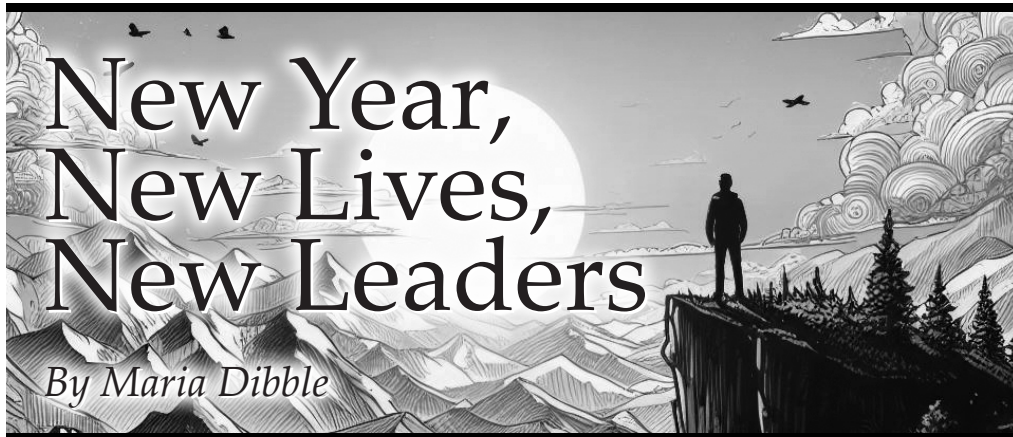




The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

AccessAbility

Winter 2023-24
Number 153



New Year, New Lives, New Leaders

By Maria Dibble

Thoughts and memories cascade through my head in a maelstrom of words and images, none of them stopping to let me catch one, even for a brief moment, as I try to write my last editorial in this newsletter as STIC's Executive Director.

I stand on the cusp of two worlds, the one I've known and loved for the last 40 years, and the new unknown vista that is spreading out before me, that of my retirement. It is hard to find the words that can express the mixture of emotions that defines me in this moment, certainly joy and celebration in the knowledge that I've always done the best I could, that I've stuck to my principles and done what I thought was right. Of course, there is the sadness and loss for what I haven't yet accomplished, the grief of letting go of something I love very much, but most of all the sorrow of knowing that people are still confined to institutions and being denied their rights.

I have never been someone who lives in the past, and so I won't here either. I look forward with hope and eagerness for what will come next in my life, and I will continue to fight the good fight as a board member of STIC. There are many things I'll miss, but many that I won't, and that balance propels me forward into the next chapter of this book of life.

The leadership of STIC is changing, but the mission and philosophy will be as strong as ever, and the commitment and dedication of the people who are taking the reins are steadfast and unwavering.

Please join me in welcoming Jennifer Watson in her new role as Executive Director, and

Lucretia Hesco as the new Assistant Director. JoEllen Dorak is our new Controller, Chad Eldred Director of Programs and Operations, and Casey Flanagan continues as our HR Director. These five people will be the new leadership team for the agency, and they each have invaluable talents and gifts that they bring to the table. I have enjoyed working with them all, and the other people that make STIC function so smoothly as well, but sadly, they are far too many to list here. I want to thank each and every employee for their ongoing support of our mission, and for all they do for STIC and the people we serve.

I also want to thank the readers of this newsletter, the volunteers and the board members that have served tirelessly, and most of all I thank consumers for trusting and believing in STIC these four decades. Lastly, I thank my husband and partner in life for his love, support and belief in my abilities, which have sustained me through thick and thin, the good and the bad and everything in between.

2024 will be a new year, as well as the beginning of the second era of STIC's development and growth. It will be filled with opportunities and challenges, triumphs and broken promises, but it will never falter.

Final Thoughts

By Ken Dibble

As my last days as your faithful Editor (and various other things) here at STIC wind down, my mind is full of many thoughts. It's a very emotional time.

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My strongest feeling now is gratitude. I am so grateful for the opportunities I was given back in 1987, when I started here as a part-time TTY operator; in 1988, when I graduated to full-time grant-writer; and again in the early 90s, when I took over the newsletter and began managing our (primitive) computer systems: opportunity to escape the soul-stealing emotional hell of OPWDD and still work in a field I had come to love; to do jobs that used my greatest strengths—writing and computers; to be in a place where my idiosyncrasies and interpersonal limitations were first tolerated, and, later, understood and accepted as harmless; to be allowed to make important contributions to this agency's growth, and to the advancement of disability rights and integration. Through it all, I was given time to

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EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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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.

learn almost everything that I now know on the job, a privilege most people don't have, and to prove my value to STIC distinct from my relationship to its founder and Executive Director. I can't thank those who made all this happen for me enough.

I won't be editing a newsletter or running an IT department any more (aside, perhaps, from a bit of software programming for STIC), but I will still be caring about the issues that it's been my life's work to take on. I'll read the newsletter, keep track of proposed laws and regulations and comment on them, maybe even serve on an advocacy committee, if I'm asked. For right now, though, I can't leave without trying to sum up a bit of what I've learned, in the hope that you can benefit from my experience as you all move forward to fight the good fight.

It matters less what people call you than what they think, and do, about you.

If changing the names of groups of people could change people's attitudes about them, then folks wouldn't feel it was necessary to keep changing them over and over. Renaming the group you're in provides a bit of personal satisfaction and pride, and expresses, perhaps, a new sense of identity for a new time, but it does not have any effect at all on how other people see you. When time and other resources for advocacy are scarce, there are far more important things to work on than changing "handicapped" to "disabled", or "black" to "African American", and the like. And we should not give politicians a reason to stop acting on our real issues and think they've done enough merely because they've passed a law to require the use of "people first language".

All groups of disadvantaged people have issues in common, but as advocates we have a responsibility to keep our unique interests front and center, and not let anyone else "in

the movement" treat us as children of a lesser god (to coin a phrase).

Unfounded stereotypes, discrimination, and horrific mistreatment have a history as long and gruesome for people with disabilities as that of any other disadvantaged group on the planet. Our experience in organizing for change may be less than that of other groups, but our suffering is not. And we all belong to each other's groups. Disabled people are male, nonbinary, old, gay, straight, Asian, white, black, female, indigenous, Latino, young, trans, and every other thing. A majority of us live in poverty, which, all on its own, without our disabilities, leads to poorer physical and mental health, including bad nutrition and exposure to toxic, polluted environments; inferior education; a higher frequency of police violence; and fewer opportunities to accumulate assets and transfer them to our children. Arguments about who is more privileged than whom and who must lead and who must be "allies" are useless, and actively dangerous in the face of those who would keep us down. We can all learn from each other, and we must do that in order to bring real change. When it benefits us to work with other groups on common issues, we must do that. But we must never abandon or soft-pedal our own issues, especially full community integration, personal autonomy, and freedom from paternalism and overprotection.

Not only will the revolution not be televised, it will be an unmitigated disaster.

As best I can tell, history has not recorded a single socio-political revolution that did not bring mayhem, suffering, and cruelty, and leave most people worse off than they were before. The American "revolution" wasn't a socio-political revolution; it was a civil war that only benefited some of the people who helped start it. The British government at the time was corrupt, but not as undemocratic or repressive as "Patriot" propaganda claimed,

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and the resulting new American regime was far from democratic or benevolent for anyone but wealthy white men. Real revolutions have only destroyed homes and workplaces, carried out revenge and persecution against various groups—many of them disadvantaged—and set up tyrannies that terrorized and killed people in huge numbers. Please give up revolutionary ideologies of the left and right. Marxism, socialism (the real one, not social democracy), nationalism, theocracy, libertarianism, and all the others, cannot save us; they can only destroy what is good about how we live now. With all its faults, frustrations, and evils, our society is not the “best of all possible worlds” for all time to come; it can get better gradually, but only if we work together while respecting each other. We can only right the racist, sexist, imperialist and ableist wrongs of the past, without also harming the innocent in the present, by trying to make sure they don’t occur in the future.

Equal, not special.

The Independent Living philosophy is a cross-disability movement that wants people with disabilities to be treated *the same* as people without them. “Cross-disability” means we are, and serve, people with all kinds of disabilities of all ages, we don’t have different expectations for different disabilities, and we don’t make separate deals that benefit some kinds of disabilities at the expense of others. “Equal” means that all of us can, and must, accept the same risks in life; be free to make the same decisions, including wrong ones; accept the same consequences; and reap the same potential rewards. Not a handout, but a hand up. Don’t give us a fish, teach us to fish. Equal opportunities, not special guarantees—including guarantees of “safety”.

Stop talking and listen.

Most of those people “on the other side” aren’t evil, and they aren’t deliberately trying to hurt you; they’re just angry, and scared, and they feel like nobody listens to them. Often they are also misinformed, but you’ve got to get past the anger, fear, and feelings of neglect before you can help them learn. If you listen to them, and respond with empathy, you may make allies out of enemies. Democracy can’t survive unless people with very different ideas agree to compromise. With compromise, you don’t get everything you want, but you get some of it, and then you go back later and get some more. Without it, you get nothing but growing acrimony and frustration, until people start thinking they need to settle their political disagreements in the streets. That doesn’t mean we should not gather expertise, connections, and funds to give greater force to our side, so

that the “line in the middle” of the compromise is as close to where we want to end up as possible. Ultimately, how close we get depends on whom we elect, so –

Please vote.

Do it in every election (yes, even school boards matter; they are breeding grounds for ignorance, hatred and authoritarianism). It’s the easiest thing you can do that makes a difference, and even when people try to make it harder, it’s still very easy compared to many other things people have to face in life. And it’s the most effective thing that most of us can ever do in order to not only protect our traditions of self-governance, but to make our dreams of better days come true.

Now I’ll take my own advice and stop talking, but before I go, I’d like to point out that it’s going to take parts of three people to do what I did here, and introduce them. Of most interest to you, dear readers, is John McNulty, an experienced political science researcher and educator, and an expert on elections. He’s taking over the policy analysis duties that Frank Pennisi and I handled, and he’ll be your new Editor beginning with the Spring 2024 issue of *AccessAbility*. He’s only been here a short time but it’s already clear that he’ll be great at it. My long-time wingman Matt Wolfram will be responsible for keeping the computers running and spammers and ransomware criminals at bay. He’s relatively young, but more than capable, and he’ll do a fine job. Finally, tak-

ing on the information security management and policy role, along with a whole bunch of stuff that I *didn’t* do, is Chad Eldred, our new Director of Programs and Operations. He’s an experienced and thoughtful former (and reformed) group-home worker, he started and ran our NY State of Health Navigators and Enrollers program, and he’ll get to learn on the job too.

I said I’d stop giving advice, but I can’t resist adding just a few other relevant points from the *National Lampoon’s* 1972 “Deteriorata”. (I kid you not, these are the actual lyrics.)

“Go placidly amid the noise and waste,
And remember what comfort there may be
in owning a piece thereof. ...
Rotate your tires.
Speak glowingly of those greater than
yourself,
And heed well their advice, even though
they be turkeys.
Know what to kiss, and when.
Consider that two wrongs never make a
right, but that three do. ...
Be comforted that in the face of all aridity
and disillusionment,
And despite the changing fortunes in time,
There is always a big future in computer
maintenance. ...
Hire people with hooks.
For a good time, call 606-4311. Ask for Ken.”

So long, and thanks for all the fish! And for everything else!!!

Clean Audits and a Smoking Gun

You may recall that some right-wing anti-Medicaid media gadflies have persistently accused the state’s Medicaid program of wasteful spending generally, and claimed that the CDPA program in particular is riddled with fraud (see *Accessability* Winter 2022-23, for example).

NY’s Office of the Medicaid Inspector General (OMIG) begs to differ. In 2022, OMIG audited about \$37 million in CDPA billing and found only \$46,000 in overpayments. That is, fewer than 1% of those bills were disallowed—and many of them were due to clerical errors, not fraud. CDPA Fiscal Intermediaries were asked to pay back a paltry total of \$46,000, of which \$41,000 was received by the end of that year. In contrast, in the same period, “\$1.3 million was recovered in traditional personal care; \$18.7 million from [managed care]; and ‘more than \$20 million’ from ... providers such as nursing homes.” Now, it’s true that those other programs involved a lot more than

\$37 million, but that’s partly because CDPA rates are lower than those of all of the other programs. In past years NY’s Comptroller found in multiple audits that Medicaid managed care plans were overpaid to the tune of \$1 billion or more. So while the state’s poorly-monitored managed care programs and nursing facilities do indeed waste or even pilfer money, CDPA is exemplary for both honest reporting and its high rate of quick repayments when errors are found.

The NYS Department of Health (DOH) has claimed that the federal Centers for Medicare and Medicaid Services (CMS) approved its plan to introduce “ADL minimums” effective April 1, 2021. The plan was created by Governor Cuomo’s “Medicaid Redesign Team” (MRT) and became law during the spring 2020 budget process, just as the COVID-19 emergency began. It never took effect because federal pandemic relief measures required “maintenance of effort” (MOE) in state Medicaid programs,

so eligibility or service reductions were suspended. We've described this many times (*AccessAbility* Spring 2021, for example). Simply put, it means that disabled people who only need homecare to help with tasks such as housecleaning, laundry, shopping, or most cooking won't be able to get it at all, and homecare as a service, including those kinds of help, will only be available to people who need hands-on assistance with at least three of the following: walking, getting in or out of bed, bathing, dressing, using a toilet, eating, cooking special diets, grooming, taking medications, turning and positioning, or using medical equipment (or, for people with dementia, if they need prompting for at least two of those items).

When asked for proof that CMS had approved this, DOH pointed to an April 15 letter from CMS, but that letter only approved rules changes to implement electronic visit verification (EVV) effective April 8; there was no mention of the ADL minimums and the letter stated that "There are no changes to services and no impact to beneficiaries." When asked again, DOH indicated that CMS told them they didn't need permission to enact the ADL minimums and that they should remove that section from their submitted state plan amendment (SPA). When asked why CMS told them that, DOH did not provide an answer.

Legal advocates for seniors and people with disabilities then submitted a NY State Freedom of Information Law (FOIL) request to compel DOH to release all records concerning this. After a very long delay, the agency finally provided a sheaf of documents that includes the "smoking gun." An email from CMS official Maria C. Tabakov to DOH on October 14, 2020, included a document entitled "CMS Informal Comments" that discussed changes she wanted made to the SPA, and it says: "Please remove the following language as it is medical necessity criteria and not needed in the state plan," followed by the language that described the new ADL minimums.

Ms. Tabakov's statement is clearly wrong. "Medical necessity criteria" under Medicaid refers to the specific medical diagnoses and needs of an individual who is eligible for a Medicaid program, in order to determine the frequency, intensity and duration of the services that will be provided to that individual, and when states agree with CMS to provide a Medicaid program, such as Personal Care, they are required to provide all medically necessary services to people who are eligible for and enrolled in that program. Medical necessity is not an element of Medicaid eligibility

generally or the Personal Care program in particular. The MRT changed the eligibility rules for Personal Care to exclude people with certain types of disabilities. Medicaid program eligibility changes must, by law, be approved by CMS.

It's probably relevant that in October 2020, CMS was run by Seema Verna, a Trump appointee who was sympathetic to state officials who wanted to cut Medicaid. She approved state attempts to impose work-requirements on their Medicaid programs, among other measures that were illegal under Medicaid law, a fact verified by federal courts. Biden's replacement for Verna, Chiquita Brooks-LaSure, didn't take office until May 27, 2021, almost a month and a half after the April 15 approval letter was issued. We don't know what was going on at CMS during that time but it's possible that some Biden Administration representative who was familiar with Medicaid procedures didn't want the agency to go on the record with an action that violated the law. So the letter neither mentioned nor approved the ADL minimums, and the fact that Verna's CMS told DOH to remove that part of the plan, while "informally" approving it, got buried.

CMS allegedly told DOH not to implement the new plan due to the MOE requirements. But those requirements only said states could not reduce the number of people who are *eligible* for Medicaid *programs*, and could not kick people already on Medicaid off it, or reduce their services. The ADL minimums plan "grandfathers in" people who already get Personal Care or CDPA; it only applies to new people seeking those services. So if the ADL minimums are not a program eligibility change but merely a change to medical necessity criteria that won't affect anybody now receiving services, how can the MOE apply to them? Obviously, it can't, so CMS had no reason to tell DOH not to implement them *unless they do reflect an eligibility change*.

Further, NY is apparently receiving additional federal funds for a "Community First Choice" program whose regulations require that homecare services be provided to all persons who would qualify for a nursing facility "level of care." In NY, people with disabilities can get into a nursing facility under some circumstances if they only have one ADL need, or even if they have no ADL needs but, due to inability to maintain adequate hygiene or nutrition, their health is at risk. NY has told CMS it will operate Personal Care and CDPA programs under the Community First Choice (CFC) authority, specifically in order to get that extra federal

money. Therefore NY cannot legally limit access to Personal Care or CDPA services to only a portion of people who would qualify for nursing facility admission. NY's CFC SPA was enacted in 2015, prior to Trump, but Verna's extra-legal CMS operation may have not understood, or cared about, that.

It is also possible that new rules to implement Section 504 of the federal Rehabilitation Act would prohibit the ADL minimums after they are finalized in a year or two (see page 5).

Meanwhile, advocates are again pushing strongly for repeal of the ADL minimums in 2024. NY State Senator Gustavo Rivera (D-Bronx), who chairs the Senate Health Committee, recently told a gathering in Binghamton that he would work to have his committee approve a repeal bill this year (see page 9), but Governor Hochul is on record as believing the minimums will save the state tens of millions of dollars annually, and with rumblings about a potential state budget deficit, that's likely to be a very tough fight. We think advocates need to take a parallel track and get some lawyers to write a very pointed letter to Ms. Brooks-LaSure, noting that CMS likely approved the measure illegally, and requesting that the approval be rescinded, and quickly, before the MOE runs out and the ADL minimums take effect.

The Caring Majority folks are also resuming their call for a homecare minimum wage set at 150% of the standard minimum in NY. We respect them, but a higher minimum wage won't help people with disabilities who are entirely shut out of the program, and those are the people we need to focus on now. We should get the ADL minimums repealed first, and only then should we expend scarce time and resources on the minimum personal care wage. That being said, Caring Majority did provide some persuasive statistics to support that fight:

- NY's total population will grow 1.3% by 2040, yet its population of people over 80 will grow by 42.2% (Cornell Program on Applied Demographics).
- 70% of us will need homecare at some point in our lives (US Dept. of Health and Human Services LongTermCare.gov website) and most people want to age at home not in an institution.
- Between 2018 and 2028 there will be over 800,000 job openings for home health care and personal care aides in NY (from PHI, which lobbies for homecare consumers and workers).

Revolutionary Regulations

The Biden Administration has taken several steps since January 2021 to improve federal regulations to support better health and more community integration for people with disabilities. We've reported on a few of these recently (see *AccessAbility* Summer 2023) and there's another one in this newsletter (see page 8). But it may be that none of those efforts has more potential to transform our future than the federal Department of Health and Human Services (HHS) proposal to modernize its regulations for Section 504 of the federal Rehabilitation Act.

The Rehab Act, originally passed in 1973, predates the Americans with Disabilities Act (ADA) by 17 years, but its Section 504 served as a blueprint for the later bill. The act primarily governs federally funded vocational rehabilitation services and funding for Independent Living Centers of a certain type, but Section 504 prohibits discrimination due to disability in all programs and activities, and in hiring, conducted by any organization that gets any federal funds. President Nixon didn't like the bill and signed it reluctantly, but 504 remained impossible to enforce without regulations to explain what funds recipients could and could not do. Nixon's successors, Gerald Ford and Jimmy Carter, weren't any more enthusiastic about Section 504. Disability rights advocates developed an accelerating advocacy campaign to get the "regs" released, including convincing a federal judge to order the federal Department of Health, Education and Welfare (HEW) to issue regulations, but without a deadline, and culminating in disruptive protests at HEW offices all over the country, especially a 26-day occupation of the San Francisco office by about 120 people with disabilities and supporters that was featured in the 2020 film *Crip Camp* (available on Netflix).

Over the years new versions of the ADA and the Rehab Act were passed, and some work was done to synch up the regs for both of them, but it's been a long time since all of the issues involved have been revisited. The proposed rule from HEW's successor, HHS, addresses decades of federal case law and hundreds of complaints to the HHS Office of Civil Rights concerning violations of 504, experience gained from the COVID-19 pandemic, developments in computer and medical technology, and other matters. The result is not perfect, but it is about as close to a masterpiece as we have ever seen in terms of disability rights regulations.

We submitted comments that were overwhelmingly supportive. We also had some criticisms, and we'll summarize it all here.

The biggest deal in the new regs is a definition of "most integrated setting." The US Supreme Court's 1999 *Olmstead* decision established that, under the ADA and the Rehab Act, if a state provides long-term services and supports to people with disabilities, failure to provide them in "the most integrated settings appropriate to the needs of the individual" may be illegal discrimination on the basis of disability. That decision did not define the term, but the case involved people seeking to leave a developmental-center-style institution to live in group homes. In 2014, the Centers for Medicare and Medicaid Services (CMS, a division of HHS) issued the Home and Community Based Settings (HCBS) rule, which included a definition of such settings, fundable from a specific pot of Medicaid money, but it was weasel-worded, and it lets programs continue to operate segregated congregate residential and day programs for disabled people that have some integrated characteristics but are clearly not the *most* integrated settings that would be appropriate for most of them. The result has been a generalized belief that it's enough to close or downsize specific types of large institutions, and replace them with smaller segregated congregate residential programs that are only somewhat less institutional. The federal Department of Justice (DOJ) issued "guidance" a few years ago that says that it is possible for state Medicaid programs to fully comply with Medicaid law, including the Settings Rule, while still violating Section 504 and the ADA's "integration mandate." But federal agency "guidance" doesn't have the force of law. HHS's new regulations will, when they are finalized.

Under those regs, "*Most integrated setting* means a setting that provides individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible; is located in mainstream society; offers access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; and affords individuals choice in their daily life activities."

The proposed rule doesn't define "mainstream society." We think that's a flaw. There should be no daylight between "most integrated setting" and ordinary society, because the latter *is* the most integrated setting appropriate to the needs of most people with disabilities. We

asked that "mainstream society" be defined as "the places and circumstances in which non-disabled people conduct all aspects of their lives. It does not include any residence, location, job or activity that was created primarily for the purpose of serving or benefitting people with disabilities."

Even if HHS doesn't add that, the rule is a huge improvement because it's not just about getting people out of big institutions anymore. It sets a new standard: *any* kind of segregation is less desirable than the "most integrated setting," and may not be legal. The rule prohibits specific behaviors by state and local governments and service providers, like providing more or better services to people in segregated settings than in integrated ones, or "establishing or applying policies or practices that limit or condition individuals with disabilities' access to the most integrated setting appropriate to their need."

Under this rule, NY's impending "ADL minimums" (see page 3) would likely be illegal because they would mean that people with certain types of disabilities could only get a complete array of services (including housecleaning, cooking, and other so-called "instrumental activities of daily living", along with more direct care assistance for bathing, toileting, dressing, etc.) in nursing, assisted living, or adult care facilities, but not in their own homes.

The ADA defines a "qualified disability" that is protected from discrimination as, in part, a condition that limits a person's ability to engage in "major life activities." Section 504 mirrors this definition. The ADA was amended in 2008 to define the functioning of the body's individual organs or systems as "major life activities," to enforce Congress's intent that "disability" be defined as broadly as possible when courts decide whom the ADA covers, and Section 504 is now being brought into line. The resulting list is long but not exhaustive; it includes many things, one of which is "caring for oneself." We think HHS could easily expand this to "caring for oneself or for family members, guests, service animals, or pets," all of which are at least as "major" life activities as, say, your pancreas's insulin-making activity, which the rule explicitly covers. We think NY's refusal to let personal care attendants (including CDPA workers) do child- or pet-care tasks for people whose disabilities prevent them from doing them could be illegal because currently, disabled parents who can't take care of their children can lose

them to the foster care system, which provides assistance to enable foster parents to care for them instead, and that would violate the new rule's prohibition on using organizational divisions to escape responsibility for preventing discrimination, but we think this issue would be handled better by adding care for family members to the list of major life activities.

HHS's focus is on "health and human service programs and activities"; DOJ handles the regs for other aspects of both Section 504 and the ADA. That's likely why law enforcement and guardianship, which seem to have more of a "legal" than a "services" focus, aren't addressed in the proposed rule. But we think they could be.

504 says funds recipients need not make "reasonable modifications" of their policies, procedures, programs, and activities if doing so would represent a "direct threat" to a person. For a "direct threat" to exist, the recipient must "make an individualized assessment based on reasonable judgment from current medical knowledge or the best available objective evidence to ascertain the nature, duration, and severity of the risk ...; the probability that the potential injury ... will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk." The police are notorious for injuring and killing people with disabilities; Eric Garner, Freddie Gray, Sandra Bland, Daniel Prude are examples. The police also are federally-funded service providers, and their service is a judicious and proper response to protect people in, and prevent, dangerous situations. When that service is delivered properly, everyone involved benefits because only those whose behavior actually justifies violent or potentially lethal restraint experience it. Although many police officers, prosecutors, and judges don't believe it, we think the police, who are increasingly better trained and understand "the best available objective evidence," have the same responsibilities as any other federal funds recipient to properly assess "direct threat" and make reasonable modifications to ensure that disabled people get the same benefit that nondisabled people do. We also think HHS's focus on "health care services" provides a way to prohibit cities from using the police as first responders when people experience a behavioral crisis, because sending trained behavioral crisis response teams first would be a reasonable modification of the cities' public safety programs.

Police, prosecutors, and judges are prone to discount the statements of disabled people because they believe they are "unreliable informants." That belief is often wrong, and the HHS rule prohibits discriminatory actions based on unfounded stereotypical beliefs.

HHS could insist that these federal funds recipients make reasonable modifications to their activities to include real investigations of whether a particular disabled person who reports or witnesses a crime is able to tell the truth, and to use people who know the person well, or disability-related communication experts, to help disabled people report what they have seen or experienced.

Guardianship falls squarely into HHS's bailiwick because it's a service similar to "care management" in ensuring that decisions about important aspects of a disabled person's life are made carefully and responsibly, and we can apply HHS's process for assessing "direct threat" when determining whether letting a person make her own decisions is actually a threat to her well-being. This could be a way to prohibit judges in NY from continuing to grant all-or-nothing permanent "plenary" guardianships to family members of people with disabilities who mail them a doctor's note without requiring objective evidence supporting the need for a guardian. The explanatory text of the new rule details how many doctors hold unfounded stereotypical beliefs about people with disabilities, and a permanent all-or-nothing guardianship is too important to trust to a doctor's opinion without clear and convincing evidence. If HHS agrees, it could mean an end to NY's Article 17-A process, ensuring that future guardianship proceedings will operate under the state's much more careful Article 81 rules.

Several other points in the proposed rule are worth noting:

HHS would prohibit medical treatment decisions based on unfounded stereotypical beliefs about people with disabilities' ability to follow treatment plans or understand their illnesses with or without services or supports, or about their "quality of life." For example, it will be illegal to deny a liver transplant to a person with a disability because a doctor assumes the person won't reliably take anti-rejection medications, or that her life just isn't worth preserving. Use of any statistical "value assessment" method that discounts the value of life extension for people with disabilities compared to that for nondisabled people when deciding about what medications, treatments, or services will be given to disabled people, would be prohibited. And medical providers would be forbidden to continuously pester disabled patients or their families to sign do-not-resuscitate orders or advance directives, or condition treatment on signing them. (Medicaid and other laws require providers to offer an opportunity to create an advance directive to all patients when they come into a

hospital—but only once, without persuasion or coercion.)

HHS, following court decisions and the current *Diagnostic and Statistical Manual* (DSM), has determined that, while both the ADA and 504 exclude "gender identity disorders not resulting from physical impairments" from protection, "gender dysphoria" as a diagnosis is a physical impairment and therefore is protected against discrimination.

The new rule will adopt technical standards for accessible medical diagnostic equipment (MDE) such as examination tables, scales, and x-ray machines, into regulation, transforming them from advisory "best practices" to mandatory requirements. HHS's proposal for what percentage of machines in a medical provider's inventory must be accessible is too low, though, and based on incomplete information about how many people have disabilities that would require such machines. The rule does require that if an accessible machine is not available, medical providers must offer physical assistance to help the person safely transfer to and from the machine.

It would be illegal to place foster children with disabilities in segregated congregate settings rather than with foster families instead of providing those families adequate services and supports to enable them to meet the children's needs.

HHS asked for advice on whether to require medical providers to give written information in "plain language" to disabled patients as a matter of course, or only on request. We pointed out that most official information that everyone gets is not in "plain language," and since fewer than half of all Americans can read above the sixth grade level, requiring all written material to be in plain language as a matter of course would not "insult" disabled people.

HHS has spent a lot of time developing proposed accessibility standards for websites and mobile apps operated by federal funds recipients. We pointed out that they almost completely duplicated work that was done by DOJ this past summer (see *AccessAbility* Summer 2023), and we'd prefer that they just adopt DOJ's regs and spend more time addressing the other issues we've raised.

There are several other items in the proposed rule that we can celebrate, but we don't have space to detail them here. It will probably take HHS a year or two to analyze all of the comments and issue the final rule. That's possibly a problem, since a new administration may take over in January 2025 and throw all of this good stuff out. Whatever happens, we'll let you know.

Going to MAS

By Sue Ruff

MAS (Medical Answering Services) is the state contractor that is supposed to arrange for Medicaid transportation. We have been hearing many complaints lately, not only from consumers, but from other agencies and organizations that assist people with disabilities to get to medical, mental health, or substance use treatment. The complaint list seems particularly pronounced in rural areas. Some of the complaints we are hearing include:

- Cabs not showing up or coming to a person's home minutes before the medical appointment, making the person very late. This has caused some people to lose their medical provider.
- Having to do complex, difficult paperwork to establish a pick-up spot or drop off site.
- Waiting for many hours at the doctor or mental health provider for a ride home.
- Refusal to take patients outside their county to specialists, especially if the person needs a wheelchair van.
- Drivers asking patients to sell their medication or pain pills or drivers soliciting sexual favors.

If you are experiencing problems with Medicaid transportation, here are some options:

File a complaint with MAS, your county health department Medicaid office, NYS Department of Health (DOH), the NYS Office of the Medicaid Inspector General, the NYS Attorney General's Medicaid Fraud Control Unit, or the federal Department of Health and Human Services. Keep a record of your complaint. Do you believe you have been discriminated against? That would be a complaint with the NYS Divisions of Human Rights. Complaints take energy and perseverance, but this is about YOUR health and your access to your medical providers.

MAS: <https://www.medanswering.com/comments-or-concerns/>

<https://www.medanswering.com/report-fraud/>
NYS DOH: medtrans@health.ny.gov or 518-473-2160

Office of Medicaid Inspector General: <https://omig.ny.gov/medicaid-fraud/file-allegation> or call OMIG's Fraud Hotline at 1-877-87 FRAUD (1-877-873-7283) or file a claim electronically.

NYS Attorney General: https://ag.ny.gov/search?term=Medicaid+Fraud&sort_by=relevance&sort_order=DESC (the Attorney General has a local office at 44 Hawley St. in Binghamton, too)

The feds: <https://oig.hhs.gov/fraud/medicaid-fraud-control-units-mfcu/>

STIC is collecting stories and helping people who want to share their stories with the press. You can also call your State Senator or Assemblyperson.

NYIAP Roll-Out Paused

In mid-November the New York State Department of Health (DOH) announced that it was indefinitely postponing its plan to begin having the Independent Assessor handle routine needs "reassessments". The change will **not** take place in January 2024 as previously announced. This was a direct response to alarms raised by disability advocates, who feared that the program would be unable to handle a huge increase in workload.

The NY Independent Assessor (NYIAP) program was introduced as part of the Cuomo Administration Medicaid Redesign Team's plan in 2020, and became law in the same state budget process that established the "ADL minimums" (see page 3). The bogus idea behind it is that the personal physicians whose orders used to start the process of getting homecare services for people with disabilities can't possibly be trusted to be objective; they have some fiendish desire to get unnecessary services for their patients. To combat this, NYIAP was born. "Independent" is a misnomer; this is a national healthcare management company called MAXIMUS, and NY has contracted with them to assess individuals' needs for homecare on behalf of the state, which has an interest in reducing Medicaid spending on that service.

Advocates have long had concerns that NYIAP's process, which is more complicated than the old one, would delay people getting necessary services, forcing them into hospitals or nursing facilities. We've covered this before (see *AccessAbility* Summer 2022). Those concerns have been borne out by the facts as far as we know; there have been many reports of serious delays, but DOH refuses to provide full information on the extent of the problem. Up to now NYIAP has only done needs assessments for people newly enrolling into homecare programs, a process that previously was spread out across several Medicaid managed care plans and nearly 60 county social service departments (DSS). NYIAP has done about 12,000 new assessments per month up to now. DOH wanted to add reassessments to the workload, which will add another 26,000 monthly assessments. We know that the NYIAP roll-out was previously slowed down due

to problems with MAXIMUS's ability to hire enough nurses to do the work.

Other problems will slow things down even more. Managed care plans and social service departments still have a role to play in helping people move through this system and DOH has not yet provided guidance to them on what changes they must make. With NYIAP, Medicaid participants must start the process by calling MAXIMUS themselves; care managers or family members are not allowed to make those calls. Previously the managed care plans or DSS would call participants to schedule reassessments. There is a real danger that people will have their Medicaid cut off because they failed to call to get reassessed. There are long hold times on the phone lines, and because MAXIMUS is also the state's "conflict free" Medicaid managed care enrollment broker, often the people who answer the phones assume the caller wants to sign up for managed care and they don't understand that they're trying to do something very different.

The cancellation is a big victory for advocates, but DOH still plans to roll this out eventually. When they announce a new schedule, it should be posted here: https://www.health.ny.gov/health_care/medicaid/redesign/nyiap/

Managed Care Slow-Walking

When governments and companies try to save money, one tactic they use is simply to delay payment of what they owe. It's not that they don't ever plan to pay all their debts, but they are focused on the bottom line for the current fiscal year, and if they can defer some payments over to the next year, or get claimants to write off "bad debts," then they've "reduced spending" for the moment. Donald Trump is famous for this; he called it "smart business." New York State is also famous for it, taking months or years to pay contractors, including social service agencies like STIC. It got so bad several years ago that the legislature enacted a "prompt payment" law. Sadly, it contained so many loopholes that it had little effect on the problem.

The problem got worse as the use of private insurance companies to administer government programs like Medicaid and Medicare grew. When STIC got involved with Medicaid managed care plans we saw it on a huge scale. Those insurance companies routinely hold back payments, claiming, just like the state, that they never got our paperwork, or that it contains errors, requiring us to resend it, sometimes several times across many months, before they would pay their bills. They say

this is all inadvertent error, but that's a lie. It's a deliberate strategy. Many organizations give up and write off hundreds of thousands, or millions, of dollars of insurance payments as uncollectible debt. We don't do that, but it's an accounting nightmare.

Now we're seeing news stories about medical provider networks and hospitals all over the country dropping Medicare Advantage plans (private-insurance substitutes for Medicare) because they constantly delay or refuse payment (see here: <https://www.beckershospital-review.com/finance/hospitals-are-dropping-medicare-advantage-left-and-right.html>). Some hospitals in smaller or more rural communities are in danger of closing because they can't reliably collect enough of the money that they are owed.

Meanwhile in NY, as Medicaid managed care moves into the mental health ("behavioral") services arena, those providers are getting jerked around as well. In November, *Crain's Health News* reported that the NYS Council for Community Behavioral Healthcare, a trade organization that represents providers, had surveyed about 130 of its members and got responses back from some 60 of them. The providers reported that they are owed about \$10 million by Medicaid managed care plans for claims, ranging between \$80,000 and \$3 million, that are over 90 days old. Many of these providers have long waiting lists for services because they have to shift resources from clinicians to clerks to try to keep the money coming in. The responsibility for ensuring that managed care plans pay their debts belongs to the state Department of Health (DOH). This is just another example of how DOH's failure to adequately monitor and discipline the insurance companies with which they contract creates havoc for the healthcare system. And it's another reason why our elected officials need to get serious about rolling back managed care.

LaTonya Reeves Freedom Act and Progress toward Independent Living

By John McNulty

Disability rights groups are continuing to make progress in pushing positive revisions in the LaTonya Reeves Freedom Act (LRFA). This bill clarifies and emphasizes the integration mandate in the American with Disabilities Act of 1990, as defined in the Supreme Court's *Olmstead* ruling in 1999: that any person eligible for long-term supports and services must be integrated into their community to the

maximum extent possible, including receiving all necessary services in their homes, as they themselves direct, so that they may live and thrive independently and enjoy the blessings of liberty to the fullest extent.

The LRFA, a revision of the Disability Integration Act, is named for the late, great LaTonya Reeves, who left her hometown of Memphis to escape institutional living, moving to Denver to live independently and to work—with great success—as an advocate for others moving to integrated living.

STIC has long held that residence in institutional settings is only appropriate for temporary post-acute medical rehabilitation or psychiatric stabilization. Yet the 2023 iteration of this bill holds that living independently or in an institution is a choice made by the consumer. We disagree. We discourage long-term institutional living, but this is a necessary concession for the bill to pass.

STIC advocates have successfully lobbied for a definition of "institution" to be included, specifying that any provider-owned or operated housing for people with disabilities that houses more than four unrelated individuals is included. STIC advocates have also made the list of types of services and supports explicitly non-exhaustive, allowing for the evolution of covered services as needs and capacities change.

The chances for passage of the LRFA have improved, with dozens of Democratic co-sponsors in the House and 10 Republicans at last count—enough bipartisan support to clear the main body. In the Senate, support is expected to be as strong or stronger. We will follow the bill's progress and keep you posted.

NY Voting Law Improved

We now have vote-by-mail for everyone in NY! Governor Hochul signed the Early Mail Voter Act into law in September. It allows any voter to request a mail-in ballot up to ten days before Election Day. The ballots come with a pre-paid postage return envelope. They must be mailed by Election Day, and received by your Board of Elections no later than seven days after Election Day. Republican Congressperson Elise Stefanik, who represents the 21st Congressional District in the North Country, filed a lawsuit to block the change in Albany County Supreme Court. You may recall that voters rejected a ballot initiative that would have amended the state constitution to allow no-excuse vote by mail a while back. Stefanik believes such an amendment is

required, but she is likely wrong; the fact that the state constitution doesn't specifically say that no-excuse mail voting *is* allowed doesn't mean that it is therefore *not* allowed. As far as we know there's been no court action, and a final decision may be years away.

The Ideal Staffing Ratio for Long-Term Care Facilities: How about zero? Does zero sound good?

By John McNulty

The Center for Medicare & Medicaid Services (CMS) sought comment on a proposed rule to increase the staff-to-resident ratio for nursing homes, so as to comply with federal Medicaid law. STIC responded with the observation that compliance with *some* federal laws is not compliance with *all* federal laws. Specifically, the mandate in the Americans with Disabilities Act and the Rehabilitation Act requires medical services and long-term services and supports (LTSS) to be provided to people with disabilities in the most integrated settings appropriate to their needs. Nursing homes decidedly do *not* fit that description.

STIC submits that if adequate levels of reliable LTSS are available in-home and in the community, then residency in nursing facilities is simply not necessary for all but those with the most acute health crises and rehabilitation needs—which we believe is their only acceptable use.

Obviously, this goal cannot be achieved overnight, nor do we expect it to be. Many resources—financial, capital, and labor—will need to shift from an institution-based approach to a community-based approach, with minimal disruption to the quality of patient care in the short term. Services are trending in that positive direction, and STIC discourages CMS from any actions that might slow or reverse that trend.

Some have worried that a mandate to increase staffing ratios could result in fewer beds being available to recoup the additional staffing cost. This is possible, but unnecessary; institutions could just shave a little off their obscene profit margins (see *AccessAbility* Fall 2023). But even if that comes to pass, we suggest that's movement in a positive direction, because too many people who can contribute to their community and live life to the fullest are instead languishing in human warehouses. Reducing residency in nursing homes is a win for everybody.

Flight with Legs Uncrossed?

After decades of advocacy, disabled air travelers have at last been granted clearance for take-off with wheelchair accessible bathrooms on some single-aisle airplanes. The federal Department of Transportation (DOT) used the occasion of the 33rd anniversary of the signing of the Americans with Disabilities Act to make this announcement: New airplanes with at least 125 passenger seats will be required to have a lavatory large enough for a person in a wheelchair and an attendant. While this is progress, it's not as momentous an announcement as we might have hoped for.

For one thing, the lavatory only has to accommodate one of those special "on board wheelchairs" (OBW) that the airlines force people to use while they stow (and often break) their own chairs in the luggage compartment. And full accommodation of OBWs isn't required, just preferred; "partial-entry" with "privacy screening" so passengers won't see half-naked people transferring from chair to toilet is all that is mandated initially, and must be in place on affected planes some time in 2026. Second, as noted, the rule only applies to single-aisle planes with at least 125 seats. Double-aisle planes already have an accessible lavatory requirement, and while DOT notes that use of double-aisle planes has declined by some 50% over the past 30 years, there are still lots of smaller planes flying commuter and longer routes that won't be affected. Also, only new planes must meet the requirements; older ones won't have to be retrofitted. Worst of all, the full requirements won't take effect until 2033, for planes ordered for delivery in 2035 or later.

Advocates still want wheelchair tiedowns like those used in buses to be required in planes so they won't have to transfer. We've heard that DOT is thinking about that idea but there's no news on what, if any, decision they have made. It would have been wise for DOT to mandate that new accessible lavatories accommodate personal wheelchairs, and not just OBWs, in case they decide to require tiedowns (which, presumably, would be located near the lavatories to avoid issues with typically narrow airplane aisles), but that apparently didn't occur to them.

So while some disabled travelers will soon not need to be afraid to drink a little liquid before flying thousands of miles, many others will still have to hold it, for the next ten years—or longer.

Feds Looking at Subminimum Wage

The federal Department of Labor (DOL) announced in September that it was starting a "comprehensive review" of the issue of payment of subminimum wage to people with disabilities, in response to increasingly vocal advocacy from those who want to outlaw the practice entirely. Beyond stating that the review would address the "14(c)" program, the department didn't provide many details about what the review would look at or how long it would take. In October it announced a series of "engagement sessions" at which "stakeholders" could provide information. Three sessions were scheduled in late October and early November.

Section 14(c) of the Fair Labor Standards Act of 1938 permits employers to pay people with disabilities wages below the federal minimum if they certify that those workers are unable to "produce" at the same rate as a nondisabled worker doing the same job. Employers have a long history of gaming the loopholes in the law, as well as outright false reporting, to justify underpaying workers who are more productive than they claim.

We don't know if more engagement sessions will be scheduled. But you can provide input to DOL any time at: TalkAbout14c@dol.gov

Health Care Summit Meeting Held for the Southern Tier

By John McNulty

NY State Senator Lea Webb (D-Binghamton) invited fellow Senator Gustavo Rivera (D-Bronx), who chairs the powerful Health Committee, to the Southern Tier to meet with leaders and advocates in the health care field on November 1, 2023. Others present included folks from local health care worker unions and the NYS Offices of Mental Health (OMH) and People with Developmental Disabilities (OPWDD), SUNY Upstate, the Community Health Clinic, the Broome County Health Department, Mental Health of Tompkins County, the CEOs of Cayuga Health and Guthrie, the Dean of the BU School of Nursing, and STIC's Advocacy Director.

The meeting was held on the top floor of the State Office Building in downtown Binghamton, which boasts a magnificent panoramic view of the Susquehanna and Chenango Valleys, especially lovely in autumn.

The specific goal was to highlight problems in the NY health care systems that are per-

tinent to the more rural upstate community. As is well understood, upstate issues are often set aside as the more populous New York City region draws disproportionate legislative and executive attention. Senator Webb organized this roundtable to bring upstate issues to the foreground.

The first issue raised was the scarcity of health care workers and service providers of all kinds upstate. There was widespread concurrence that increasing the wages paid to these folks was a necessity, but it was unclear how to bring that about; it was noted that Medicaid reimbursement rates being lower upstate versus downstate (indexed to cost of living) was a major factor. One solution, fairly easily achievable through legislation, to staffing shortfalls was to relax regulations to enable lesser credentialed or licensed workers to perform certain tasks that they're generally fully capable of doing. For example, NY is one of the last states that requires nurses to perform vaccinations; it was suggested to open that up to EMTs and other underused resources.

The staffing problem was said to be most acute in mental health and services for people with developmental disabilities. OPWDD maintained they just can't find enough workers to provide satisfactory service for all of its clients; licensing reform won't help here, because most of the work is performed by laypeople. But doctors are scarce as well; Tompkins County reported that they have one psychiatrist responsible for a five-county area, with a little support from part-time Nurse Practitioners. In the past, they employed five psychiatrists and three full-time NPs.

STIC's Advocacy Director Susan Ruff offered one concrete solution for a shortfall in in-home services and supports. A new Medicaid eligibility rule for home care in NY requires a person to need assistance with three "Activities of Daily Living" (ADLs) before they would be eligible for home services. Senate bill S.328 would eliminate this rule, enabling consumers to get in-home services more conveniently and at a lower cost than in the institutional settings the rule would force them into. However, S.328 has languished in the Health Committee for over two years. Ruff observed that since the bill's primary sponsor also chairs the Health Committee, quick action can probably be taken. Chairman Rivera laughed and said he would see that it was.

About 40% of people with developmental disabilities also have mental health disabilities, but getting services for both needs at once is difficult, sometimes impossible. OPWDD refers people to OMH, and OMH refers people to OPWDD, and nothing happens—a classic

case of falling through the cracks. It was suggested that eligibility requirements be revised for people with these dual diagnoses to clarify responsibilities and get people the help they desperately need.

Transportation also arose; this problem is largely foreign to dwellers of the five boroughs, where public transit is ample and travel distances rarely reach double digit

miles. Upstate, people routinely travel 20 or 30 minutes by car to reach primary providers, and visiting specialists in Binghamton, Syracuse, or Rochester can require hours of round-trip travel that some people just can't afford, physically or financially. Medicaid pays for transportation, but there are major problems with the availability, reliability, and sometimes safety of this service (see

page 7); intervention from the state is needed to remedy this.

The meeting ended affably, with great appreciation for everyone's participation and information, and sincere promises to "get [stuff] done" in the Health Committee. We hope that many policy enhancements will arise from Senator Webb's initiative and Senator Rivera's leadership.

courts watch

Laufer v Acheson Hotels: Still Untested

We reported this case in *AccessAbility* Summer 2023. Deborah Laufer, who uses both a cane and a wheelchair, sued Acheson because one of its hotels, in Maine, had a website that didn't say if the place was accessible to people with disabilities. That violates federal regulations that enforce Title III of the Americans with Disabilities Act (ADA), which covers "public accommodations." Laufer apparently was a "tester"—a person who checks whether public accommodations comply with the rules without necessarily planning to actually use them—but we've since learned the details on that are pretty murky. She lost in federal district court, but won on appeal. Acheson then took the case to the US Supreme Court.

The issue is important to disabled people because in the 33 years since the ADA passed, we've seen two trends: widespread ongoing noncompliance with the law's accessibility requirements, especially by smaller venues, and growth of an ADA lawsuit "industry" that seeks to capitalize on that noncompliance and make money for lawyers. It's also important to a broader range of people who care about civil rights and illegal discrimination because the case had the potential to undercut a 40-year-plus history of compliance testing that goes back to the federal Fair Housing Act and its prohibition of discrimination due to race in the rental or sale of housing.

The case took a very strange turn over the summer. An attorney who represented Laufer in many, if not most, of her hundreds of hotel website testing lawsuits, Tristan Gillespie, was suspended by a federal district court in Maryland for ethical violations involving suits he filed for Laufer and another client. That court investigated what appears to have been an ADA hotel website lawsuit factory run by Gillespie's employer, Thomas B. Bacon. Gillespie admitted that he used pre-written templates to file complaints and obtain settlements, changing only the name of the hotel being sued, while

billing for two or more hours of work per complaint though the actual time spent on each was just a few minutes. Most of the actual work, including meeting with clients, appears to have been done by a private investigator named Daniel Pezza, who apparently was paid at least \$600 per complaint by Bacon. Pezza is the father of one of Laufer's grandchildren, and he received "several hundred thousand dollars" for his part in the operation.

We don't know if Laufer benefitted financially from the relationship; money damages aren't available in ADA lawsuits in most cases, but legal costs can be paid. The boilerplate agreement between Gillespie and Laufer for each case specified that Laufer would be responsible for paying for the costs of the litigation unless fees were recovered from the defendant. However, there was an informal "side agreement" that the clients—Laufer and one other—would never be asked to pay. The official agreement was presented to the hotels, apparently to elicit sympathy for the disabled clients, who would appear to be on the hook for several thousand dollars if the hotel didn't settle. Gillespie offered three standard flavors of settlements to the hotels: 1) hotel corrects the website and pays \$10,000 in attorneys' fees to Bacon's firm in return for the client dropping all claims; 2) hotel corrects the website and pays \$6,700 in fees and the client abandons the immediate claim but might sue again later; 3) hotel corrects the website and both parties agree to let a judge determine the costs. If the hotel didn't respond to the complaint at all, Gillespie requested, and often got, a "default judgment" to cover his heavily-inflated costs.

Despite information indicating that she was a "tester" who had no intention of staying at the hotels—a point that was central to the argument of whether she had "standing" to sue, and the point that makes the case so important—Laufer had apparently signed affidavits in which she said that as soon as the COVID-19 pandemic lifted she planned to travel all

over the country and visit all of the hundreds of locations of the hotels she had sued, a claim the Maryland court did not find credible. But the court also considered whether Gillespie had suborned perjury by Laufer, and decided he had not. The court did not find that Laufer had done anything wrong, but it didn't rule that possibility out either. Some travel by Pezza with Laufer and her granddaughter as companion testers seems to have been involved in preparing the lawsuits, and the court's report raises the possibility that the granddaughter may have been paid by Pezza for her testing activities, and that some of that money may have come into Laufer's hands.

Gillespie did *not* represent Laufer in the Acheson suit. However, after Gillespie's suspension in July, she asked the Supremes to dismiss the case, and for the appeals court to void its decision in her favor. Her new lawyer, Kelsi Corkran, said, "The allegations against Mr. Gillespie were pretty devastating to her, and she didn't want to pursue these cases anymore." Also, Acheson Hotels added a statement to the hotel's website that the venue was not accessible, and eventually sold the property. So neither the plaintiff nor the defendant have any further interest in the suit's outcome, and the violation the lawsuit was about has been corrected.

However, that happened after the Supremes agreed to take the case. So while Justice Elena Kagan pointed out, during oral arguments on October 2, that the case is "dead, dead, dead in all the ways that something can be dead," there was still an opportunity for the other Justices to weigh in on the matter, and they took it, declining to dismiss the case and instead hear arguments about whether it is "moot." That may seem obvious, but different federal appeals courts have ruled in different directions on whether "testers" have standing to sue, at least in ADA cases, which means that the Supremes will eventually have to settle the matter one way or the other. The oral arguments showed that most of the Justices were leaning toward mooting this case and waiting for a "live one" that better showcases the issues; only Roberts and Barrett seemed poised to continue. We should have a decision by early summer 2024.

Tae'jon Vega v Broome County: Missing Evidence

Tae'jon Vega is a black Latino man with bipolar disorder and other disabilities. He was in the Broome County jail awaiting trial when, he alleged, he was assaulted by jail guards, verbally abused with racial slurs, and severely injured. We reported on his case in December 2021.

The case is ongoing and has not yet gone to trial, but a federal district court judge handed down a decision on September 28, 2023, that held the Broome County Sheriff and the county responsible for losing important evidence. The judge's decision is interesting and complicated, and it adds a few facts to the story we published two years ago.

At that time, we reported, "On February 20, 2020, the jail guards conducted a random search of Vega's housing unit (known as a 'pod'). They ordered all the prisoners in the pod to lie down on the ground, a standard procedure. Vega complied and lay down on his stomach. As some guards passed him, he asked them how their day was going. One of the guards said, 'Oh, you think this is a joke?'" and we then summarized the story of a brutal beating as it was described in the complaint filed by Vega's lawyers.

As it turns out, there must have been more to that exchange between Vega and the guards, because the judge reported that Vega "admitted he talked with inmates, made sarcastic remarks, and laughed at officers and continued to do so even after officers repeatedly ordered him to be quiet during" the search. Although we didn't know that when we ran the story, we wrote, "Even if Vega had used a sarcastic or mocking tone when he asked the guards how their day was going ..., his remark did not justify what they did to him," and that's still true.

Vega called his mother on a prison phone after the incident, and she was able to see and capture video of cuts and bruises on his body. Other cameras were in use during the incident, including a stationary surveillance camera, a handheld camera used by one of the guards, and a body camera worn by another guard. The jail medical service recorded that his injuries didn't seem severe and described some "scratches" as being "in a very odd pattern" and were "questionable [as if] self-inflicted." According to the judge, the guards wore rubber gloves, implying that they couldn't have scratched him, and Vega "admits that he told a corrections officer about either 'coughing up blood' or 'urinating blood' in order to be seen by Facility medical personnel."

Two of the cameras weren't in a position to capture relevant evidence, but the body camera was, and it ran for at least a few seconds during

the incident. Unfortunately, the recorded video is lost. The judge ruled that the jail guards tried to make sure the video was safely stored because it was likely going to be important evidence, but apparently they didn't understand how to do so. The guard who wore the camera properly uploaded the video to a website called "Evidence.com," and another guard tried to download it from the website to his computer, where it would be safe from the standard semi-annual purges of data from the website, but either he didn't actually succeed, or he downloaded it to a location that wasn't permanent storage and so it was eventually overwritten. Although the judge found no evidence that the guards deliberately tried to lose or destroy the video, she did rule that neither Broome County, whose IT department supports the jail, nor the Broome County Sheriff, had a proper policy for protecting video evidence.

The judge dismissed Vega's claim that the search was "unreasonable" because his lawyers didn't bother to defend it after the initial complaint. These types of general searches, including the strip search that Vega experienced, are standard procedure in the jail when the guards are looking for "contraband," and Vega was not specially targeted; all of the inmates in the pod were searched.

The central issue of whether excessive force was used will still go to trial at some point.

We can only repeat that bipolar disorder can cause people to behave in socially inappropriate, even outrageous, ways; that police and prison guards are aware that many people they deal with have disabilities that can cause undesirable behavior and they need to know how to treat them fairly; that the criminal justice system is the wrong place to address the needs of people with mental health disabilities; and that there are good reasons to avoid jailing people merely accused of certain types of crimes, including the need to protect them from violent guards.

Klossner v IADU Table Mound: Fair housing isn't always affordable housing

Suellen Klossner has both physical and mental health disabilities and she lives in the Table Mound Mobile Home Park in Iowa. Her only income is "benefits from the government." The park got a new owner in 2017, and after that her monthly rent (which included utilities) increased rapidly to the point that it was more than half her income. So she applied for and received a federal Section 8 housing voucher through the local housing authority. That should have cut her cost to 30% of her monthly income, with the housing authority paying "the rest" (usually the total amount of rent must not be higher than what the lo-

cal housing authority, operating under federal rules, says is the "fair market" value of the property to be rented, and that number is often lower than the actual rent that the landlord could get—or, at least, what the landlord wants to get, especially in communities with housing shortages—so landlords may have to agree to accept less than they would like in order to make these arrangements work).

The landlord refused to accept this arrangement, claiming that dealing with two rent checks—one from Klossner and one from the housing authority—would be an "administrative burden." So Klossner asked the landlord to accept her voucher anyway as a "reasonable modification" for her disability, which would be required by the federal Fair Housing Act (FHA).

Klossner sued and won in federal district court, and the landlord appealed to the Eighth Circuit. That court ruled that the reasonable modification requirement only applies to actions taken to address her actual disability—such as physical accessibility improvements. The court found no federal legal requirement for a private landlord to accept a Section 8 voucher as a reasonable modification. Klossner then went to the US Supreme Court, which declined to take the case.

This isn't particularly shocking on the merits, especially in modern times when we in the disability rights movement understand that most people with disabilities can work for a living. Disability does not, by itself, preclude making enough money to pay market rent, though most people with significant disabilities don't have those kinds of jobs due to discrimination, limited or inferior education or training, lack of accessible transportation, lack of reliable homecare (which many disabled people need to be able to get ready for work and to a job on time every day), and a culture that encourages working-age people with disabilities to believe, falsely, that they can't work or that they have a "right to choose" not to work. It's also not very shocking that a Supreme Court that has been trying to weaken various civil rights laws over the past 20 or so years would refuse to take an action that could broaden the FHA's protections.

The saving grace for us in NY is that we have a "source of income discrimination" law that prohibits landlords from refusing to rent to people merely because the rent money comes from the government, whether they have disabilities or not. Of course, NY is a "progressive" state, and it's tough to say if it would be easier for folks in other places to get such a law through their legislatures and governor or to push for changes to the FHA to address

this nationally. We would not support a regulatory or statutory change to require acceptance of vouchers by landlords as a “reasonable

modification” due only to disability, because we oppose “special things for special people.” We think accepting vouchers would be a rea-

sonable modification due to poverty for everybody who can’t afford to pay rent, but it’s clear the FHA doesn’t go that far right now.



STIC NEWS



Celebrating 40 Years of Success!

By Lucretia Hesco

After 40 years of dedicated service and exceptional leadership, our esteemed Executive Director, Maria Dibble, will be retiring at the end of this year. As one of STIC’s original founders, Maria’s guidance and expertise have been invaluable, shaping STIC into what it is today. We are eternally grateful for her tireless efforts and remarkable contributions. Please join us in extending warm wishes for a well-deserved and fulfilling retirement!

We are pleased to announce Jennifer Watson as the successor to the position of Executive Director at STIC. Jen, a mother of children with disabilities, has been an integral part of our leadership team for over 20 years and has a deep understanding and commitment to STIC’s values and mission. We are confident that her vision and strategic direction will lead us into the future with success.

As we reflect on our past accomplishments, we are energized by the endless possibilities that lie ahead. With your continued support, we are excited to embark on the next chapter of our journey, striving for even greater heights. Together, we will continue to make a positive impact and help shape a more inclusive future for people with disabilities.

Lastly, let us all take a moment to express our gratitude to Maria for her contributions to STIC. Maria has been an invaluable member of STIC, contributing immensely to our suc-

cess and growth. Maria’s vision, dedication, and leadership have shaped STIC and she will be greatly missed. We are indebted to her for her tireless efforts in driving STIC’s mission and achieving remarkable milestones.

We look forward to many more years of growth, advocacy and shared achievements! We are moving closer and closer to a world where people with disabilities are valued, included and empowered to live their best lives and access their world.

The Direction of Self-Direction

By Lisa Gavazzi

My name is Lisa Gavazzi and I am the newest member at STIC in the self-direction program. I come to this position with experience in self-direction both as a parent and through previous roles that I have been involved in professionally. As I learn my new role, don’t hesitate to reach out to me at lisag@stic-cil.org and if I cannot answer your question, I will find someone who can and will respond promptly.

Self-Direction gives you the chance to choose your own services so you can live the life you want. When you self-direct your services, you have increased flexibility to choose the right supports for you, the staff you want to work with and a schedule that works best for you. This gives you more control over how you want to structure your life.

Things you can self-direct:

- where you live
- how you spend your days
- what you do in your spare time
- how you stay healthy and active
- your relationships with family and friends
- who you hire to assist you

Care Managers can play an important role in assisting with the start of the self-direction process and guide the steps you need to take. Our Fiscal Intermediary (FI) can also answer questions if you contact us at 607-724-2111 ext. 386. Lisa Gavazzi, FI Coordinator or lisag@stic-cil.org.



DSP STIC-nic

By Lucretia Hesco

On October 18, STIC hosted a DSP Appreciation Picnic for our Direct Support Professionals. It was a day full of karaoke, brunch and loads of fun! Every day, and especially on this day, we celebrated and honored the support that STIC DSPs provide to people with disabilities. Direct Support Professionals (DSPs) provide essential care and support to people with disabilities. This includes assistance with daily activities, fostering skill development, offering emotional support, promoting community inclusion, advocating for individuals’ rights and maintaining meaningful personal relationships. “Thank you” does not seem to describe our gratitude for all of our DSPs who work so devotedly to assist people with disabilities and make a difference each day. We hope that each and every one of our DSPs knows how important and amazing they truly are! It’s not just a job; it’s a mission, and we appreciate each and every one of them.

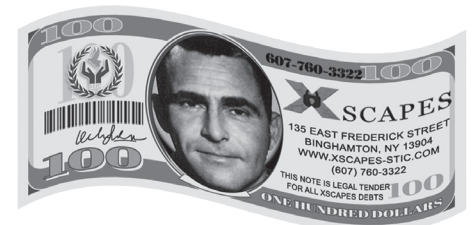
Thank YOU DSPs, for all of your incredible work and for being champions of inclusivity, dignity and respect.

Tis the Season!

By Todd Fedyshyn

Give Xscapes Bucks Holiday Gifts to your loved ones. Give the gift of knowledge and entertainment this holiday season.

With Xscapes Bucks you can purchase as much or as little as you need for your holiday gifts. Share the gift of entertainment and knowledge with your family and friends this holiday season. It’s the gift that keeps on giv-



ing, while supporting STIC's mission in our community and independence for the individuals we serve.

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Xscapes bucks come with a holiday certificate. This will be mailed to you or your family as requested during your purchase. Xscapes Bucks can also be purchased in person at STIC. We accept cash or credit card payments.

Xscapes is also a great team building option for your business associates. We offer five different games with exciting themes that will put players into immersive environments while encouraging communication skills and teamwork. Your management team can also have the option to watch your employees play our games from the control room with our game masters running your experience. Xscapes features conference rooms for team building break-out meetings or food you can bring with you to make your overall experience spectacular here at Xscapes. We also often see schools or camps use Xscapes for amazing community outings. Call (607) 760-3322 or email info@xscapes-stic.com for more information.

To book your next escape room experience visit: www.xscapes-stic.com

We also do take calls for last minute bookings and are happy to work your team into our schedule if possible. Call (607) 760-3322 for available last minute time slots.



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INVEST IN THE COMMUNITY HABILITATION WORKFORCE NOW!


CHEC's mission is to advocate for equity in Community Habilitation billing and rates, in order to achieve a living wage for their DSP workforce.

CHEC is comprised of families, Care Coordination Organizations, Provider Agencies, DSPs and most importantly people with intellectual and developmental disabilities.

Please Join Us!

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13904

OR JOIN VIA ZOOM



My Story

By Lisa Gavazzi

I desperately wanted a child and at age 36 it didn't appear promising. After going through a lot of infertility treatments and tests, I received the glorious news that I was indeed pregnant. I was so thrilled, and celebrated with my family and friends. I had regular ultrasounds and doctors' care during the first trimester. However, at 4 months gestation I went for a follow up ultrasound and received the news that my unborn child had spina bifida. Abortion was illegal in the state I was in for that stage of gestation, so the doctors suggested that perhaps I go to another state and terminate the pregnancy. I responded by informing

them to never suggest that to me again, it didn't matter the outcome.

My beautiful baby boy was born at 37 weeks gestation. The first time I saw him and they placed him on my chest, he was in a plastic bag to protect his open spine and back. I saw him very briefly before he was swooped away by ambulance to a children's hospital and I was taken to a regular room instead of going back to the maternity floor where all new moms went after birth. It was depressing and I was treated almost as if my new baby passed away, when in fact he went to a children's hospital, was medically made to stop breathing and placed on a breathing machine. That evening he went into major neurosurgery to repair his spine and back. Three days later I pushed myself

to be able to get out of the hospital after a c-section and be at his side for his brain surgery on day 3 of life.

Fast forwarding, my son is now 18 years old, well-adjusted and about to graduate from high school. Our son is on an Office for People with Developmental Disabilities (OPWDD) self-directed plan and will plan to live independently with self-directed staff to support him. He has made us proud as parents as he navigates through life in a wheelchair and is very social. He attends school events such as football games, school dances, field trips and his junior prom. He made the high honor roll every quarter last year and so far in his senior year as well.

STIC's Offices Will Be CLOSED FOR THE HOLIDAYS

December 23 2023 –

January 1 2024

We will Reopen

on January 2 2024

*Happy Holidays
to All!*



Do You Need Assistive Technology?

We Can Help!

National Disability Institute (NDI) can provide affordable loans to help people with disabilities purchase the assistive technology that best meets their needs.

What is assistive technology?

Assistive Technology are products or devices that can improve your independence and quality of life.

Examples include:

- Accessible bathrooms
- Computer equipment
- Hearing aids
- Modified vehicles
- Scooters/wheelchairs
- Smart home technology
- And more!

If you are a resident of New York or New Jersey, you may qualify.



Contact:

Laurie Schaller
lschaller@ndi-inc.org



202-449-9521
1-877-771-1962 (Toll Free)



**To learn more, visit NDI's website:
assistivetechloans.com**





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The Southern Tier Independence Center would like to thank the following local businesses and organizations for helping to make our 2023 Trunk or Treat a hauntingly HUGE success!

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<https://stic-cil.org/index.php/accessability/>

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STIC is a 501(c)(3) corporation, and governing documents, conflict-of-interest policy, and financial statements are available to the public upon request.

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

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

THANK YOU!

Southern Tier Independence Center

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