the discussion with the governor during budget negotiations. Last year it didn't get very much attention.

A group of mostly for-profit home health-care providers billing itself as New York Advocates for Home Care, along with other "advocacy groups," have filed suit against DOH in the NY State Supreme Court for Albany County for refusing to provide requested records on how it conducted its apparently arbitrary and capricious review and approval process for the Request for Offers (RFO) for CDPA Fiscal Intermediaries (FIs) that led to denial of contracts to most of the FIs in the state, including STIC. Although STIC is not a party to this suit, we applaud the efforts of anyone seeking to expose what really happened here.

# Nursing Homes Hound Hochul

We reported last summer on a new state law to establish minimum staffing requirements for nursing facilities and to require them to spend at least 70% of their revenue on “direct resident care,” including 40% for “direct resident-facing staffing,” beginning in January 2022. The nursing facilities, predictably, sued the state in federal district court over these requirements on December 29. The complaint charges that this is an illegal “taking” of private property for a public purpose, and a violation of the US constitution’s Supremacy Clause (which says that federal law supersedes state law) because federal law designates the Medicare dollars those facilities receive for the use of those facilities. The complaint contains detailed information on how much the facilities would have to pay back to the state if the law takes effect. Advocates say this data proves that most nursing facilities have plenty of “excess profits” that they could use to improve the quality of their services. The facility operators dispute that interpretation. We didn’t have time to review the numbers and form an opinion before we went to press.

The nursing facilities also argued that due to pandemic-related staffing shortages, they would not be able to meet the minimum staffing requirements. Governor Hochul bought that argument; she signed an executive order on December 31, delaying those requirements until January 30. On January 31, she extended the delay to at least March 1.

Meanwhile, the Long Term Care Community Coalition released a detailed report on the extent to which nursing facilities are illegally using anti-psychotic drugs to dope up residents and keep them quiet instead of hiring enough aides and paying them enough to keep them working to serve those residents. Nationally, almost 21% of nursing facility residents are given those drugs, even though the incidence of actual psychosis in the general population is in the low single digits. It’s illegal to use anti-psychotics as a form of chemical restraint, so the facility doctors are writing prescriptions on the basis of bogus diagnoses. The report included these figures:

Three nursing facilities in Broome County had drugging rates over 20%: Absolute,

Bridgewater, and Vestal Park. Four were above 15%: Elizabeth Church Manor, Good Shepard Village Endwell, Good Shepard Fairview, and Willow Point. Only two were below 10%: Ideal and Susquehanna, though both of them were still well above the rate that they should be at. You can read more here: <https://nursinghome411.org>

On December 9, 2021, the *New York Times* published a detailed account of how the federal government’s “Care-Compare” nursing facility rating website contains highly misleading information about the quality of many nursing facilities. Facilities that are cited for serious deficiencies are allowed to appeal before the citations are made public, and even if they lose those appeals, often those citations never get factored into the Care-Compare ratings. As a result, there are facilities with 5-star ratings that have seriously injured or killed residents through abuse or neglect. The federal Centers for Medicare and Medicaid Services (CMS) acknowledged that there are “problems” with the website and claimed it is working to fix them.

## courts watch

### Rotenberg Redux

Last time we reported that the Rotenberg Center, which tortures people with disabilities by means of electric shock, had won its appeal of the federal Food and Drug Administration (FDA) plan to ban the electric shock devices it uses. A three-judge panel of the District of Columbia Circuit Court of Appeals overturned the ban. The FDA exercised its right to request that the full court reconsider the decision. The court refused.

Advocates are now calling on the FDA to quickly issue a revised rule to get around the court’s objections. The agency can easily do so by banning only electric shock devices that cannot be removed or controlled by the wearer, as we suggested last fall.

### Rite-Aid to Provide the Right Aid

Some time last year the federal Department of Justice (DOJ) reviewed the Rite-Aid drugstore chain’s COVID-19 vaccine website for accessibility “compliance.” All we’ve seen is a November 1, 2021 settlement agreement between the company and the United States Attorney for middle Pennsylvania, so we don’t know what prompted this action. Presumably civil rights complaints were filed, leading to an investigation, and DOJ threatened to sue the company.

Rite-Aid’s page for scheduling COVID-19 vaccinations had several problems. For example, people who use screen readers could not find available appointments on the

page’s calendar, and “people who use the tab key instead of a mouse could not make a choice on a consent form that they needed to fill out before scheduling their appointment.” Digging into the guts of the web page, reviewers found “(1) certain images, buttons, links, headings, and form fields that were unlabeled or had inaccurate alternative text or labels; (2) pop-up windows and error messages that were not reported to screen readers; and (3) tables that were missing header information and proper mark-up.” Those are all common, easily-fixed problems with inaccessible websites.

What’s shocking is that Rite-Aid claimed that it followed the industry-standard guidance for making websites acces-



sible: the World Wide Web Consortium's WCAG guidelines (Web Content Accessibility Guidelines, at [www.w3.org](http://www.w3.org)). They said they hired a web accessibility consultant and used an automated tool to scan their site for WCAG compliance issues. Sadly, it continues to be our experience that people who claim to be experts in this field often aren't.

The settlement required Rite-Aid to fix the website by the end of last November, although if they had trouble they could seek brief extensions from DOJ. Rite-Aid also must continue to use consultants and automated tools to periodically review the site's accessibility and provide reports to DOJ. Unfortunately, Rite-Aid can continue to use its current consultants, who apparently didn't know what they were doing, and its current tools that don't seem to actually work.

It is notable that DOJ took the position that Title III of the Americans with Disabilities Act (ADA) definitely requires websites to be accessible, and that "compliance" requires following the WCAG guidelines. This has been a matter of much dispute in the courts, as we've reported (most recently in *AccessAbility* Winter 2021-22). DOJ's argument is that even though the ADA allows public accommodations to offer alternative methods to access their programs, goods or services, such as by telephone instead of a website, the ADA's requirement that the benefits provided to people with disabilities must be equal to those provided to others, effectively requires organizations to ensure that people with disabilities can obtain everything those organizations offer the public in pretty much the same way that non-disabled people can. Federal appeals courts covering New York and several other states have supported DOJ's position, but the Third Circuit court governing Pennsylvania has ruled that only physical locations are required to be accessible. In taking on this case, DOJ was setting itself up to be slapped down by the Third Circuit, leading

to an eventual appearance in the Supreme Court. It's surprising that Rite-Aid chose to settle rather than continue to fight a case that it had a good chance to win.

### ***Payan v LACCD:* Paving the road to hell**

Title VI of the federal Civil Rights Act of 1964 states, "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Section 504 of the federal Rehabilitation Act of 1973 says, "No otherwise qualified individual with a disability in the United States ... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." The Americans with Disabilities Act of 1990 (ADA) provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."



What do we mean when we say discrimination happens "on the ground of," "by reason of,"

"due to," or "because of," something like race, sex, or disability?

Right-wing judges have been saying for over 20 years that it means that it's only discrimination if it's intentional. In fact, these judges keep saying that because the "plain language" of various civil rights laws use those phrases, those laws only outlaw intentional discrimination. That argument is completely nonsensical. The "plain language" here has nothing to do with anyone's intent. The earth is warmed "because of" the heat of the sun. Does that mean the sun intends to heat the earth? Houses are destroyed and people are killed "by rea-

son" of the fact that a river overflowed its banks. Did the river intend to kill and destroy? A child grows into an adult "due to" the nutritional content of the food s/he eats. Did the food intend to grow a human being? Okay, only humans are believed to be capable of having intent. But that doesn't mean that every harm that people cause is intentional. The definition of "involuntary manslaughter," for example, literally states that someone was **unintentionally** killed, but it's still illegal. Causes and effects occur routinely without anyone intending them. And people, including Congress members, use those phrases without—permit me—intending that they imply intent.

Much of the discrimination that people with disabilities experience is not intentional. But if the needs of people with disabilities are not considered when designing buildings or websites or textbook procurement policies, then discrimination happens on the basis of disability. How could it not? Non-disabled people don't experience anything unpleasant because of such decisions. The only difference between the people who are harmed and those who are not is disability. The harm occurs "because of," "by reason of," and "due to" the fact that they have disabilities. That is very plain language. There isn't anybody who can't follow that logic, except, perhaps, for right-wing judges who are quite intentionally grinding certain axes to a very fine edge.

But if it's not plain enough, then we have the ADA's "Findings and Purpose" section as amended in 2008, which specifically states the law's "Congressional intent": "In enacting the ADA, Congress recognized that physical and mental disabilities in no way diminish a person's right to fully participate in all aspects of society, but that people with physical or mental disabilities are frequently precluded from doing so because of prejudice, antiquated attitudes, or the failure to remove societal and institutional barriers." "Prejudice" and "antiquated attitudes" might be evidence of intent to discriminate, but "failure to remove barriers" is an obvious reference to the sort of "benign neglect" that right-wingers love to blame for discrimination. And the original law contains this finding: "Individuals with disabilities

continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities.” That sentence makes it perfectly clear that “outright intentional exclusion” is only **ONE** of the types of “discrimination” that the ADA outlaws.

Those types of unintentional discrimination are referred to as “disparate impact”; that is, a seemingly neutral action that is not intended to be discriminatory has different effects on different groups of people, and for some groups, those effects are discriminatory.

The problem is that the Supreme Court has adopted this bogus argument that “by reason of” and similar phrases mean “intent” with regard to other civil rights laws, and right-wing judges keep angling for an opportunity for the Supremes to extend it to disability rights legislation. We discussed this in our last issue (*AccessAbility* Winter 2021-22), when we reported that advocates had gotten the CVS drugstore chain to drop its appeal of a case involving its requirement that CVS employees use a mail-order pharmacy. Now another case threatens to upset the applecart.

Roy Payan and Portia Mason were two blind students at Los Angeles Community College (in the Los Angeles Community College District, LACCD). The college wouldn’t accommodate their disabilities; it required them to use inaccessible websites to see their grades and complete class assignments, and didn’t provide accessible versions of textbooks or PowerPoint presentations. It didn’t even follow its own written procedures for evaluating the accessibility of these items before requiring students to use them. The students, along with the National Federation of the Blind, sued the college under Section 504, which, with its rules governing any organization that receives federal funding, more clearly covers colleges than the ADA. That point doesn’t matter so much because the lan-

guage of both laws is so similar, as we’ve seen above.

They won in federal district court, so LACCD appealed to the Ninth Circuit, arguing, among other things, that Section 504 does not prohibit disparate impact, and they lost again. The district is now working on an appeal to the Supreme Court. There are other issues at stake in the lawsuit, and it’s possible the Supremes could issue a narrow ruling on them, but most advocates believe it’s far too risky to let any case like this reach them. They’ve organized a petition drive to get LACCD to drop its appeal, but it seems unlikely to succeed. However, if they also submit “friend of the court” briefs that make the arguments outlined above, they should have a good chance of settling this issue once and for all.

### ***Baerga, et. al., v New York City:* Send lawyers and money, but no guns**

This case poses a direct challenge to NY’s history of failure to provide adequate community based services to people with mental health disabilities. Although it is focused on New York City’s police department, and its official policy of detaining people who appear to have mental health disabilities regardless of whether they are violent, resistant, or breaking any laws, the suit implicates all communities that rely on the police as first responders to mental health crises.

The New York City police department has a written “Emotionally Disturbed Persons” (EDP) policy that requires cops who are called to address mental health crises to detain and forcibly hospitalize any person who they “reasonably” believe to have a mental health disability, even when “the EDP is unarmed, not violent, and willing to leave voluntarily.” It was, inexplicably, enacted in the wake of a 1984 shooting of a black woman who appeared to be in emotional distress; the officers involved claimed she was wielding a knife. Since then the rate at which the police, rather than qualified helpers, have responded to mental health crises in the city has skyrocketed, as has the number of people with mental illnesses killed by NYC police.

In addition to this inflexible policy, in New York City when people call 911 requesting an ambulance for someone experiencing a mental health crisis, 80% of the time they are greeted by armed police officers instead.

The complaint points out that other cities have been successful in creating teams of mental health professionals and peers—people with mental health disabilities who have been mistreated by police—that handle nearly all mental health crisis calls. New York City is only inching its way forward along these lines. The city has been running a small pilot program that pairs emergency medical technicians (EMTs; fire department paramedics) with social workers. Tiny as it is, by July 2021 it was getting better results in terms of cooperation from people in crisis and reduced hospitalizations than the police get. However, the program was so small because EMT participation was low; apparently—and strangely, given the nature of their work—EMTs aren’t very well trained in dealing with people in crisis. Their union spokesperson indicated that they are afraid of being attacked if no police are with them. People with mental health disabilities are mostly not violent, even when in crisis; “attacks” are rare, though some, like any other person, may resist being forcibly handled or screamed at, both of which are common police tactics. Lying about the presence of a weapon is another common police tactic; in the age of cell phone and body cameras, frequently the video evidence proves there was no knife or gun.

The lawsuit alleges violations of the Americans with Disabilities Act, Section 504 of the federal Rehabilitation Act, the fourth and fourteenth amendments of the US constitution, and the New York State constitution, Human Rights Law and “common law.”

The ADA, 504 and Human Rights Law allegations should hold water. The suit claims that NYPD and the city discriminate against people with mental illness by refusing to reasonably accommodate their disabilities by providing non-police crisis response services to them. The question then arises as to whether the defendants provide non-police crisis response services to nondisabled people. Of course they do;

the cops don't respond with tasers or guns to a call for an ambulance by somebody having a heart attack, for example.

Also interesting are the federal constitutional issues—is forcing someone to go to the hospital an unconstitutional search and seizure under the fourth amendment, and is such use of excessive force a violation of due process rights under the fourteenth? Again, probably so.

The plaintiffs charge the police in these situations with criminal assault and battery and false imprisonment. This is a class-action civil lawsuit, not a venue for convicting the police of crimes, and the police who do this to people are following a specific written policy, not (at least formally) acting on their own. Still, the plain facts of some of the specific complaints support such charges. For example, a 67-year-old woman with no history of mental health issues was struggling on the phone to get appropriate medical services for a liver ailment. She got angry with the medical office secretary she was speaking to and she said, "I'm so frustrated with you all that I feel like jumping off the bridge." The secretary hung up on her, and a few minutes later three armed cops showed up and banged on her door. She told them she was fine. The police insisted that when they get a suicide threat they have to take the person to the hospital. The woman was wearing a bathrobe and little else. Although she agreed to go with them, the police wouldn't let her go get dressed; instead, they jumped on her, knocked her to the floor, handcuffed her, and pressed a thumb into her neck until she passed out. When she awoke she was bleeding from a big gash on her thigh, but the cops would not let the EMT who came with them treat her. The cut became seriously infected, and she spent two months in the hospital.

Notably, the complaint alleges that the city insisted on having the police invade people's homes and forcibly seize them, often injuring them, and confine them to hospitals even though its history of pilot programs involving non-police, non-confinement responses to mental health crises has been successful in getting better results. Rights activists would also add that a key missing feature of the city's pilot

programs is the use of peers with mental health disabilities.

Although there are better ways to help people in crisis than sending in cops with guns and tasers, even when successful pilot programs prove it, states and cities commonly drag their feet in making those programs both permanent and universal. The reasons range from bureaucratic inertia to police and firefighter unions that fear the workforce cuts that would result if we stopped using their members for crisis response.

The suit was filed in the US district court for the Southern District of NY on December 29, 2021. If the plaintiffs win, this could create a valuable precedent. City and state governments that stand to lose tens of millions of dollars in damage claims may, in theory, prefer to actually reform their systems. We'd like to believe that's true. However, many cities have experienced those levels of cash drain for decades as a result of multiple civil suits for police misconduct. Yet their leaders have taken few or no effective reform measures. Ultimately, we may need a successful lawsuit that drains tens of millions of dollars from a police union treasury before we will get real change.

## Hail to the Chief!

On Valentine's Day disability activists throughout New York State scored a big win when Governor Hochul signed a bill creating NY's new Chief Disability Officer and announced the appointment of Kim Hill for the position.

Activists have been campaigning for several years to re-establish a cross-disability advocacy presence in the state's Executive branch. Last May a bill to revive the state's Office of the Advocate for People with Disabilities was passed by the legislature. It then lingered in the hands of the legislature for several months. Under NY's peculiar procedures, if the legislature sends a bill to the governor while the legislature is in session, the governor has ten days in which to sign or veto it. If the bill is delivered after the legislature has adjourned, that time period is stretched to 30 days. Either way, the clock starts ticking when the legislature formally sends the bill to the

governor. That's a constitutional gray area; some people think all bills should go to the governor as soon as they are passed, while others point out that the legislature may pass hundreds of bills at the end of a session and if they all went to the governor at that point she wouldn't have enough time to even read them. So when to transmit a bill is often a matter of political strategy, or at least luck. If this one had been sent to then-Governor Cuomo immediately after passage, he likely would have vetoed it, as he had with similar bills previously. We don't know why it was held back until long after Cuomo was gone.

When it finally went to Governor Hochul, the legislature was in recess and she had 30 days to think about it. At first, it didn't look like she was thinking good thoughts. Another strange aspect of NY's legislative process is "chapter amendments." If the governor doesn't like something in a bill, she can ask for changes before she signs it. Typically an agreement is reached among the governor, the bill's sponsors, and the leaders of both houses of the legislature on what changes to make. The changes must be passed by the legislature, but once there's an agreement, the governor will sign the bill, and the legislators will get around to passing them later.

We heard through the grapevine that Hochul wanted some changes. The bill set up an Office of Advocate for People with Disabilities under the Secretary for Human Services and Mental Hygiene in the Executive Branch. Hochul wanted this changed to "Chief Disability Officer," and she proposed that it be under the Office of People with Developmental Disabilities (OPWDD). Activists had real problems with this. First, after one of his vetoes, Cuomo had promised to issue an executive order to appoint a Chief Disability Officer in his cabinet. This resulted in no significant action—and even if it had, an executive order can be revoked at any time. Activists wanted this to be a permanent thing, and they didn't want a repeat of something that hadn't worked before. Second, the cross-disability character of this office is paramount. We have been saying for decades that people with different types of disabilities are treated differently in NY, and some, includ-



ing those served by OPWDD, get a lot more services and supports than others. This office needs to give equal attention to people with all types of disabilities.



*Kim Hill accepting her appointment*

After the bill went to the governor, a massive campaign geared up to urge her to sign it as is. She got hundreds of emails and phone calls from people with disabilities and advocates all across the state. Some of them had pretty good high-level connections in the legislature and the media, and those were also used to put pressure on Hochul. In the end, a chapter amendment was agreed on that changed the name to “Chief Disability Officer,” but the office was created in the Executive Branch, and we heard it would have a budget that would support three full-time employees.

That’s probably not enough to carry out all of the Chief Disability Officer’s duties. Two of those are to chair the state’s moribund Most Integrated Settings Coordinating Council (MISCC) and oversee the state’s efforts to carry out its sadly neglected “Olmstead Plan.” Disability activists were optimistic that Kim Hill’s appointment would bring a revival of those efforts.

Kimberly T. Hill, who uses a wheelchair, has been a very well-regarded advocate for people with disabilities in NY for over two decades. She was involved in the passage of the laws that adopted the Medicaid Buy-In program and established the state’s Traumatic Brain Injury Medicaid waiver, among many other achievements. She has served as Director of the NYS Assembly Task Force on People with Disabilities, and most recently as Principal Analyst for the Assembly Standing Committee on People with Disabilities.

It is notable that Governor Hochul held a press conference announcing Hill’s appointment at the Independent Living Center of the Hudson Valley in Troy. We can’t remember a recent action by a New York governor that placed such a focus on independent living centers like STIC.

Hochul acknowledged the strength of the disability community in her speech at the

bill signing, and she said, “I’ve gotten more compliments from selecting Kim Hill than anything I’ve done as governor, so I’m feeling good about that.” The speech emphasized

employment issues. She noted that only 35% of New Yorkers of working age have jobs, and she said NY is 38th among the 50 states in employment of people with disabilities. She promised to require state agencies to set aside 1200 jobs for qualified people with disabilities, including up to 500 disabled veterans.

In her acceptance speech, Hill got in a couple of zingers that showed she was going to be independent of the governor and her agenda: She said she looked forward to heading up a “fully funded” office, and she said that part of the work that needed to be done was to get fair pay for homecare, an item that is not in Hochul’s budget.

There was a clinker in Hochul’s speech. She pledged to expand the NYS Commission for the Blind’s “Business Enterprise Program.” This program, which dates back to 1936, gives blind people a monopoly on running “newsstands” in state government buildings. Most disability activists decry the program today as a type of segregated employment.

The original Office of the Advocate was created by an executive order from Governor Mario Cuomo. Early on it had a decent reputation for spreading the word about the ADA and providing technical assistance to local advocates. However, under Cuomo’s son, it was merged with the state Commission on Quality Care for the Mentally Disabled (CQC), an oversight body for state disability service agencies like OPWDD. Before Andrew Cuomo came in, the CQC, under Clarence Sundram, was well-regarded for shining a light on neglect and abuse in state facilities. But in later years, under Gary O’Brien and then Jane Lynch, the agency gained a reputation for covering up those same abuses. Not long after Cuomo 2 took office, the federal Department of Health and Human Services (HHS) audited the CQC and found violations of federal law. HHS also criticized the agency for

conflicts of interest resulting from its position in the same branch of government as the agencies it was supposed to monitor. Simultaneously, Cuomo and the legislature, responding to a major neglect and abuse scandal in OPWDD programs, set up a new alleged watchdog agency, the Justice Center for the Protection of People with Special Needs, incorporating the CQC’s duties, also in the executive branch. This did not satisfy HHS or advocates. Under pressure, Cuomo agreed to designate a not-for-profit Albany law firm that specialized in disability rights cases as the state’s official Protection & Advocacy organization, now known as Disability Rights New York. During this reorganization, the cross-disability, non-legal advocacy role of the Advocate’s Office was simply dropped, leading to the calls for revival that resulted in Hochul’s Valentine’s Day gift to New Yorkers with disabilities.

## Hochul Heightens, Hacks Housing Hopes

Governor Hochul’s budget contains a lot of proposals to increase the availability of affordable housing. This is necessary if we are going to get more people, most of whom have very limited incomes, out of nursing facilities and group “homes.” We don’t have room to cover all of these ideas in detail, but there are some points that we’d like to emphasize.

New York, and the entire country, have been “underbuilding” affordable housing for decades, and housing scarcity increases rent and mortgage costs.

This trend has racial undertones. The issue of race is important in the disability world because people of color are more likely to be disabled than white people, and because most of the low-wage workers who provide support services to people with disabilities are non-white. If they cannot achieve stable incomes in safe and affordable housing, they won’t be able to do that essential work. The prevalence of shoddy housing in segregated neighborhoods is one of the most frequently mentioned ex-

amples of “structural racism,” making it a direct cause of the shortage of affordable accessible housing for people of all colors. I’ve used that buzzword deliberately, to give myself an opportunity to explain what it really means.

It doesn’t mean that somebody is accusing those of you who are white, and comfortable—and not in charge of housing policy—of being racists. It’s about historical behavior whose results have been literally embedded in the structures of our homes. Back the late 1920s the federal government began to take an interest in helping people achieve, and maintain, home ownership, initially by offering to guarantee low-interest loans for people with limited incomes. Those programs were greatly expanded by Franklin Roosevelt’s New Deal in the 1930s, and yet again by the post-World War II “G.I. Bill.” “Urban renewal” projects also began to appear in the 1930s, with the initial justification of providing better housing for poor people, and they reached their zenith in the 1950s and 60s. All of those programs had racial segregation and discrimination officially built into them. Low-interest loans were not offered to people of color, not even to black soldiers who fought to defend our country in the war. Many ordinary Americans who have a reasonable amount of financial stability have gained it through home ownership; usually, the value of a home increases as time goes by, and home owners pass on those homes, or their cash value, to their descendants. Those inheritances enable people to get better educations and jobs than their parents had, and help succeeding generations climb up the social ladder. Huge numbers of white American families got their start up that ladder through government mortgage guarantees. Black and brown families

were not given that opportunity, and that is a big reason why, generations after the end of slavery and legal segregation, many of them still don’t have good jobs or own nice homes. Meanwhile, urban renewal in northern cities demolished racially mixed low-income neighborhoods and replaced them with big apartment buildings that were, by explicit regulation, racially segregated. Many of the white people in those neighborhoods took advantage of federal loan guarantees to buy modest houses in other parts of town. The people of color, unable to do that, were stuck in brand-new high-rise ghettos. That’s right; “modern” urban renewal created new segregation where there had been none, right up through the early 1970s.

People often throw up their hands about residential segregation: “If those people choose to live with their own kind, what are we supposed to do about it?” The question is based on a false premise. No matter which people we’re talking about, “those people” did *not* choose to live with “their own kind.” Nearly all of the white people forced to move by urban renewal would have been perfectly content to continue to live with their black neighbors who were forced to remain behind.

It used to be that when a new subdivision was being developed by white people, they would often impose racial “covenants” on homeowners: To buy a house in a new development, you had to sign a contract agreeing never to sell or rent that house to a non-white person. Beginning in the 1940s, federal courts began ruling that those covenants were an unconstitutional violation of civil rights. That’s when restrictive residential zoning really took off.

Lots of neighborhoods are zoned for single-family houses only, and sometimes requiring large lots. Ordinary people will say that this is intended to keep the neighborhood “nice.” Some of those people really are racists, and what they mean is, it will keep people of color, presumed to have low incomes, out. Other people don’t have racist intentions; they simply believe that having lower-income people in their neighborhood will re-

duce their own property values. That turns out not to be true, though for reasons that aren’t pretty. The fact is that when people of color start buying homes in all-white neighborhoods, property values actually go up, because anxious white residents put their houses up for sale and black people in search of homes are encouraged by realtors to buy into those neighborhoods. It is a statistical fact that black people, in general, end up paying more for homes than white people would pay for the same or similar homes, and despite fewer restrictions on mortgage assistance than there used to be, they still end up with higher interest rates on their home loans than white people get.

Even as racist official policies began to be rolled back in the last couple of decades of the 20th century and the first decade of this one, mistaken beliefs about property values, and the zoning laws they led to, continued to proliferate. Then came the Great Recession. Lots of people lost their homes, and demand for new housing crashed as millions of young people who were laid off moved back in with their parents. New construction tanked, but population growth did not. When the recession ended, housing prices soared, and the shortage of affordable housing worsened.

And now we come back to the issue of affordable homes for people with disabilities.

A common zoning restriction that is used to keep population density down, and resale values purportedly higher, is a prohibition on “accessory dwelling units”—basement or converted-garage apartments—that are part of, or on the same lot as, a one-family house. These “in-law apartments” are often set up to enable one’s elderly parents to have independence and privacy while still being near enough for their dutiful children to help them when needed.

Many families who have children with developmental disabilities or parents with physical or cognitive disabilities would like to make such arrangements for their relatives. In too many cases zoning restrictions stop them. (Some people do it anyway, in violation of zoning laws.) Accessory units could be an ideal solution for a big part of the problem of affordable, accessible housing. Most of these families will charge only token rent, or no rent at all, to relatives who





have little or no income. And they will be available to provide some support and supervision in a world where homecare is scarce. Some disability rights advocates are concerned about overbearing influence that might be exercised by some parents of people with developmental disabilities. There are some grounds for such concern. But the fact that parents want to give their kid a completely separate apartment argues strongly for their intention not to hover unnecessarily. And elderly people with cognitive issues such as dementia typically need a lot of supervision; they don't get enough of it to be safe even in nursing facilities, so having them just a few steps away from a willing family member is a good solution for many people.

Governor Hochul initially proposed a couple of measures to ease the effects of structural racism in housing. The most promising was a bill to require municipalities to allow at least one accessory dwelling unit on every owner-occupied residential lot, and to grant amnesty to those who have built them illegally. There would also be a lending program to help low- and moderate-income homeowners build these units. Another proposal would have incentivized municipalities to rezone areas that are close to commuter or long-distance railway stations to allow multifamily dwellings.

Then came a firestorm of push-back. Some people claiming to be environmentalists said that increasing population density would create “groundwater”, septic and other pollution problems. But other complaints sounded like what we've heard from certain quarters for decades: increased population density in single-family neighborhoods would threaten “quality of life” and mean a loss of “home rule”. Hochul caved in and withdrew these proposals.

Many of Hochul's other ideas are specific to New York City, but two are aimed at upstate communities. One would make home-ownership easier for people with lower incomes by repealing state laws that prohibit traditional mortgages for manufactured homes. Another plan is to beef up free legal assistance with evictions for people with incomes at or below 200% of the federal poverty line in upstate counties, and also to expand fair housing testing across the state. In a fair

housing test, two people apply to rent the same housing unit or for a mortgage to buy the same house. One of them is white and nondisabled, the other is a person of color, disabled person, and/or or a member of another protected class. If the white nondisabled person is approved but the other person is not, a fair housing discrimination case is opened. This can be a very effective way to begin to desegregate formerly white-only neighborhoods, and to put an end to landlords denying housing to people whom they incorrectly believe will be bad tenants.

## Latonya v DIA

As we mentioned previously (see *Accessibility* Summer 2021), advocates were rewriting the proposed federal Disability Integration Act (DIA) to fix issues that kept it from being passed. They completed that rewrite last fall, and the new Latonya Reeves Freedom Act (LRFA) was introduced in the US Senate by Senator Michael Bennet (D-CO) on December 16, 2021. A House of Representatives version was expected in late February.

Latonya Reeves has limited vision and cerebral palsy and uses a power wheelchair. She lived in Tennessee and got personal assistance services from her godparents until they became unable to care for her in the early 1990s. Home and community-based services were virtually non-existent in TN at that time, and if she had stayed there she would have been forced into a nursing facility. She had been involved with activists from the disability rights organization ADAPT from Colorado, where the organization was founded as an outgrowth of Denver's Atlantis Community, and they encouraged her to move to CO, where the community would support her. Since then Atlantis and ADAPT have brought many more people out of TN and into community living in CO with Reeves' help—so many that the process took on the honored name of the Underground Railroad. Senator Bennet chose to name the bill for his resourceful constituent.

We've been critical of the DIA in the past. The LRFA language is mostly identical with that bill, but there is one very impor-

tant improvement: a definition of “institution” has been added.

The LRFA definition lists several traditional types of institutions, including nursing facilities, Intermediate Care Facilities (ICFs) for people with developmental disabilities, and psychiatric hospitals, among others. Critically, though, it also includes “any congregate health care services setting that is not community-based.” Both DIA and LRFA define community-based residential settings not owned by the person or his/her family as having no more than four unrelated people with disabilities living in them. In order to be covered by either bill, a person must have a disability that requires various forms of assistance, and must also either be living in an institution or at risk of being placed in one. So LRFA, unlike DIA which has no definition of “institution” at all, will now apply to people who live in larger group homes and want to get out.

The LRFA also avoids a dangerous loophole that was present in DIA. Both bills' definitions of “community based” residential settings repeat the requirements in the Centers for Medicare and Medicaid Services (CMS)'s famous “settings rule” (see *Accessibility* Spring 2014). That rule lets facilities of *any size* qualify as community based as long as they take steps to, ostensibly, ensure that residents have control over their living space and optimum personal autonomy, and do not experience starkly regimented or otherwise “institutional characteristics.” The rule is flawed because facility operators can easily meet the minimum requirements on paper, while still treating capable adults like helpless children. Both bills also only apply to state or local governments if they operate or fund institutions. So-called “assisted living facilities,” which, when funded by Medicaid are much like nursing facilities, are deemed community-based by the settings rule. Under DIA, states could avoid having to comply at all simply by redefining all of their nursing facilities, residential hospitals and large group homes as assisted living facilities. LRFA won't allow this because none of those places have, or will ever have, only four “beds.”

Unfortunately, the LRFA still has the DIA language that would require states to spend their own money to provide enough af-



fordable and accessible housing, including housing that doesn't come with built-in supports, to enable disabled people with the lowest income levels to live in their own homes. We aren't saying that wouldn't be a good thing if states did that. We are saying that this part of the bill cannot be enforced, because states have sovereign spending authority. The only way this could work would be if the feds provided all of the money needed to achieve those goals. The LRFA doesn't offer any funding for this. It only contains \$10 million to pay for federal administration of its requirements.

Both bills require states to carry out self-assessments of what is needed to ensure that all eligible people with disabilities will be able to get the community-based services and supports that are required, and to create a transition plan to have those things fully in place no later than 12 years after the bill becomes law. Unlike DIA, the LRFA specifically requires the federal

Department of Health and Human Services to review and approve or disapprove those transition plans.

Also unlike DIA, the LRFA requires states to consider how to ensure that services and supports are provided equitably to people regardless of race, ethnicity, sex and gender. Ensuring equal coverage for people who are lesbian, gay, bisexual, or transgender is specifically required. That's a good thing. But right-wingers are likely to regard that last provision as establishing civil rights for people who fit those categories—and they would be right. This is a civil rights bill—though, unlike DIA, it does not specifically say that the bill is intended to establish a federal right to community based long-term services and supports for people with disabilities. Because this bill is not about money, it can't be passed by the so-called "reconciliation" process in Congress, which only requires 50 votes in the Senate. Instead,

it will need at least 60 Senate votes under the current filibuster rules. In 2022, that means at least ten Republican supporters. At press time, it had one. We believe this provision will make it very hard to get those ten votes.

So, while we are more enthusiastic about this bill than we ever were about DIA, we must report that it is highly unlikely to pass unless the voters elect a lot more progressive senators, and House members, for that matter, this fall.

We also discussed the HCBS Access Act last June. That bill was seriously flawed as well, but it had the advantage of making community based long term services and supports mandatory for state Medicaid programs, and it would have paid 100% of the costs of providing them. However, it appears that there has been no significant action on it since our last report.

We'll let you know if anything changes.

# NYAIL Disability Rights Agenda 2022

*(abridged)*

Under the Cuomo Administration, the budget and policy priorities of the disability community were routinely under attack, as critical programs and services disabled people need to live in the community were either cut back or ignored. Policies were passed that did not prioritize the needs or rights of disabled people and legislation that did this was routinely vetoed. The Hochul Administration provides an opportunity for New York State to once again be the national leader in ensuring the rights and independence of people with disabilities.

NYAIL's 2022 budget and legislative priorities would advance independence and community integration for New Yorkers with disabilities. It is imperative that NY makes up for so much lost time by prioritizing laws to protect the civil rights and programs that allow people with disabilities to live independent and integrated lives in their communities.

*NYAIL strongly supports many of the budget and legislative initiatives proposed by Governor Hochul.* Most of these are

described elsewhere in this newsletter. These initiatives include:

- **The Executive budget's proposal to increase Independent Living funding to \$16 million, but we call for an additional \$2 million to match what the NYS Board of Regents endorses.**
- **Creating equity in Medicaid eligibility for seniors and people with disabilities as has been recommended in the Executive Budget.**
- **Funding the recently enacted Office of the Chief Disability Officer. The initial proposal calls for three full-time positions, but this will not be adequate to carry out all of the duties of the office; we urge the state to ensure that the office is fully funded.**
- **Making it easier for people to vote by extending voter registration deadlines and ensuring a polling site on eligible college campuses.**
- **Competitively bidding managed care plans to allow for at least two, but no**

**more than five plans in each region.**

This is an opportunity for the state to develop an RFP that prioritizes community living and strengthens consumer protections. It should include the following: ensure disability competence, requiring for example, all selected plans demonstrate a commitment to community-living, a robust plan for person-centered planning, and to contract with disability-led organizations. Further, a certain percentage of providers should be regionally-based not-for-profits. Also essential are strong transition rights for participants since many will have their coverage interrupted as a result of this reorganization.

- **Improving the 55B and 55C program to increase career mobility for people with disabilities and veterans working for the state.**

The Executive Budget proposes amending the 55B and C programs that are intended to promote the hiring of people with disabilities and veterans by the state, by letting 55B/C employees move to a competitive

class if they meet the necessary criteria. This would enhance career mobility for employees who joined the state workforce through these programs. However, the state is simply not filling these positions. 55B and C let disabled people and veterans apply for jobs without taking competitive exams. However, because they don't sit for these exams, they don't get put on hiring lists. The

Employment First report had recommended hiring a 55B and C Coordinator to work with hiring managers to make sure people are hired through this process. The state had also previously been working on smart technology to match qualified applicants with open positions, but the Employment First Commission stopped meeting and these efforts were paused.

*NYAIL strongly opposes some other proposals in the governor's Executive Budget.* Most of these are explained elsewhere in this newsletter:

- **Extending the Medicaid Global Cap, which has led to harmful cuts and limited eligibility for essential community-based services.**

- **Eliminating prescriber prevails.**

- **Expanding and extending Kendra's Law.**

Kendra's Law provides for court-ordered assisted outpatient treatment (AOT) for people with mental health disabilities who are unlikely to survive safely in the community without supervision based on a clinical determination, along with other criteria. Under this law, a court may not issue an AOT order unless AOT is the least restrictive option available for the person. Yet, this proposal seeks to expand instances when forced treatment can be ordered by changing the standard to when the person "has experienced a substantial increase in symptoms of mental illness." This is far too broad a standard for subjecting people to forced treatment and should be rejected. People with mental health disabilities have a right to high quality, voluntary

treatment. They should not be subjected to involuntary outpatient treatment because the mental health system has failed them.

*NYAIL calls for certain measures that are not addressed by the governor's budget proposals:*

*The Hochul Administration provides an opportunity for New York State to once again be the national leader in ensuring the rights and independence of people with disabilities.*

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

The ongoing homecare aide shortage that has made it difficult for people in certain regions to obtain home care is now an acute crisis in all parts of the state. The homecare crisis is by far the primary barrier to transitioning people from nursing homes back into the community. NY has an obligation under the US Supreme Court *Olmstead v L.C.* decision to provide people with disabilities with supports and services in the most integrated setting, their home communities. Yet the lack of available home care is making this impossible for many.

The homecare crisis is primarily due to falling wages and disparate treatment of women and people of color who comprise most of the homecare workforce. In 2006, homecare workers earned 150% of minimum wage, and people were more readily able to get the hours they were approved for. Yet, these wages remained stagnant while wages increased in other sectors. Now homecare workers earn less than they could working in a fast-food restaurant, which reflects poorly balanced priorities. The Fair Pay for Home Care Act would effectively address this crisis, ensuring seniors and people with disabilities are able to obtain homecare, while the people who provide their services can get paid a living wage.

- **Repeal Medicaid eligibility changes that make it harder for people to receive vital community-based long-term supports and services (LTSS).**

Governor Hochul failed to include in her Executive Budget the repeal of the harmful Medicaid Redesign Team II (MRT) recommendations that severely limit eligibility for home care for new applicants. Despite the MRT II's directive to advance policies that would achieve Medicaid savings without affecting access to services, multiple proposals were enacted that make it much more difficult for certain people to receive community based LTSS (see page 4). We call on the legislature to repeal these changes.

- **Increase the state's share of funding for the Long-Term Care Ombudsman program by \$6.2 million.**

The Long-Term Care Ombudsman Program (LTCOP) serves as an advocate and resource for people living in nursing facilities and other institutions. It promotes and protects residents' rights, health, and safety by receiving, investigating and resolving complaints made by or on behalf of residents. The pandemic demonstrated that people in institutions must be able to access an ombudsman when needed. The LTCOP receives insufficient federal funding to provide adequate services across the state, and NY's funding for this program is among the lowest in the nation, leaving providers overly reliant on volunteers, who are increasingly difficult to recruit. We urge the state to increase funding by \$6.2 million, which would double staffing levels.

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

Access to Home is an important program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow individuals with disabilities and older New Yorkers to stay in their homes and out of costly institutions. For many people, the addition of a ramp to their front door makes the difference between being able to leave the house and being homebound. Program funding was cut by 75% several years ago, and since, has been funded at a mere \$1 million statewide, leaving much of the state without it and resulting in years-long waiting lists. We urge the state to increase HCR funding to \$10 million for Access to Home, allowing seniors and people

with disabilities to remain in their homes and out of institutions. NY will more than recoup this investment through other state agency expenditure reductions.

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

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

• **Prohibit the practice of paying people with disabilities below the minimum wage in NY. A.3103 (Steck) and S.1828 (Skoufis).**

For too long, people with disabilities have been segregated from the rest of society, shut away in institutions and facility-based employment settings. At these segregated settings and enclave type jobs in the community, employers are allowed to pay disabled workers well under minimum wage under section 14(c) of the Fair Labor Standards Act (FLSA). The *Olmstead* decision held that people with disabilities have the right to live and receive services in the most integrated setting. Most facility-based employment settings are segregated, focused on production style work, and fail to provide adequate training or income to workers. Many people with disabilities are not suited to production work and it is time we stop equating them with this form of employment. We have developed many successful integrated employment models in the decades since 14(c) was enacted. Subminimum wage no longer serves any purpose that cannot be better addressed by programs that develop each person's latent skills and talents

and allow them to become successfully employed like their nondisabled peers.

• **Waive the state's sovereign immunity to claims under the Americans with Disabilities Act (ADA) and Section 504. A.7121 (Kelles) and S.1119 (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 disabled people with a 7% hiring goal for state agencies, contractors, the legislature, and the courts. A.3137 (Epstein) and S.1629 (Skoufis).**

One of the primary goals of the ADA was to significantly increase employment opportunities for people with disabilities. Yet the employment rate, at roughly 34%, has not significantly improved over the three decades 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 will make NY a leader in the hiring of people with disabilities by setting a hiring goal of seven percent 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.

• **Change local, village, county, and New York City elections to coincide with the dates of state and federal elections. A.8560 (Paulin) and S.6197 (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 have accessible, universally designed voting machines for all state and federal elections. However, local elections are not held to the same

standard. While local elections are no longer allowed to use lever machines, many use paper ballots only. Paper ballots are inaccessible to many people with disabilities. Holding these elections on the same dates as state and federal elections, under County Boards of Elections, will ensure they will be held in an accessible manner.

• **Create minimum standards for design and construction of new homes that receive state or federal assistance to make them more accessible. A.2247 (Simon) and S.942 (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—"inclusive home design" or "visitability"—would meet the needs of people throughout the lifespan and allow homes to be visited by friends and family members with disabilities. Renovation of homes is much more expensive than including accessibility features in the construction of a new home.

• **Require counties to expand paratransit beyond ADA minimums. A.3181A (Steck) and S.5092 (Kennedy).**

The limited availability of accessible transportation is a major barrier faced by people with disabilities, often leading to unemployment, inability to access medical care and voting sites, and isolation from friends, family, and full community participation. Failure to provide paratransit service throughout the state is a major contributor to this pervasive problem. The ADA requires counties to provide accessible paratransit service to disabled people who are unable to take the fixed route bus. At minimum, paratransit service must be provided within  $\frac{3}{4}$  of a mile of the closest bus stop. This was always meant to be the floor, not the ceiling. As fixed route bus lines are eliminated, people are being cut off from paratransit service. This leaves them 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.





# STIC NEWS



## Walk Like an Egyptian at Xscapes!

By Todd Fedyshyn

Xscapes / STIC is proud to share our exciting new plans to build a new escape room starting in Spring of 2022. This will be our 5th game for our successful escape room fundraiser, Xscapes, here at Southern Tier Independence Center.

The new game will be called “The Last Pharaoh” and is based on the history of Cleopatra. She was queen of the Ptolemaic Kingdom of Egypt from 51 to 30 BC and was the last active ruler of the Egyptian Empire. Cleopatra 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 history of her life and discovering hidden secrets and gems in her tomb with your archaeological team. Players of this escape room will work to solve the mystery of her life and the cause of her untimely death to complete their mission.

“Valley of the Kings” has been our most popular escape room to date, so we decided to build a follow-up Egyptian theme with new technology and improved scenic design

to provide a more in-depth immersive experience for our guests. “Valley of the Kings” will also be getting some updates and the plan is to make these two games Part 1 and Part 2 of the overall Egyptian experience here at Xscapes, the Southern Tier’s Premiere Escape Room.

Please feel free to book an escape room at [www.Xscapes-STIC.com](http://www.Xscapes-STIC.com) or call (607) 760-3322 for more information or to purchase our Xscapes Bucks, the gift that keeps on giving.



## Growing with Self Direction

By Rhonda White

As spring and the smells of new growth take hold around the area, I think it is a good time to talk about program, as well as personal, growth. The Self Direction (FI) program at STIC is growing. We are doubling in size and learning through the people we serve to become a better program for them. It is true, for our first two years there has been a lot of “I am sorry we cannot!” due to this regulation or that executive order. But our group persevered and worked together to provide opportunity for succeeding.

With that I would like to introduce Sam. Sam has been with STIC for many years through one program or another. He has had many different care managers or Community Habilitation providers. Sometimes the new staff came through the natural order of changes in an agency, and sometimes it was due to Sam’s lack of cooperation. Either way, he had little growth until he started to direct his services with the STIC Self Direction program. Sam was able to sit down with his broker and design what he felt he needed to succeed at healthy and safe independent living. He picked things like cell phone reimbursement, gym membership, professional house cleaning, and rental

assistance. He also chose to give his staff a substantial raise. These are just a few things that Sam and his Broker personalized in his budget for him.

Then it was time to interview and hire staff. The team assisted him in collecting resumes and conducting interviews to pick the best staff for him. Sam will tell you that a year ago he was not in a good place physically or mentally. He was in an apartment that was not clean and had some structural issues along with many other safety concerns. He was dealing with people borrowing money and asking for favors without reciprocal treatment. Sometimes when he tried to ask for what he felt was fair, he was afraid. Sam became very confused and frustrated because he also felt these people had been there for him throughout the pandemic. He was living through some very confusing stuff that led to not taking care of himself. So finding staff who really understood all the complicated issues was tough. It did take a couple of tries, but with the assistance of his team he has now found his best staff for him.

Sam has moved to a better apartment with furniture in all the rooms. With the assistance of his staff, he has been cooking at home and learning all kinds of new ways to live. Sam is also learning to manage his finances. He is learning to put together a schedule to keep his apartment and person

clean, while still having time for fun things like going to museums or out to dinner. Sam has also reconnected with some good friends that help him feel at home and vice versa. He has them over for a visit or attends dinners at their house. Sometimes this progress is disrupted and we, as a team, take a step backwards, but with guidance Sam continues to make positive strides forward.

Recently, Sam’s care manager put in his referral to ACCESS-VR. He will begin to explore what he needs to learn so he can work in the community. One of these things is looking into higher education opportunities. This is a big goal that Sam has had for a very long time. He is so adamant that he wants a higher education; he may have signed up at different colleges over the years that have caused some negative impacts on his financial health and credit scores. His Broker has assisted him to find ways to fix this and his staff has worked with the follow-through so that he can begin to work on this lifelong dream. Along with working towards a career and attending classes, Sam is also looking into becoming a part of a self-advocate group. He would like to share his story with hopes that we all can keep working towards making better programs to assist him and his peers. On behalf of the STIC Self Direction program we would like to congratulate Sam and his team for a lot of hard work and perseverance.



This newsletter is also available in large print, on cassette, and online, at:  
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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!**

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