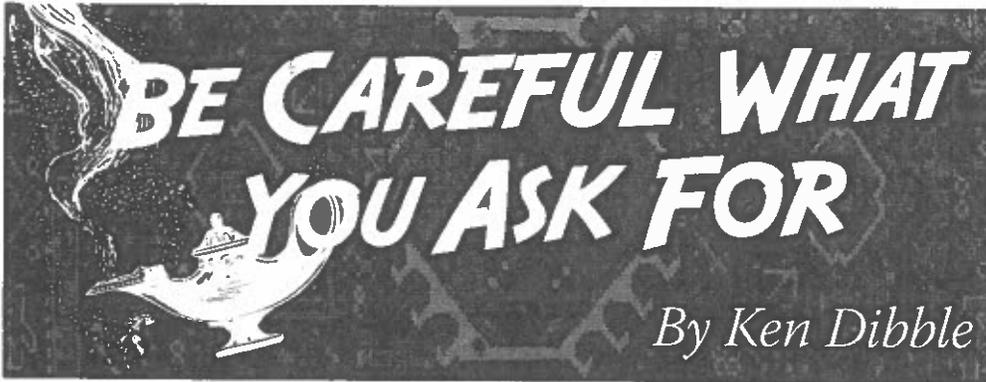


AccessAbility

Summer 2022
Number 147



People should be careful what they ask for. “Social determinants of health” is a slippery slope that could leave many of us at the bottom of a cliff.

Way back in the late 1960s, when Ed Roberts and some other pioneering disabled college students invented the “Independent Living Center”, they had the idea that there could be a place where they could make their own decisions about what they needed, and accept responsibility for the consequences—whether positive or negative—of those decisions.

The Center was a place where people who considered themselves to be disabled could get a wheelchair repaired, cobble together some innovative piece of adaptive equipment, find a personal attendant, share tips with each other on how to find places to live and get other things done in an “able-bodied world”, and work together to make that world better for them. That included getting politicians to increase physical accessibility and do away with rules that embodied negative attitudes about the worth and abilities of disabled people.

The first Center was run by those folks and it didn’t have a government budget. A few years later some of those

same folks got federal funding to create more Centers under the Rehabilitation Act. In the immortal words of Mark Knopfler, “Then came the lawyers, and then came the rules.” The first rule was that federally-funded Centers were now “rehabilitation programs”, subject to medical-model requirements like “minimum eligibility standards,” “needs assessments”, “service plans”, and “cases” that had to be “open” or “closed”. Further, these Centers had to report “outcomes”: whether or not the people served “achieved” their formalized “goals”. This kind of stuff takes control away from ordinary people and gives it to program operators who must justify their existence by pushing people to “achieve” something.

When advocates in New York arranged to get state funding for Centers, they rebelled against the rehabilitation model and succeeded in getting rid of all that stuff at Centers that only get NY Independent Living money. But every dollar of government funding since then has brought with it compromises that diluted the original idea of an Independent Living Center.

On the other hand, the Independent Living Philosophy was so useful, and became so popular in the Western world, that it now

INSIDE	
Hochul and the Legislature Make it Rain	3
Independent Assessor, Professor?	5
CDPA – 1; Personal Care – 0	7
Vote Like Your Life Depends on It!	8
NY May Have an Aversion to Aversives	10
Courts Watch	11
DOJ Issues Web Accessibility Guidance	14
Savings Penalty Elimination Act	14
STIC COVID-19 Update May 2022	14
Mobile Escape Rooms	15
2022 NYSILC Statewide Consumer Needs Survey	15
Free Internet!	15

competes effectively with old-school paternalistic and institutional service models in many places.

But paternalism always fights back, in ever sneakier ways. It’s not just about the over-protective parents at Autism Speaks, or the public-employee unions behind Voice of the Retarded (I know, I know, but we didn’t make that name up). In recent years the paternalists have been killing a lot of sheep and donning their skins under the guise of “social determinants of health”.

The concept is a good one—an accurate one. It means that people’s physical and

AccessAbility

June 2022

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

AccessAbility is published seasonally (Spring, Summer, Fall, Winter) by Southern Tier Independence Center. Letters, information, articles and ads are always welcome. Deadlines are February 15, May 15, August 15 and November 15.

Our address is:

AccessAbility

Southern Tier Independence Center
135 E. Frederick Street
Binghamton, NY 13904

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All articles appearing in this newsletter are written by Ken Dibble unless otherwise noted. Generally, I get tired of seeing my name on every page, and I'd rather use the space for something more interesting. I do put my name on controversial stuff, though, so you'll know who to blame.

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mental health are strongly influenced by things other than their genes or disease processes. Things like whether you live in a place where it's easy to get nutritious food, whether the places where you spend most of your time are polluted by harmful chemicals in the air or water or embedded in the walls, whether you have a stable family life or are subjected to frequent stresses such as inadequate shelter, income uncertainty, physical or emotional abuse, or bullying or bigotry.

That's good as far as it goes. And it meshes nicely with the progressive beliefs of so many disability advocates. But another social determinant of health is your own behavior. And here's where we start sliding off that cliff.

It's true that medical issues are an important aspect of disabled people's lives, and therefore of some interest to the Independent Living and disability rights movements. But we've said before that when those movements start focusing too heavily on "health care", they risk losing their roots. Both movements grew out of a desire to give people with disabilities increased control over their own lives and destinies. In most cases the only reason the services and supports that people with disabilities need have anything to do with "health care" is because the money that pays for them comes from government health insurance—Medicaid and Medicare. Having somebody transfer you from bed to wheelchair, or wash your dishes or your face, or cut up your meat, isn't really "health care", and certainly helping you get or keep a job, or to be in an integrated public school classroom or live in your own accessible home are not "health care"—*even if your health will be better as a result*. It is certainly possible to define every single thing that contributes to human well-being as "health care"—but such definitions are pure sophistry, and you don't have to dig very far to see that the only reason people do this is to get some of that huge pile of government health insurance money transferred to their pet programs.

The thing is, no matter how you define "health care", it is, and always will be, a paternalistic, top-down way of looking

at things, in which "smarter" or "better educated" people grant to themselves the right to judge the rest of us and tell us how to live—and expect us to knuckle under and do as we're told.

There are lots of human rights that are frequently violated and worth campaigning to save. But when money is involved, some people are all too willing to forget one of the most important: The right to be left alone. This is sometimes called the "right to privacy", and it's been much in the news lately. So maybe this is a good time to remember what it really means. It applies to everyone, not just "right-thinking" people who do "pro-social" things, however you define that.

See, there has to be a big red line drawn around the right of adults to make their own choices. Without that right, we are no longer autonomous adults; we are dependent children, or servants of somebody else's agenda. And that right includes the freedom to take a chance on doing our own selves harm—otherwise known as the "dignity of risk".

"Dignity of risk" has been an important term in the disability rights movement. It means that people with disabilities should have the same freedom to make what might be, from some point of view, a "bad" decision that nondisabled people have. You may think this is just a matter of equity—treating people the same whether they are disabled or not. But it's much more than that.

It is fundamental to human growth and development. Everybody makes bad decisions from time to time, and they usually learn from them. In fact, it is often the *only way* that people can really learn how to navigate in the real world. The more we try to avoid risk and protect people from themselves, the more we royally screw up the entire human race. There is pretty clear scientific evidence now that keeping infants and toddlers in antiseptically clean environments instead of letting them get exposed to a little dirt and dust stunts the development of their immune systems, which leads to debilitating and dangerous allergies and a plethora of auto-immune diseases later in life. And evi-

dence is beginning to come in that proves that “helicopter parenting”, rewarding “trying” the same as “succeeding”, and refusing to let kids have unstructured and unsupervised play time has led to an entire generation of young adults who cannot solve unexpected problems, cope with adversity, or get along without constant praise and encouragement.

Many people think it’s just fine for insurance companies, whether government or private, to poke their noses into other people’s private business if it will save tax dollars or lower premium costs. For those who think it’s all about the money, I would invite you to consider that if that’s really true, then it really is *ALL* about the money. For example, air pollution is dangerous to people’s health, is expensive to clean up, and, by contributing to global warming, makes it much more likely that people’s houses will be destroyed by floods or windstorms. How about we make it illegal to buy those huge SUVs or monster pickup trucks that people who have office jobs and fewer than four kids really and truly do not need, because it would reduce air pollution? Let’s amend the Constitution to remove the right of gun ownership for people who are not actual hunters because guns injure people at a rate that leads to skyrocketing health costs. Many people feel that rigorous outdoor activity or strenuous sports

are beneficial to health—but they are not beneficial to health care costs when you break your leg skiing or your neck falling off that rock you were climbing. So why not charge those who enjoy such things an extra, say, 100% on your insurance premiums and co-pays? Oh—here’s a popular one: Folks living out in the country—or even in those sprawling suburbs with mandatory half-acre lots—but working in the city cost the rest of us a whole lot of money when they drive their gas-wasting SUVs 20 or 30 miles each way to work, increasing the carbon dioxide content of the atmosphere and imperiling us all. So let’s make rural living illegal for people who aren’t farmers; we’d all be so much better off if we moved into gentrified urban neighborhoods and walked to work in the rain and snow (all, that is, except for the poor people who would get forced out of those neighborhoods).

Do you see where this is leading? All of us have our pet peeves with the behavior of other people, but none of us has the right to use that as an excuse to interfere with that behavior.

The paternalistic wing of the progressive movement has been making big strides lately by pushing health insurance funding to address the social determinants of health. The last round of NY’s “Medicaid Redesign Team” waiver had a version of

this, but the money got hijacked by hospitals: a new one is now under review that allegedly will ensure that much more money flows to “community based organizations”. It looks like it could be a way for all of our under-funded right-thinking not-for-profit social service agencies to get big boosts to our budgets.

But it’s not for me, not if I have to guarantee some sort of “health improvement outcome” as a result of the completely non-medical support services I provide, and especially not if I have to poke my nose into other people’s private business and shame or cajole them into changing their behavior. As long as I live, I promise it will be okay with me if you eat what you want, exercise or not as you choose, smoke whatever you want, drink whatever you want, and do nothing but watch TV in your leisure time, and I will be okay with paying my share of your health care costs, however high they go. I will consider it a bargain if it means holding on to our personal liberties.

Disability advocates need to seriously sort out their thinking on this. This is not Independent Living, and it does not respect disability rights. We should not support “value based payments” or any other form of meddling in people’s private lives, no matter how much money it might put into our pockets.



This year’s NY State budget battle dragged on past the end of the fiscal year on March 31 due to serious disagreements on some items, but most of the largesse in Governor Hochul’s initial proposals made

it through, while some of her worst ideas got canned.

Governor Hochul was frightened about how pressure from the right could affect

her re-election hopes. She faced a primary challenge from Democrat Tom Suozzi, who was running to her right, and she believed that whomever the Republicans put up would also be a threat. So bail reform was an issue that ground the budget negotiations to a halt. Hochul was desperate to seem tough on crime, while Democrats, especially in the Senate, held firm on previously-enacted reforms. And, for the first time in decades, two very contentious disability issues also figured into the final negotiations. One was an attempt to expand Kendra’s law to make it easier to force people into mental health treatment. The other was the huge outcry over wages for homecare workers.

As part of her “tough on crime” campaign, and facing pressure from New York

City's conservative Democrat mayor Eric Adams, who has gotten a lot of bad press about the behavior of homeless people in the subways. Hochul proposed an expansion of Kendra's law. Kendra's law allows people who have significant relationships with someone who has mental health issues to request a judge to order that person to accept *outpatient* mental health treatment for six months if the person is at serious risk of doing harm to themselves or others. If, at the end of that time, further treatment is needed, it can be continued if ordered by a judge. The law was set to expire this year, so as part of a 5-year renewal plan, Hochul wanted to include law enforcement officers in the list of those who can request a court order, allow more-or-less automatic six-month extensions without due process, and broaden the criteria for behavior that could justify the initial court order. There was a separate bill in the state legislature, not part of Hochul's proposal, that would make it very easy to force an indefinite *inpatient* commitment in a psychiatric hospital on people whose difficulties with maintaining food, clothing or shelter are "likely to result in serious harm," broadly defined. The press conflated these two things, making it appear that they both came from Hochul.

Her plan was rejected in the final budget agreement. Kendra's law was renewed for five years, with an expansion to include that a court order can be requested for a person whose previous six-month treatment order has expired and who is, as summarized by the NY Association on Independent Living (NYAIL), "experiencing a significant increase of symptoms ... [that] limit one or more major life activities." The person who "previously oversaw the court-ordered treatment" can refer the person for more treatment if a physician agrees. That physician must testify in court that the new treatment order is "clinically necessary," and the proposed treatment must "be the least restrictive option." The separate bill concerning forced inpatient treatment was still in committee in the Senate and Assembly as of mid-May. We don't know if it will move.

Advocates promoting the Fair Pay for Homecare campaign to have the minimum

wage for homecare workers set at 150% of the prevailing minimum wage barraged the governor, senators, and assemblypersons with hundreds of emails and phone calls daily. People with disabilities, including STICsters, maintained a constant physical presence in the State Capitol building in Albany, decorating the Rotunda and "War Room" (a meeting room with walls covered with murals depicting military history) with signs and pictures. On the evening of March 31, eleven protesters were arrested by the state police for refusing to leave the War Room, but were released when the cops realized they couldn't hold them in the inaccessible state police barracks. These efforts gained overwhelming support for the proposal in both houses of the legislature. Hochul, however, was unmoved. In fact, anonymous sources reported that she was quite angry that the Assembly and Senate leadership held up the budget agreement on this point.

Eventually a deal was reached to provide a modest wage increase for these essential workers. On October 1 of this year, the minimum hourly wage will be increased by two dollars for homecare workers, and on October 1, 2023, it will grow by another dollar. Further, every time the minimum wage goes up, so will the homecare wage, so it will always be three dollars higher, no matter how high that number goes. In upstate regions, that wage will be \$15.20 on October 1, 2022, and on October 1, 2023, it will be \$16.20 plus whatever January's minimum wage increase will be. The upstate minimum wage will continue to rise annually until it reaches \$15/hour, and at that point the homecare wage will be \$18/hour upstate. That is certainly not close to what advocates wanted, but it's not chump change either. And it's not necessarily the upper limit, because other budget items will make it at least theoretically possible for service providers to raise those wages even more to improve recruitment and retention (see below).

(Some people say this small increase may push homecare workers "off the benefit cliff," making them ineligible for Medicaid themselves, or other benefits such as food stamps. But hey, these same people have been complaining that homecare

workers have been deserting the profession to take somewhat higher-paying fast-food jobs. If that's true, then the same "benefit cliff" problem applies to them, but it apparently hasn't stopped them. Advocates need to learn that making contradicting claims achieves nothing but the destruction of credibility.)

Of course, to get this increase, something else had to give. Managed care plans may get rate bumps as a result of this, but unlike the Fair Pay for Homecare bill, there is no language in the final budget that clearly requires those plans to pass through those wage increases to the service providers. (There's also a provision that lets CDPA providers pay time-and-a-half for overtime, but no requirement that DOH must increase their rates accordingly.) Advocates need to keep a very close eye on how all this unfolds. Also, Hochul withdrew her proposal to provide longevity bonuses to homecare workers in Department of Health-funded programs, including Personal Care and Consumer Directed Personal Assistance (CDPA) services.

Those bonuses were retained for most workers in programs funded by the Office of People with Developmental Disabilities (OPWDD), the Office of Mental Health (OMH), and the office of Addiction Services and Supports (OASAS). The eligibility requirements were changed though; the original proposal made bonuses available for people who had worked at least one year in those programs and did not apply to anyone whose annual salary was over \$100,000. The final budget includes people who have worked at least six months and raises the salary limit to \$125,000. The bonuses apply to people whose six months of work began between October 1, 2021, and March 31, 2024. Those people can get bonuses in up to two six-month rounds, and we believe the amounts for each round are the same as we reported last time: 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.

The proposed 5.4% cost of living adjustment for those same programs (OPWDD,

OMH and OASAS) also made it into the final budget, and the cancellation of the 1.5% “across the board” Medicaid rate cut, as well as a 1% “across the board” rate increase, were adopted as well. Both items apply to funds encumbered on April 1, 2022, or later; rates paid for services provided before that date will still be subject to the 1.5% cut. How this money gets spent is determined by the program operators; much of it may be needed simply to keep up with inflation in costs such as health insurance, electricity, and heating fuel. However, some (though probably small) portion of those across-the-board increases could theoretically be applied to homecare wages.

Another benefit that could affect the homecare shortage is childcare. The final budget includes a \$670 million increase in state subsidies for childcare services. The annual income limit for these subsidies will increase from 200% of the poverty level to 300% (or almost \$55,000 for a family of two people), on August 1, 2022, and the 17.5-hour work requirement will be removed on June 1 for people in college or trade school. Childcare availability is very important for homecare workers, most of whom are women of child-bearing age. It’s been a big reason why many such workers who lost their jobs during the pandemic have not returned to the workforce.

Also approved was the change in how the Global Medicaid Spending Cap is calculated. As we reported last time, Hochul wanted to change this from “whatever percentage the 10-year rolling average of the medical portion of the federal Consumer Price Index worked out to be to the 5-year rolling average of CMS’s National Health Expenditure projections. ... That number accounts for growth in the number of people who receive Medicaid, as well as the increasing needs of our aging population.” So rate increases should be significantly higher year-to-year than previously, adding more leeway to raise homecare wages. And the cap was extended into 2024. Some advocates have concerns about what happens if, after the pandemic ends and all that extra Medicaid relief money dries up, that National Health Expenditure projection goes down.

Would that mean there would be cuts in New York Medicaid funding? We don’t think so. According to NYAIL, the Global Cap “shall not exceed” those CMS projections. The percentage by which NY’s Medicaid spending *can increase* can’t be higher than that projected percentage, but there is no language requiring a cut to that spending if the projection goes lower. The projection is unlikely to go negative because it’s a five-year rolling average—long enough to absorb the loss of special pandemic funding—and because the nation’s population will continue to age, increasing the need for Medicaid-funded services, for at least the next decade.

Hochul’s proposal to increase income eligibility for Medicaid for people with disabilities and seniors was partially enacted. The maximum income will grow from 87% of the federal poverty level to 138%, in January 2023, making it the same as for nondisabled New Yorkers under the age of 65. Hochul also wanted to remove the limitation on assets for Medicaid-eligible people, but that didn’t happen; instead, the asset limit will go up by 50% that month. Income eligibility limits for the Medicare Savings Program will also go up at that time.

The Child Health Plus insurance program got an expanded list of covered services, including some behavioral services, and the \$9 monthly co-pay is eliminated for families with incomes at 200% of the poverty level. And all immigrants over age 65 will be able to apply for Medicaid.

All of those Medicaid items require federal approval, so those start dates aren’t set in stone.

The annual effort to end “prescriber prevails” in the Medicaid drug benefit was again defeated.

Advocates had sought \$6.2 million to double the Long Term Care Ombudsman program’s staffing but received only \$2.5 million. Access To Home, which pays for accessibility improvements to people’s homes under some circumstances, remained level-funded at \$1 million, despite a request to increase it to \$10 million.

Hochul’s proposal to require all Med-

icaid managed care plans to re-apply for contracts with the state was not approved, but a study will be conducted for “informing the development of a plan to reform the delivery of services offered by managed care organizations in the Medicaid program,” with a report deadline of October 1, 2022. Almost half of “studies” like this are never completed, or even started, according to the NYS Senate’s Committee on Investigations and Government Operations, so we won’t hold our breath for that report.

An increase in state funding specifically for Centers for Independent Living like STIC was also approved, though it isn’t as large as we reported last time. That’s because it wasn’t clear that Hochul’s proposed \$2.6 million “increase” actually included the two previous \$500,000 raises the Centers got over the last couple of years: the “baseline” funding was never permanently updated with those increases. So while the increase is \$2.6 million over baseline, the actual increase over the Centers’ current level of funding will be \$1.6 million, or about \$39,000 per Center. That’s helpful, of course, but it doesn’t keep up with inflation in operating costs and it won’t keep smaller Centers with no other sources of funding from having to downsize.

Independent Assessor, Professor?

When the state legislature severely limited eligibility for Medicaid Personal Care Services (including CDPA) in the 2020 budget process, it also put an end to allowing disabled people’s personal physicians to determine that they need personal care. Why did they do this?

These were recommendations of the Cuomo Administration’s Medicaid Redesign Team, a bogus collection of Cuomo cronies and flunkies who followed pre-determined orders to find ways to cut homecare as much as possible. Sadly, the successful efforts of disability

rights advocates to ensure that Cuomo's "Managed Care for All" would include CDPA helped justify the cuts. The purpose of Medicaid managed care organizations (MCOs) is to maximize profits (at the for-profit MCOs), or at least to maximize executive salary and benefit packages for non-profit MCOs. To do that, MCOs try to cut spending on actual medical and long-term care services. CDPA is the least expensive form of homecare, so when MCOs were mandated to offer it, they saw it as a benefit and began steering thousands of people into CDPA. For the same reason, MCOs also prefer "traditional" Personal Care services over more expensive Certified Home Health Aides and Visiting Nurse Services. Meanwhile, NY's population continued to age. These factors caused a rapid rise in spending for homecare, which boosted Medicaid spending. Spending also grew because Cuomo frequently violated his own "global" Medicaid spending growth cap when his cronies in the hospital and nursing facility industries wanted more money. Professional right-wing Medicaid haters like the Empire Center and Upstate United became media darlings; every time the state does anything with Medicaid, reporters run to them for quotes claiming NY spends too much. This generated a lot of negative press for Cuomo, who wanted to be known as both "progressive" and tight-fisted. Since he wasn't going to stop catering to his Big Medical buddies like Northwell Health's CEO Michael J. Dowling (a former top aide to his father Mario, and also the chief rubber-stamper on the Medicaid Redesign Team), he targeted personal care and CDPA, which do not enjoy the support of wealthy executives.

Pervasive among right-wing budget zealots is the false belief that there are thousands of New Yorkers getting homecare who really don't need it. They seem to think disabled people conspire with their doctors to trick the Medicaid program into giving them "free maid service." This is why personal physicians got cut out of the formal process for deciding who gets personal care.

Instead, a behemoth, Maximus Health Services, got an exclusive contract with New York State to carry out an independent needs assessment. In this case, "independent" does not mean "independent of the state's desire to minimize spending."

This change was enacted two years ago but it didn't start until May of this year. You may think this was due to the Maintenance of Effort (MOE) requirement for federal COVID relief funding, which says the state can't cut any part of its existing Medicaid program during the public health emergency. DOH looked into it; the feds told them they could not enact the new ADL-related eligibility limits on personal care, but they could go ahead with the Independent Assessor. This makes no sense to us. If "existing" refers only to people who currently get Medicaid Personal Care or CDPA services, neither of these changes would result in cuts, because those people are permanently grandfathered into the program. If "existing" refers to eligibility and scope-of-service rules, then both changes are cuts, because the Independent Assessor is meant to be a new gatekeeper whose job is to make sure new applicants for Personal Care or CDPA who don't meet the new more restrictive eligibility requirements won't get those services.

So if the feds said it was okay to go ahead, why didn't they? The new Independent Assessment process relies on ordinary nurses to do the actual assessing; physicians (or physician assistants or nurse practitioners) then review and sign the assessments. The pandemic, and vaccination mandates for medical workers, have caused a massive shortage of nurses. In the old system the personal physician's order was only the first step; that order went to the MCO or the county, triggering an assessment process. So each MCO and county did a few thousand assessments every year. In the new system, they'll all be done by Maximus, and Maximus was having trouble recruiting enough nurses to meet the very stringent deadlines in the DOH regulations for the process. The process has a lot of moving parts and back-and-forth paper shuffling, and any single

step can easily get delayed. Allegedly by May 16, those problems had been resolved, but even so, for the foreseeable future the Independent Assessor will only handle a small portion of cases.

Basically, only new people seeking personal care services will be affected for now. Here's how it will work (thanks to the NY Legal Assistance Group's Evelyn Frank Legal Resources Program):

Starting May 16, 2022, the following groups of adults (age 18+) will call the NY Independent Assessor at 1-855-222-8350:

- Adults seeking to enroll in a Medicaid Managed Long-Term Care plan (MLTC) or Medicaid Advantage Plus (MAP; for people who are dually eligible for both Medicaid and Medicare), and who already have Medicaid.
- Adults in mainstream managed care plans (for people without Medicare) who are newly requesting approval for Personal Care or CDPA services from these plans, where the request is made on a standard timeframe (14 – 28 days allowed for processing).
- Adults who are not allowed or required to enroll in MLTC plans, who request Personal Care or CDPA from their local Department of Social Services (DSS upstate; HRA in New York City). These include those who are age 18-21, or who are enrolled in home hospice or in waiver programs (OPWDD, TBI, or NHTD waivers). The requests starting May 16 are only those filed on a standard time frame, not "Immediate Need" requests, which are always expedited.

Starting July 1, 2022:

- Immediate Need applicants who apply to DSS or HRA for personal care or CDPA.
- Adults in mainstream managed care plans (for people without Medicare) newly requesting approval for Personal Care or CDPA services from these plans, where the request is made on an expedited timeframe (72 hours – 17 days).

Not Yet Scheduled—For now, the following assessments will continue to be done as they always have, by the nurse from the MCO or local DSS:

- Annual reassessments in MLTC, MAP, and mainstream managed care (there are no more 6-month reassessments).
- Assessments for sudden change of condition or upon enrollee request for increased hours.
- Assessments after a hospital or rehab stay.

If you requested an assessment before May 16 and it is scheduled after that date, the assessment will use the old rules. This means the MLTC plan may still do its own assessment as well. Also, NY Medicaid Choice (the Medicaid managed care “enrollment broker,” also Maximus) should not also conduct the extra Clinical Assessment by the Independent Practitioners Panel or require the new high-need review for those who need more than 12 hours per day.

CDPA – 1; Personal Care – 0

People with disabilities scored a significant victory, and failed to win another battle, on the personal care front.

After a couple of years of lawsuits, administrative challenges from service providers, and push-back from state legislators, the Hochul Administration finally cancelled the Cuomo campaign to decimate the state’s Consumer Directed Personal Assistance Fiscal Intermediary (CDPA FI) program. Instead, any FIs, including STIC, that met the minimum qualifications for submitting the Request for Offers and were serving at least 200 people in New York City, or at least 50 people in the rest of the state, between January 1 and March 31, 2020, will get contracts from the NYS Department of Health (DOH) to continue to operate.

This means you won’t be forced to try to find some other agency to work with

you in CDPA, and we hope you think that’s a very good thing.

On the other hand, the effort to repeal the drastic cuts to personal care eligibility that were enacted at the same time as the attack on CDPA FIs was launched, in the spring of 2020, did not succeed. Bills to do this were introduced in both houses of the legislature but were not included in the final budget agreement. Although advocacy continued during the remaining weeks of the legislative session, hopes dimmed when it became clear that Hochul, and her Cuomo budgeting hold-over Robert Mujica, were attaching millions of dollars in projected savings to those cuts, insisting that the issue could only be addressed during the annual budget process.

The cuts put an end to stand-alone “Level 1” personal care services (things like house cleaning, cooking, and shopping) for anyone whose personal physician certified a need, and imposed a requirement that a person must need assistance, as determined by an “independent assessor,” with at least three “Level 2” activities of daily living (ADLs) like bathing, mobility, using the toilet, or eating, in order to get Personal Care services (including CDPA) unless they have some form of dementia, in which case they would need assistance with at least two ADLs. (DOH later claimed unofficially that it would extend that exception to people with significant mental illness, but so far has not issued that promise in written regulations or guidance.)

These cuts clearly violate the Americans with Disabilities Act (ADA) because they treat people with some types of disabilities differently than those with other types, and because they do not permit many people who would be eligible for nursing facility placement to choose to

use less expensive and more integrated homecare services instead.

Although the new “Independent Assessor” for homecare needs finally got started in mid-May (see page 5), the eligibility cuts have not taken effect because they would run afoul of the “Maintenance of Effort” (MOE) requirements of various federal COVID relief packages. The MOE will remain in place until the federal health emergency is lifted. That emergency

was recently extended to as late as July 15, 2022—though the feds could revoke it sooner than that. After the MOE ends, civil rights lawsuits will likely be filed as soon as somebody is denied homecare under the new rules, and the state will very probably lose in court.

Now that at least some wage increases for homecare are on the way, personal care eligibility is the most important advocacy issue for New Yorkers with disabilities. Yet we continue to hear much more rabble-rousing from Fair Pay advocates than from people who are concerned about that issue. Perhaps they feel that since the state will inevitably lose in court, there’s no need for concern. The problem with that notion is that people will actually have to be harmed, and likely forced into nursing facilities, in order to bring those court cases. That’s not the right way to think about this. We need the Fair Pay folks to put their issue on the table for now and use all the available influence and political capital we have to get these cuts repealed. Higher wages for homecare workers will do absolutely nothing for thousands of people who won’t be eligible for homecare because of these cuts. If we are only going to get one thing out of Hochul over the next year, it has to be repeal. Once that’s done, we can start up the Fair Pay bandwagon again.



Vote Like Your Life Depends on It!

This is an election year. You may already be tired of hearing about that. We understand. The endless repetition of opposing extreme viewpoints on what usually is a rather small range of hot-button issues gets tedious at best, and may at times generate the kind of anger and anxiety that all of us would rather avoid. After all, we have enough stuff going on in our lives that produce those feelings already. In recent years, as American society has grown more and more politically polarized, the endless hammering on divisive topics only seems to get worse. And most of us understand, on some level, that much of this is being propagated by people whose only goal is to obtain and hold on to power for their own personal satisfaction. We don't want to cause you more misery by making you think about this again.

But this is extremely important.

Many, if not most of you, never attended a high school Civics class. They seem to have gone out of fashion with dial phones and avocado green refrigerators. That is a tragedy, because that means that most of you have never been told by someone you trust and respect about some very basic principles. So we're going to take a little time here to do that.

The United States' form of government is a representative republic. It is not a democracy. That means citizens are represented at all levels of government—local, state, and federal—by officials who are elected directly by the people in most cases (the president and vice president are not directly elected, nor are federal judges). The key word here is “elected.” Although this is, as Abe Lincoln said, government “by the people,” and under our Constitution, Americans have the right to peaceably assemble and to petition the government for redress of grievances, the only time when citizens get to put their fingers on the actual levers of government is on election day.

You have an obligation, a duty, to take advantage of every single one of those opportunities. No, it's not a legal requirement. It's more important than that, because in order for elected officials to truly represent the people, the people—all of them—must participate in elections. It's more like a need: you need to eat and breathe in order to live. You need to vote in order to stay free.

When the Constitution was written in Philadelphia, and the delegates who wrote it were leaving what's now known as Independence Hall, one of them, Benjamin Franklin, was asked by a woman on the street, “What kind of government will we have?” Franklin famously replied, “A Republic—if you can keep it.”

That wasn't a cute joke. It was a historical reference. Prior to that time, republics did not have a reputation for surviving for very long. It was too easy for them to be manipulated by power-hungry demagogues and transformed into corrupt oligarchies or dictatorships. That happened a lot, and not just in ancient history, as in Rome. After the French Revolution established a republic in the late 18th century, France went through four republics, each of them overthrown by corrupt and cynical autocrats, right up into the mid-20th century. In February of 1917, Russians overthrew their Czar and established a republic. It was so weak that Lenin and his Bolsheviks were able to destroy it just eight months later. When most of the independent German states joined to create Germany in the 1860s, they set up a parliamentary republic; it was corrupted by a military autocracy shortly before World War I and re-established after that war. Only 15 years later, a few cynical and overconfident right-wing politicians allowed Adolf Hitler to become its head, believing, incorrectly, that they could control him. You know what happened next.

Americans may think it can't happen here because it hasn't so far. The American re-

public has survived longer than any other in history. That may be because its founders highly valued the idea that to keep a republic healthy, its citizens must be well-informed and actively involved. Even so, it was almost destroyed by the Civil War, a war that happened because a relatively small group of wealthy southerners, who had a tradition of authoritarian attitudes toward people who were below them on the social scale, and lived in a region which, unlike the North and Midwest, did not highly prize public education for everyone, seized control of eleven state governments and revolted. And we've seen cynical and overconfident right-wing politicians mistakenly believe they could control a presidential demagogue right here, right now.

No, we are not immune, and all of the ingredients necessary for a republic to fail are starting to gel in our country. It begins with citizens who are no longer well-informed. Public schools stopped teaching civics decades ago, as post-Watergate, post-Vietnam cynicism about government began to grow. More recently the very idea of public schools has come under increasing attack. What does it mean to be “informed” or “educated”? It means to have a correct understanding of a broad range of objective facts, as promulgated by people who are recognized experts, whose work has been carefully scrutinized and accepted as accurate by other recognized experts. The splintering of our education system into isolated enclaves, many of them run by religious zealots who do not particularly value objective facts, and the splintering of our media into hundreds of tiny web and cable outlets, most of which feel no compunction about spreading lies because lies get people more excited and involved than facts, has created a population of people who can no longer objectively analyze what they see and hear and reach agreement on what the truth is. This leaves them vulnerable to manipulation by demagogues who are seeking power for power's sake, and by even

more evil people who are deliberately trying to overthrow the republic and establish an authoritarian government that will suppress our freedoms and ruthlessly carry out some twisted ideological agenda. The first attempt to do that failed because of the stupidity and ignorance of its principal leader. Some of those waiting in the wings are neither stupid nor ignorant, including a large, well-organized and well-funded group of prominent right-wing leaders who are promoting Victor Orban's Hungary—with its anti-Semitic rhetoric and racist policies, its suppression of free speech and independent media, and its ongoing campaign to shut down independent not-for-profit advocacy organizations—as a model for their vision of a new America, and they now know what mistakes to avoid.

That all sounds very scary, and hopeless, but it's not. The way to prevent this is super easy.

In every single case, in the early days when a republic was beginning to die, it could have been saved if its citizens had simply stayed vigilant and taken advantage of every opportunity they were given to preserve it. The way to do that now, in America, is by voting. Not just in presidential elections, but in every single election. And in overwhelming numbers.

Voting is such a simple and easy solution that you may think, "Well, if that's all it takes, then the situation can't really be all that dire, can it?" Yes, it can. The problem is, there's a sharp divide between the time when a republic can be saved just by making sure to vote in every election, and the point when authoritarian oppression takes hold and the only way to end it is with organized violence. In every case, the many good citizens of republics that were in their death throes did not realize what was happening at the time; to them it was a slow, gradual process where not much changed from day to day, and nothing seemed very urgent or important. That's the stage we're in now. We have to stop it now, when it's easy, so people won't have to die to stop it later.

You may also think the situation isn't so urgent in a non-presidential election in NY, where continued dominance by

more or less progressive elements seems certain. STIC, and *AccessAbility*, do not endorse or oppose candidates for elective office. We only provide information and you, the voters, must make your own decisions. We can report that one of the most extreme right-wing politicians in the US Congress represents a district in upstate NY; this person is in a leadership position in the House of Representatives and has publicly called members of the opposing party "pedophiles" and promoted the same "Great Replacement" lie that motivated a teenager from Conklin, NY—just a few miles from STIC's office—to massacre ten innocent people in Buffalo because they were black. We can also add that moderates in both main parties are increasingly being driven out of the political process because extremists on both ends of the spectrum have taken over the local political organizations that control who gets to run for office. And how about judges? If you're concerned about recent federal court rulings, remember that while presidents appoint judges, the Senate has to approve them. If you don't vote, you can't ensure that there are enough progressive senators to approve good judges.

If you believe that only crooks and fanatics do politics, that politics—of which voting is the most basic form—is not an appropriate activity for people who are calm, rational, objective, and sensible, then you are abandoning the field to the people who want to destroy your way of life.

The truth is that most American citizens support moderately progressive ideas. The reason why they don't get implemented is because not enough of those citizens vote.

For at least two decades, surveys have shown this. Most recently: In 2019, CNBC, a centrist cable news channel, found that 84% of Americans support paid maternity leave, 75% support government-funded childcare, 60% want to raise the mini-

imum wage (a Reuters poll that year had 59%), 57% are for free public college tuition, and 54% favor "Medicare for all." In 2021, the Siena College Research Institute found that 61% of Americans support a ban on assault weapons, 63% favor a path to citizenship for undocumented im-

migrants, and 84% want federal legislation to protect voting rights and make voting easier—that's *after* the 2020 election. Each year since 1975, the Gallup Poll has asked Americans whether they believe abortion should be legal in at least some circumstances. In every one of those

polls, a majority said yes. In fact, in some states that have enacted "trigger laws" that will outlaw abortion if the Supreme Court overturns *Roe v Wade*, a majority of those citizens don't approve of those laws. How did they get passed then? Too many people refused to vote, allowing right-wing extremists to take over the government.

As we said last time, in 2020 over 66% of eligible voters cast a vote. If we could regularly turn out 85% of eligible voters, and each of those voters supported only those politicians who agree with them, right-wing extremists would almost completely vanish from government, and moderately progressive reforms would be carried out everywhere.

So what does it take to vote?

Register if you're not already.

Then, on election day, ***Just Show Up*** at the polls and vote. It only takes about ten minutes to fill in a ballot in NY unless you have disabilities that affect your ability to read or write. A while back we reported on a lawsuit against NY for failure to offer accessible ballots. That suit was settled, so if you have such disabilities, you can request an absentee ballot online, fill it out on your home computer, print it and mail it. Yes, you may need help with that. No, it is **NOT POSSIBLE** to vote securely over the in-



ternet, or without a paper record. No, it is not okay to demand compromises in the security of our election systems in order to get 100% accessibility. Quite frankly, the integrity of our elections is more important than your frustration over not being able to do it alone. Get help if necessary, and don't use that as an excuse not to vote.

New York doesn't throw many roadblocks in the way of people voting, but it doesn't allow universal vote-by-mail anymore. The pandemic is sufficiently controlled that you can safely vote in person if you wear a mask. If you hate masks, get vaccinated (it's free) and don't wear one.

Also in NY, during the budget process Governor Hochul got her wish to have polling sites set up on the campuses of colleges that have more than 300 resident students registered to vote at that address. That will be very convenient for students who live on campus, but if you don't, register where you live and vote anyway, even if the polling place is a few miles from your home.

You can go to this website, find your county's board of elections, and get contact information, learn how to register, request a mail-in ballot, or ask other questions about voting in NY:

<https://publicreporting.elections.ny.gov/CountyBoardRoster/CountyBoardRoster>

You can contact the NYS Board of Elections here:

Phone: (518) 474-6220

TTY: Call the New York State Relay at 711

Email: INFO@elections.ny.gov

To report problems with your accessible absentee ballot, contact Disability Rights New York:

<https://www.drny.org/>

Phone: (800) 993-8982

TTY: (518) 512-3448

Email: PAVA@DRNY.org

If you're reading this in a state where extremists control the government and they've passed laws to make it harder to vote: Remember, even with those laws, voting is still pretty easy. Just make sure you understand the rules and be prepared. Register early, and get an acceptable form of identification early. Get up early and go to the polls early to make sure you get in before they close, even if you have to wait on a long line. Yes, long lines are annoying and tiring. Bring your own refreshments. Bring a positive attitude. ***Vote in person***; a huge public voter turnout that the media can plainly see will be the best defense against corrupt politicians seeking to use new laws to claim fraud and overturn election results. Even in those states, voting is still the easiest, simplest, and most effective thing you can do to protect our republic. And if you all show up and vote, you'll elect enough progressive candidates to repeal those ugly laws.

VOTING – IT'S EASY! IT'S ESSENTIAL!

JUST DO IT! IN EVERY ELECTION!

NY May Have an Aversion to Aversives

In the wake of the Food and Drug Administration's failure to make its ban of the Judge Rotenberg Center's electric shock punishment devices stick (see *Accessibility* Spring 2022), advocates have been pursuing other means to stop the torture.

In NY a bill has been introduced in the legislature that would prohibit the state from purchasing services from any organization that uses aversive conditioning methods, including electric shock.

Currently there are 55 people still authorized under a court ruling to receive shocks from the Center. None are NY residents. However, several New Yorkers get Rotenberg services, paid for by the NY State Education Department (SED) and, possibly, by the NY Office of People with Developmental Disabili-

ties (OPWDD). We don't believe any of them are subjected to aversives as a matter of formal programming, as both of those state agencies prohibited those techniques several years ago, and when NY pays for out-of-state services, NY's rules apply to them. It is possible that New Yorkers experience aversives "informally" at Rotenberg, though.

As we've reported previously (see *Accessibility* Winter 2021-22), the Judge Rotenberg Center in Massachusetts is a service system primarily for people with developmental disabilities that uses "aversive conditioning," including electric shocks, to control the behavior of some of the children and adults it serves.

Aversive conditioning means using punishment to reduce undesired behaviors. "Punishment" is a very precise term in the psychiatric world: it is a stimulus that causes the frequency or intensity of a behavior to lessen. That connection between cause and effect is very important; regardless of whether most people regard the stimulus as unpleasant, if it doesn't reduce the behavior, it isn't a punishment. And if it does reduce the behavior, then it is a punishment, even if most people wouldn't see it that way. Electric shock isn't the only stimulus that can be used as a punishment, and the Rotenberg Center is the only program in the US or the rest of the western world that uses it in this fashion. More commonly-used aversives include a spray in the face with lemon juice or water; pinching; slapping or spanking; withholding food or water; or unpleasant-tasting foods.

Apologists for the Center's use of electric shocks claim that it is the only method that works for certain people who have severe self-destructive or violent behavior issues, that it does not injure them, and that it is only used under highly-controlled circumstances in response to extreme behavior. Extensive evidence has shown that none of those claims are true. In fact, Matthew Israel, the Rotenberg Center's founder, only avoided prison by agreeing to step down after incidents in which children were repeatedly strapped down and shocked—as much as 30 times in rapid succession—as punishment for such minor infractions as

refusing to take off a jacket or for “talking back” to program staff, none of which was authorized by their service plans. It is not likely that this incident put an end to this type of abuse. A program that condones the use of any type of aversives under any circumstances will always have some employees who feel justified in using them in circumstances of their own choosing, and not just for prescribed behaviors. Further, there is strong evidence that the effects of aversives in reducing unwanted behavior are temporary at best; to the extent they can be maintained, it is necessary to periodically increase the intensity of the punishment to continue to get results. As for injuries—people have suffered burns from the shocks, and have experienced joint and muscle injuries resulting from their desperate struggles to get away from the pain-inducing devices, which are strapped, and locked, onto their bodies. Finally, several people who were shocked eventually got away from the Center and have been receiving more humane services and supports—and are doing just

fine, proving that those methods do in fact work when used correctly, and that torture is never necessary.

The proposed bill is remarkable in that it applies to a broad, unspecified range of programs, not limited to those outside the state. It doesn't just say the state won't pay for aversive treatment to be applied to specific New Yorkers; it says it won't pay any program that provides that treatment to anyone at all. It does let people under the age of 21 complete their current school year at such programs as long as they do not experience aversive conditioning during that time.

The bill was introduced in both houses of the legislature; it was scheduled for floor debate in the Senate in mid-May. The bill numbers are S.8935 and A.10289. There was predictable opposition from several families of people who are in the Rotenberg system. They pointed out that they sent their children there because they could not find any programs in NY that would accept them due to their violent

behavior, or merely because, due to lack of funding, they could not find programs with openings for new people. Some families also have said that they would rather have their children experience aversive treatment than drug treatment.

The state needs to fully fund services so nobody has to go on a waiting list. The state should also prohibit any agency that gets state money for serving people with disabilities that affect behavior from rejecting applicants on the grounds that they are “too difficult” to deal with. Positive Behavioral Supports, sometimes in conjunction with a reasonable medication regimen, has been shown to be highly effective with people with the most significant behavioral issues. These programs should be using it. And some people need to discard their peculiar beliefs that it is better to hurt people than to sedate them in order to get their behavior under control.

As we went to press, passage of the bill was uncertain; it depends on how loud those families get.

courts watch

Cummings v Premier Rehab Keller: nothing new here, move along

Jane Cummings, a woman from Texas who is deaf and legally blind, asked a physical therapy provider called Premier Rehab Keller to provide an American Sign Language interpreter for her therapy sessions. The provider refused, saying Cummings could communicate with the therapist by lip-reading, writing notes, or gesturing. Cummings refused to accept this and got her therapy elsewhere. She later sued Premier Rehab in federal district court under Section 504 of the federal Rehabilitation Act, and the Affordable Care Act (ACA), and only requested compensatory money damages for emotional distress that resulted from the humiliation of being discriminated against. The district court ruled against her; she appealed to the Fifth Circuit, which upheld that decision, so she took it to the US Supreme Court, which upheld both decisions.

Advocates, such as the Bazelon Center, decried this result, claiming the decision “weakens” civil rights for people with disabilities.

Although the decision is somewhat questionable, it doesn't change the situation for disability rights—at least, not as that situation has existed since 2002 when the Supremes issued a decision in *Barnes v Gorman*. The federal Civil Rights Act of 1964, Section 504 (and the later ACA) all contain sections prohibiting discrimination by recipients of federal funds, but do not specifically say that people can sue for damages under those laws. That opens the door to a lot of court cases. Over time the Supremes have ruled that those “spending clause” laws essentially establish “contracts” between the federal government and recipients of federal funds, and since there are generally-accepted ways in which entering into contracts establishes liabilities under which contractors can be

sued for damages, then damage suits in such situations are allowable. People like Cummings are “third parties” in these cases; the Supremes have agreed that there is an “implied right of private action” allowing individuals to sue federal funds recipients under these laws. The contractor—in this case a medical service provider—promises not to discriminate due to disability in exchange for federal money; if the contractor then discriminates, it is in “breach of promise” for which it can be held liable. Case law has established that, although damages for emotional distress can be awarded when “the contract or the breach is of such a kind that serious emotional disturbance was a particularly likely result,” such awards are not “generally” made.

Since 2002 it appears that in only one case did a federal appeals court, the Eleventh Circuit, rule in favor of an award of damages for emotional distress under

a “spending clause” civil rights provision: *Sheely v MRI Radiology Network*, in 2007. The Fifth Circuit was aware of that ruling but disagreed with it and adopted the reasoning in *Barnes*.

So when the Supremes ruled in *Cummings*, they were simply upholding their own precedent in order to resolve the dispute between those two circuits. This 6-3 majority ruling was written by Chief Justice Roberts; the three liberal justices, Breyer, Kagan and Sotomayor, dissented.

There’s certainly a good argument to be made that discrimination is especially likely to cause emotional distress, and that this is likely evident to anyone who thinks about the effects of deliberate discrimination before deciding whether to accept federal funds. The dissenters made that argument. They lost. The gist of *Barnes* is familiar to students of recent right-wing federal court opinions: “exceptions” like the one that allows damages for emotional distress in contract cases where emotional harm is clearly very likely, are “too fine-grained” for courts to resolve. If Congress wanted to let people sue for emotional distress, they could have said that in the law. Absent such specific language, the court risks usurping Congress’s power, and creating a situation in which any court can allow any kind of damages for any kind of alleged harm if Congress didn’t specifically mention it in legislation.

That kind of slippery-slope analogy is pretty weak in this case. The rule is “Recovery for emotional disturbance will be excluded unless . . . the contract or the breach is of such a kind that serious emotional disturbance was a particularly likely result.” That is very specific. There’s no room in it to conclude that other kinds of un-legislated compensation would be allowed for other kinds of harms. The case was just a convenient excuse for right-wing judges to ride their usual hobby horses. It’s an unavoidable fact of life in the federal courts now, and the only solution is to elect legislators who will write laws that say exactly what they mean.

However, the notion that this decision “weakens” anything is overblown. There have been very few cases after *Barnes*

in which anyone was awarded money damages for emotional distress where violations of these “spending clause” laws were involved, and not many even before *Barnes*. It is really true that money damages for emotional distress are mostly not available under these laws, and it has been true for a very long time.

Had Cummings simply said that she suffered, or was likely to suffer, *physical* harm because of her inability to adequately communicate with her physical therapist, she would have been on firmer ground and likely have won her case at the district level. Why she didn’t is a mystery. But it wouldn’t be the first time an incompetent lawyer screwed up a disability rights case.

Payan v LACCD: Blind justice?

As we reported last time, blind community college students in Los Angeles sued the college for refusing to reasonably accommodate their disabilities: for example, they refused to install screen-reader software on library computers available to students, and failed to provide accessible versions of required readings. They sued under Section 504 of the federal Rehabilitation Act, which forbids organizations that get federal funds to discriminate on the basis of disability.

The students won in federal district court, and when the college appealed to the Ninth Circuit, they won there too. The college was preparing an appeal to the US Supreme Court, which frightened a lot of disability rights advocates because the right-wing justices there have been steadily whittling away at civil rights laws that have been interpreted by courts to outlaw so-called “disparate impact” discrimination: That is, discrimination that happens “inadvertently” as a result of policies or procedures that do not take into account the ways in which people with different characteristics can be affected in different ways by the same set of rules or actions. The advocates conducted a national petition and protest campaign to try to convince the board of the Los Angeles Community College District to abandon its appeal efforts.

Our article, which was written in late February but published in mid-March, mostly focused on how the Americans with Disabilities Act (the ADA) is different from other civil rights laws because its amended 2008 version clearly explains that it is intended to outlaw such disparate impacts. Lawyers have a tendency to sue educational institutions under Section 504 rather than the ADA, perhaps because even most private schools get some federal money, but that maybe wasn’t such a good idea in this case. The ADA covers “public entities”—that is, governments—and a state, county, or city-operated community college should certainly qualify.

The protest campaign was initially successful. On March 2, the district board voted to hold up its appeal and try to settle with the students. If those efforts fail, the board retained the option to go back to court. As of April 6, settlement talks were ongoing, but we haven’t heard anything since.

United States v Uber and others

We reported this case in the Winter 2021-22 issue of *AccessAbility*. The federal Department of Justice (DOJ) sued Uber because it automatically charges a “wait time” fee to disabled riders who take longer than two minutes to board an Uber vehicle due to the unavoidable amount of time it takes to break down and stow a wheelchair, or for a blind person to find the vehicle.

As we predicted, Uber responded with its usual claim that it is not a “transportation company” but rather a “software” or “technology” company, and therefore it is not subject to the public transportation requirements of the Americans with Disabilities Act (ADA)’s Title III (governing public accommodations), or to the ADA regulations issued by the federal Department of Transportation. Uber asked the court to dismiss DOJ’s complaint for that and other reasons.

In February 2022, DOJ sent a response to the court that totally demolished Uber’s claim that it is not a transportation company. Notably, this response gave a brief history of how various other federal dis-

trict and appeals courts have also rejected that claim, not only by Uber but by Lyft. Although DOJ didn't suggest it, it might be a good idea, the next time Uber tries this, for a judge to charge the company with contempt for wasting its time with obviously frivolous arguments.

This case isn't decided; the court will continue in its ponderous course and eventually rule on Uber's motion for dismissal, after which the case will proceed to discovery, and then to trial, at some point later in the decade. If we're still alive when a ruling is issued, we'll report it here.

C. K. v Bassett: Prompting Reasonable Promptness

This is a class action suit filed on March 31, 2022, against NY State Department of Health (DOH) Commissioner Mary Bassett in her role as top Medicaid administrator, and against the Commissioner of the Office of Mental Health (OMH) in her capacity as lead authority for the state's mental health service system. The suit alleges that the state systematically violates federal Medicaid law, Section 504 of the federal Rehabilitation Act, and the Americans with Disabilities Act (ADA) because it doesn't provide adequate levels of mental health services to children in the most integrated settings.

This may have a major impact on NY's decades-long failure to provide enough integrated community based mental health services to people of all ages. The case only represents children, but the outline of deficiencies in the state's mental health service system described here applies equally to adults. If this case goes well, can a similar suit concerning adults be far behind?

For example, so-called "Intensive Case Management" is not really "intensive" at all. An ordinary reasonable adult would think "intensive" means that case managers spend a lot of time giving individual attention to each "case" to ensure that people's needs are clearly understood, that appropriate services and supports are authorized to meet those needs, that those services are provided reliably and with quality, and that, as a result, the person's

life improves. Almost none of that happens in real life. Basically, Intensive Case Managers send standard referral letters to service providers and, in the case of children, report back to the child's parents or guardians to say that those letters have been sent. The case managers have no responsibility to ensure that services are actually provided—and they often are not, or at least, not enough to notice.

There is a whole menu of services that Medicaid-eligible children with mental health disabilities can receive. Some of them, under the rubric of "Early and Periodic Screening, Diagnostic, and Treatment services" (EPSDT), are a mandatory part of every state's Medicaid plan. Home and Community Based Services (HCBS) are not mandatory, but when states agree with the federal government to provide them, as NY has done, then the state is obligated to actually provide them. And all Medicaid services must be provided "with reasonable promptness," according to federal Medicaid law. EPSDT includes, importantly, behavioral support services such as developing and carrying out Positive Behavioral Support plans in the child's home and natural community locations. HCBS can also include behavioral supports as well as habilitation services and other things, all of which can only be provided in the person's home or community locations.

Section 504 and the ADA reiterate that people with disabilities have a right to receive services from the state in the most integrated settings appropriate to their needs. "Appropriate to their needs" does *not* mean segregated or institutional settings merely because there are no other equally or more appropriate settings available.

Despite these rules, kids who need these services simply can't get them reliably, or sometimes at all. NY's HCBS program for children with mental health disabilities has been in the planning stage for several years without ever becoming a real, going concern. Other types of services are subject to severe shortages in personnel or available openings. Children may get a few hours of service, then suddenly be cut off because their provider person quit or the provider agency went out of business.

Or they are put on waiting lists until a provider comes up with a "slot" for them. In the meantime, these children may engage in self-destructive, aggressive, or suicidal behavior, and the only options are segregated institutional settings, such as CPEP, OMH "community residences," or psychiatric hospital wings or facilities. Those places are intended to be temporary until the child's situation is stabilized, so these kids get released without any community-based supports being available, they deteriorate, and they get institutionalized again. Or they get into trouble and get mistreated, injured, or killed by the police. Sound familiar? It's exactly what happens to adults with mental health disabilities in NY, in huge numbers.

These service shortages happen because NY consistently refuses to pony up enough money to keep the services running reliably and in adequate supply. This has been happening since the late 1960s, when the state started closing large mental health institutions, which was the right thing to do because people with mental illness have rights to freedom of movement, association, and personal choice like everybody else, and instead of moving all of the funding those places got into community-based services and supports for the people those places served, it put most of it into the General Fund and spent it on other things, or handed it back to citizens by means of tax cuts. We can't even tell you how often we've reported on that situation here in *AccessAbility*, but it bears repeating: This has been going on for *over 50 years*. The problem is well-understood, and the solution is obvious. The reason the solution hasn't been applied is equally obvious: people with mental health disabilities have no political clout themselves, and they have no well-organized lobbying networks of upper-middle- and upper-class family members to go to bat for them like the state's best-served disability group, people with developmental disabilities, do.

The suit doesn't take on the funding issue directly. Medicaid law requires states to pay service rates that are adequate to ensure that services are available across the state at the same level as they are for

people using other forms of medical insurance, but over time, federal courts have made it impossible for anyone to enforce that requirement. But the same courts have held that the “reasonable promptness” requirement is more like a direct promise to service recipients that those people can enforce in court. If this argument works, this suit may solve one of the toughest legal problems facing disability rights advocates.

Stay tuned.

DOJ Issues Web Accessibility Guidance

(from a DOJ press release)

On March 18, 2022, the US Department of Justice published guidance on web accessibility and the Americans with Disabilities Act (ADA). It explains how state and local governments (entities covered by ADA Title II) and businesses open to the public (covered by ADA Title III) can make their websites accessible to people with disabilities in line with the ADA’s requirements.

The guidance discusses a range of topics, including the importance of web accessibility, barriers that inaccessible websites create for some people with disabilities, when the ADA requires web content to be accessible, tips on making web content accessible, and other information and resources. The guidance offers plain language and user-friendly explanations to ensure that it can be followed by people without a legal or technical background.

“We have heard the calls from the public on the need for more guidance on web accessibility, particularly as our economy and society become increasingly digitized,” said Assistant Attorney General Kristen Clarke for the Justice Department’s Civil Rights Division. “This guidance will assist the public in understanding how to ensure that websites are accessible to people with disabilities. People with disabilities deserve to have an equal opportunity to access the services, goods and programs provided by government and businesses, including when offered or communicated through websites.”

The full guidance is available here: <https://beta.ada.gov/web-guidance/>

Savings Penalty Elimination Act

There’s a bipartisan bill in the US Senate that would dramatically increase the cash asset limit for the Supplemental Security Income (SSI) program.

SSI is available to people who are age 65 or older, or who have permanent disabilities that qualify under Social Security Administration rules as making them “unable to work,” and who have very low incomes. As of now you also must not have more than \$2,000 in savings if you are single (or more than \$3,000 if married) to qualify. There are other things you need to do in order to qualify for SSI; information is here: <https://www.ssa.gov/pubs/EN-05-11069.pdf>). You can apply for the program online here: <https://www.ssa.gov/benefits/ssi/start.html>.

The bill would raise those savings limits to \$10,000 for individuals and \$20,000 for married couples, and it would, for the first time, index them to the inflation rate.

The bill, S.4102, is sponsored by two Ohio senators, Sherrod Brown, Democrat, and Republican Rob Portman. We don’t know what its chances for passage are. Portman, whose term expires at the end of 2022, has said he will not seek re-election this fall.



STIC NEWS



STIC COVID-19 Update

By Maria Dibble

I truly hope that this will be the last COVID-19 update I will have to write for this newsletter.

I’m very pleased to announce that all employees are back in our offices, conducting their business in-person or via zoom as circumstances dictate. Also, the front doors are now unlocked, so people won’t have to wait for someone to let them in. We continue to ask that people make appointments before coming here, to ensure the person they need to speak to is actually available.

Masks are optional for visitors. However if you’ve been exposed to COVID or are experiencing any symptoms of the virus, we ask that you reschedule your appointment for another time. Additionally, while we have relaxed some of our COVID policies, we still ask that people maintain six feet of distance from others, for everyone’s safety and protection.

Considering the fact that most people worked from home for almost two years, our employees are adjusting to their return, and are enjoying the ability to communicate with their coworkers face-to-face. COVID

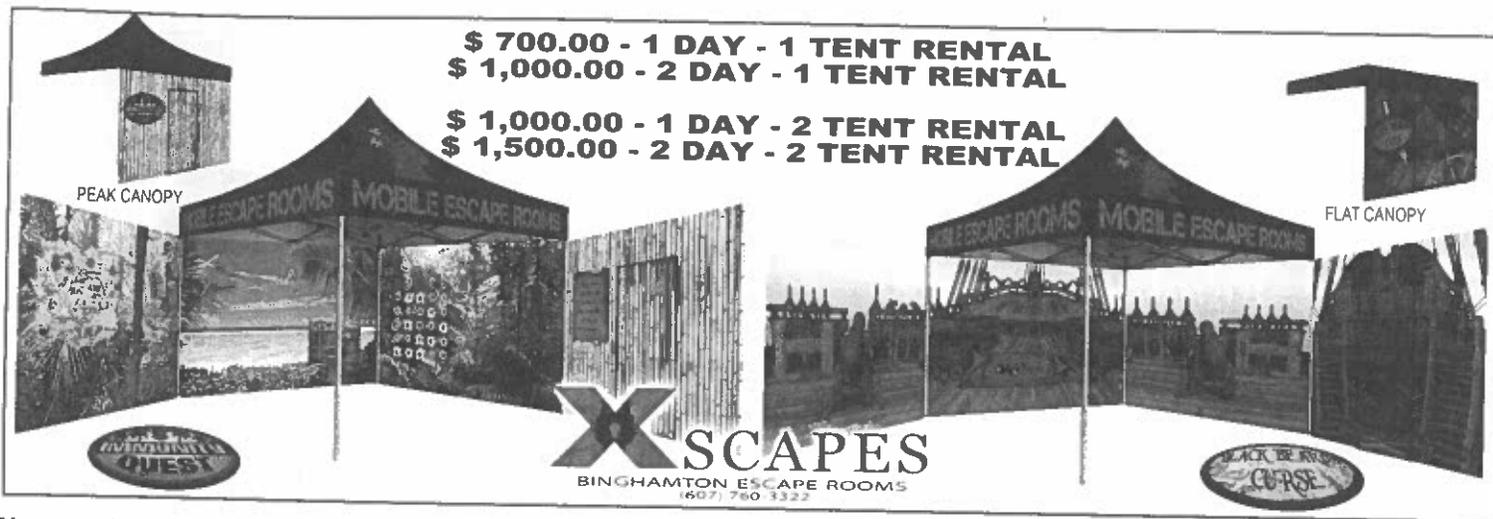
is by no means gone, but at least we have the option to get vaccinated and boosted, and if we do get sick, now there are at least effective treatments against the virus. We should still be vigilant and careful though, protecting ourselves, our loved ones, and others with whom we come in contact.

Social interactions and direct communication with people are crucial for the work we do at STIC. It feels so good to return to the culture and camaraderie we shared before the pandemic. I believe we’ve reached the point where perhaps we are controlling the pandemic, instead of the other way around. I profoundly hope so.

We are back, and we hope you return as well. Our doors are open in welcome!

\$ 700.00 - 1 DAY - 1 TENT RENTAL
\$ 1,000.00 - 2 DAY - 1 TENT RENTAL

\$ 1,000.00 - 1 DAY - 2 TENT RENTAL
\$ 1,500.00 - 2 DAY - 2 TENT RENTAL



Xscapes is proud to share our Mobile Escape Rooms experience for summer 2022 rentals. We have three games for rent as part of our successful escape room fundraiser "Xscapes" here at STIC. The mobile games are an island-themed adventure called Immunity Quest, a pirate ship voyage called Blackbeard's Curse and a mysterious journey into the land of wizardry called Wizard Academy. These mobile games require a 15 feet x 15 feet level floor space and a ceiling height of 15 feet for peak canopy set up and at least 8 feet for our flat top canopy set up.

These mobile escape rooms are perfect for team building events, school functions or private parties. Rental for one tent is \$700 for one day and \$1,000 for two days. If you would like to rent two tents the cost is \$1,000 for one day and two days is \$1,500. All money raised with Xscapes and our mobile escape rooms benefits STIC's mission of supporting individuals with disabilities in our community.

Book an escape room at www.Xscapes-STIC.com or call (607) 760-3322 for more rental information or to purchase our Xscapes Bucks, the gift that keeps on giving.

**STIC's Offices
will be Closed
June 27 through July 4
For Employee
Appreciation Week.**

See you on July 5.

Happy Summer!

2022 NYSILC Statewide Consumer Needs Survey

(from NYSILC)

The New York State Independent Living Council, Inc. (NYSILC) is a statewide organization that develops a plan for Centers for Independent Living (CILs) to serve people with disabilities in New York State. We invite you to participate in this year's consumer needs survey. Your answers will help us make sure that your needs are included in the statewide plan for services. Our goal is to make sure that all people with disabilities can fully be part of their communities and receive the services they need. Your opinions matter!

The deadline for the survey is June 25, 2022. Hopefully many of you will have received STIC's newsletter before that date. To further encourage you to reply, NYSILC will enter you in a drawing for one of FIVE \$50 Amazon gift cards (only if you opt in). Other-

wise, you won't need to enter any identifying information at the end of the survey.

You can access the Survey Monkey version of the survey here:

<https://www.surveymonkey.com/r/2022ConsumerNeeds>

Survey Monkey doesn't work well for everyone, so you can also use a Microsoft Word version, here:

<https://nysilc.org/resources/key-documents/393-2022-nysilc-needs-assessment-consumer-survey/file>

If you do the Word version of the survey, please send it to Amy Wink at NYSILC:

Email: awink@nysilc.org

Snail Mail: NYSILC, 111 Washington Ave., Suite 101, Albany, NY 12210.

All responses will be kept completely confidential and only the aggregated data will be reported.

Free Internet!

On May 9, 2022 as part of the Infrastructure Investment and Jobs Act signed into law last year, President Biden announced the Affordable Connectivity Program (ACP), which provides eligible households a \$30 per month discount off monthly bills for high-speed broadband service. Eligible families who pair their ACP benefit with one of 20 participating plans can receive high-speed internet at no cost.

People who get Medicaid, SSI, SNAP, and/or several other government benefits are eligible. If you don't get any of those things, you can qualify if your income is low enough. Spectrum, Verizon (FiOS only) and Frontier participate in NY.

Details are available here:

<https://www.whitehouse.gov/getinternet/>



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

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PAID
BINGHAMTON, NEW YORK
PERMIT NO. 126

135 E. Frederick St.
Binghamton, NY 13904
(607) 724-2111 (voice/TTY)
Toll Free (877) 722-9150
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If you would like to support STIC, please use this form.

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135 E. Frederick St.
Binghamton, NY 13904

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Address _____
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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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