

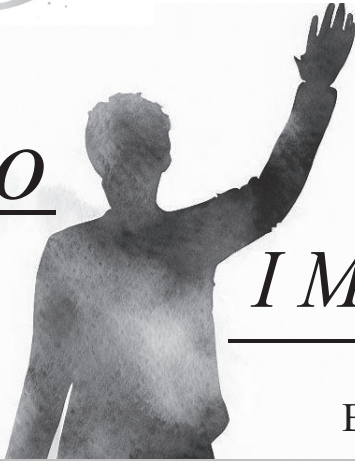


The Voice of Disability Rights in the (Bureaucratic) Empire State since 1984

AccessAbility

Fall 2023
Number 152

Hello



I Must be Going

By Maria Dibble

STIC held our 40th anniversary event in June, celebrating four decades of service to the community. At the event, I announced my retirement from STIC at the end of this year, and introduced our current Assistant Director, Jennifer Watson, as my replacement. Jen is deeply dedicated to STIC's mission and philosophy and will be a strong and effective leader for the organization moving forward.

I have been at the helm for 40 years, and it is with mixed feelings that I'm stepping down. The decision was a very difficult one to make, especially since I am one of the organization's co-founders, and I've invested more than two thirds of my life in STIC's development and growth, and in equality and independence for people with disabilities. I cannot begin to describe how much I have learned from the people we serve, as well as from my colleagues across the state.

When I was young and people asked, "What do you want to be when you grow up?" I would either say a poet or a writer. Little did I know about the journey that awaited me as I took up the mantle and began the advocacy necessary to free people from institutions, to promote their independence, and to fight for equality and a level playing field for those with disabilities.

Being totally blind and having experienced discrimination in my own life, as well as being ignored or discounted because of

my disability, I'm passionate about people getting the rights that they are entitled to. The passage of the Americans with Disabilities Act was a tremendous step forward in the right direction, but regrettably, it was not enough. People still languish in nursing homes, sheltered workshops and other segregated institutional settings, their very existence robbing them of the ability to grow and experience their full potential, or to even decide on the course of their own lives. As long as one person with a disability is controlled by the decisions of others, without allowing them to be involved to the best of their abilities, we cannot rest or stop fighting. Segregation is a model that has long outlived its usefulness, and it is time for it to die.

Lest you question this even just a little, think on this. When I was a baby (I'm a twin and my brother is also blind) the doctors told my parents to put us "away" and forget about us, because we'd never amount to anything. So there but for the grace of God and the determination of my mother and father, I could have been institutionalized and never founded STIC. Perhaps someone else would have, but I like to believe that I was put on this earth for a reason, and that reason was "STIC" and all that it entails.

I could never fully leave the agency or the Independent Living movement as long as there is more advocacy to be done, so I will be joining STIC's Board of Directors in

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2024, continuing to contribute and support our efforts as I can. I look forward to the next chapter in my life and the new journey I'll be embarking on, with the knowledge that STIC is in good hands under Jennifer Watson's leadership. She has been with STIC for more than 20 years, and has the same drive and fervor for justice and equality for all people with disabilities as I do.

I thank everyone who has supported STIC and contributed to our advocacy efforts, as well as each and every consumer who has trusted us enough to enter our doors and accept our services. I may have been one of the founders of STIC, but you are the true owners.

AccessAbility

September 2023

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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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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.

I'm not saying goodbye at all, I'm just giving a friendly wave and a smile, and sticking around to offer what I can of my knowledge and experience as a board member, without the day-to-day involvement. I'm very much looking forward to it, as well as to sleeping a little later in the mornings. My pas-

sion for the organization and for all that it stands for is still as strong as ever, and I consider my retirement as part of the natural evolution of STIC's development. You'll be seeing me in these pages again in the December issue, as I prepare to pass the baton to the next generation of advocates.

Unmanaged Managed Care

Now we have it straight from the horse's mouth: "Capitated payment models, such as the model used in Medicaid managed care, can create an incentive for insurance companies to deny the authorization of services to increase profits." At last, the feds are repeating what we've been saying for well over a decade: "Three factors raise concerns that some people enrolled in Medicaid managed care may not be receiving all medically necessary health care services intended to be covered: (1) the high number and rates of denied prior authorization requests by some MCOs [Managed Care Organizations], (2) the limited oversight of prior authorization denials in most States, and (3) the limited access to external medical reviews."

That's from a report by the Office of Inspector General (IG) of the federal Department of Health and Human Services, published in July 2023. The IG further stated, "Despite the high number of denials, most State Medicaid agencies reported that they did not routinely review the appropriateness of a sample of MCO denials of prior authorization requests, and

many did not collect and monitor data on these decisions."

The IG did its review at the request of Congress, some of whose members were concerned about several media reports of Medicaid managed care companies denying essential health care to their enrollees, 50% of whom are people of color. The IG reviewed data from seven selected "parent" insurance companies that had at least 1 million people enrolled in 115 Medicaid managed care plans across 37 states in 2019, and collected data generated from 2017 through 2019. The report found serious problems all over the country. For example, the average denial rate for prior authorization requests by Medicaid MCOs nationwide was 12.5%—one out of eight—as compared to a 5.7% rate for Medicare Advantage plans, which are also managed care but serve a much higher percentage of white, middle-income people, and are more closely monitored by the federal Centers for Medicare and Medicaid Services (CMS). Of course, we're most interested in our own state, and homecare is one of the services that must receive prior authorization and is fre-

BAD WEATHER?

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quently denied, or at least, some amount of needed service hours are denied.

The IG found that the NYS Department of Health (DOH) uses “denials data” for “oversight” but does not “regularly review prior authorization denials for appropriateness.” The IG reviewed the following MCOs that serve NY: Anthem’s Health-Plus HP, Centene’s Fidelis and WellCare of NY, Molina, and United Healthcare’s UHC. Two of them, Anthem and Molina, had the two highest Medicaid denial rates of all of the Medicaid managed care plans that were included in the report: Molina, at 41%, and Anthem at 34%. Denial rates for those plans were much lower in NY, and Anthem’s, at 6.1%, was lower than the national average for all such plans, but Molina’s NY percentage was 19.5% and WellCare’s was 16%. If DOH really was doing anything with the results of its alleged “oversight,” it should have investigated those two companies and made them change their practices, or revoked their contracts.

Unfortunately, the federal Centers for Medicare and Medicaid Services (CMS) only requires states to review data on internal appeals of MCO decisions, and Medicaid Fair Hearings, and report it to CMS annually. It does not require regular review of prior authorization denials. About two-thirds of MCO internal appeals result in a second denial, but most of the people who then ask for a Fair Hearing win their cases, at least those involving long-term care in NY. Many people are discouraged by this and don’t request the Fair Hearing, which is why the state should examine denials when they first happen. Again, compare to Medicare Advantage, where, if a plan denies authorization, the request automatically goes to an independent reviewer that can reverse the denial, and Medicare Advantage offers another level of review, the “Medicare Appeals Council,” if a person loses a fair hearing. Possibly due to this extra scrutiny, Medicare Advantage plans overturn their own denials on internal appeal a whopping 82% of the time.

An “external review” is available for Medicaid managed care enrollees in NY under some circumstances, though it’s questionable how really “external” it is: Enrollees who request such an appeal are

liable for a fee of \$50, payable to the insurance company if they lose, which suggests that the reviewers are actually employees of, or at least under contract to, the insurance company, and not truly independent. Nationwide, only about 5% of people whose states offer external reviews request them. Only about 2% request a Fair Hearing. Taken together, this data indicates that a whole lot of people are being illegally denied medically necessary services, and nearly all of those denials could be “caught” if there were automatic external reviews.

The IG made several specific recommendations to CMS. Those most relevant to New York are:

- Require states to conduct regular reviews of MCO prior authorization denials.
- Require states to have automatic external medical reviews of prior authorization denials. These reviews should be separate and independent, and conducted by a clinician with expertise in the enrollee’s specific condition(s).

CMS, in its response, did not immediately agree that either recommendation was necessary, and pointed out that implementing them would require issuing a proposed rule for public comment. The recently issued proposed rules for Medicaid managed care (see *AccessAbility* Summer 2023) included a requirement for MCOs to publish their denial rates for consumers deciding which MCO plan to enroll in, but did not specifically address the issues raised in the report.

It’s clear, though, that there are major inequities between the Medicare Advantage managed care program, which largely serves the white middle class, and Medicaid managed care, which mostly serves poor people, half of whom are not white. Further, only Medicaid offers permanent long-term care, and many states, including NY, make the lion’s share of that available only through managed care, without enough oversight. So those inequities fall heaviest on people with disabilities. It’s time for a change, and while CMS thought about what it might do, in August we learned that Congressman Mike Pallone (D-NJ), ranking Democrat on the House Energy & Commerce Committee, was looking to start an investigation into how

insurance companies use prior authorization. We don’t know how that will pan out in the Republican-controlled House, but we think this is another clue that our elected officials in NY need to begin thinking seriously about whether Medicaid managed long-term care is a good idea at all.

Schools Restrained from Restraining Students

In the wake of a national series in the Hearst newspapers last fall concerning abusive restraint and seclusion practices in schools, including Albany *Times-Union* articles about the situation in NY (see *AccessAbility* Winter 2022-23), bills were introduced in the state legislature to address the issue, and nearly simultaneously, the state Board of Regents proposed new regulations.

We reported on one of the bills, the Keeping All New York Students Safe Act (Assembly bill number A.3311), in the Spring 2023 issue. It would outlaw dangerous prone physical restraints and limit use of any type of physical restraint to situations in which there is an “imminent danger of serious physical injury” to a student or school employee, and only if less restrictive methods had been tried and found ineffective. It would prohibit use of seclusion (isolating a student in a locked room), and only permit “time out” as a response to a behavioral crisis when the student is able to freely leave the time-out area or room. It would forbid all forms of mechanical restraint as a form of punishment or to control behavior, including handcuffs. It would require all school employees who work with the student, and the student’s family, to meet to discuss any use of physical restraint within 5 days to find ways to prevent further incidents. It would grant students and families a private right of action to sue a school district that violates the rules and would allow the Commissioner of Education to take up to half a school district’s state funding away if the district willfully disobeys them. The bill applies to all public and private schools in New York State, and to Head Start programs and schools outside NY that receive NY funds. That bill did not pass this spring.

There was a competing bill in the state legislature, A.6213, this spring as well. That bill claimed to address the epidemic of dangerous physical restraint and seclusion incidents in NY schools that were highlighted in the media, but in fact would have allowed that epidemic to continue unabated. It would have permitted the use of physical restraint merely for “the maintenance of reasonable discipline.” It did not create the expectation that less restrictive methods, such as positive behavioral support plans, should be tried first before resorting to restraint. It did not require a post-incident meeting, did not provide a private right of action for injured students, and did not apply to private schools. That bill also did not pass.

Last summer (see *AccessAbility* Summer 2022) another bill, A.10289, proposed to make it illegal for NY to spend any funds on facilities, including residential schools, that used any form of aversive “treatment” on people with disabilities, whether in- or out-of-state. “Aversive” means any seriously unpleasant stimulus, such as pain or nasty-tasting food. Notably, it includes electric shocks of the type that are generated by devices worn by some inmates of the Judge Rotenberg Center in Massachusetts. This was especially notable because it didn’t just forbid the state to pay specifically for aversive treatment for some person, it forbade it to give any money at all, for any purpose, to a facility that uses aversives on anybody. That bill died a quiet death last year.

However, this year it was revived as part of the Regents’ new regulations on restraint, seclusion, and corporal punishment in schools (effective August 3), which contain some of the best parts of A.3311 and A.10289, and fewer loopholes than A.6213. They prohibit prone restraint and any other restraint that restricts breathing, and all types of aversive treatment, in public or private schools, and forbid the state to give any money to any facility that uses them, whether in NY or not. They allow physical restraint only “in a situation in which immediate intervention involving the use of reasonable physical force is necessary to prevent imminent danger of serious physical harm to the student or others.” Well, not quite only then. They say “Physical restraint shall not be used to prevent property damage except in situations where there is imminent danger of serious physical harm to the student or others and the student has not responded to positive, proactive intervention strategies.” We’re not sure what that really means, but the issue of property damage was a big bugaboo for opponents of any new regulation limiting use of restraint, so maybe it was inserted to mollify them. But changes were made in several places in two different sets of State Education Department (SED) regulations, and different, somewhat weaker language concerning allowable circumstances for physical restraint appears in some places. There is also a specific exception in the section on acceptable forms of mechani-

cal restraint to allow police (er ... “school resource officers”) to handcuff students and haul them away, another hobby horse of regulation opponents. That is *never* a good response to a student whose disabilities cause behavioral issues, and there is now a danger that schools, especially in New York City, which had been using this option far too often, will simply dispense with any intervention other than calling the school cop. This may violate federal law (see page 10).

The regulations specify a limited post-incident meeting, involving only the student and the employees who carried out the restraint, with no requirement to involve other teachers and employees who work with the student, or the student’s parents.

There is no private right of action for injured students, and no enforcement language at all.

We submitted comments asking SED to tighten up the regs and bring them more into line with A.3311, but they were ignored.

While the new regulations are a big improvement, there is still a need to enact the rest of the provisions in A.3311 to prevent schools from substituting police action for appropriate crisis intervention, and to ensure that injured students have legal recourse and that schools that flout the new rules in the same way they flouted the old ones (as described by the *Times-Union*) will face real consequences. Our legislators must hear that SED’s action did not solve this problem.

Mental Health Wars

Last time we reported that it wasn’t clear if New York City Mayor Adams, who announced an apparent about-face in mental health policy, was actually carrying out his previous plan to have police round people up and force them into hospitals. Up to that point we hadn’t seen any media reports to that effect. This spring, though, the *New York Times* published a story about several such incidents. The story won’t give much comfort to those who oppose forced hospitalization.

The *Times* reported that “relatively few” people have been rounded up this way, and that those who were taken to hospitals were not “typically” violent.

The city contracted with community service providers to conduct outreach to homeless people with mental health disabilities who are “unable to meet basic living needs.” They approach them and offer the opportunity for shelter or hospital services. If they refuse, the provider may then call the police and have the person forcibly removed. According to the *Times*, one such provider, BronxWorks, has caused nine people to be hospitalized in this way. BronxWorks has been “keeping tabs” on several people for a long time. The first one they hospitalized was a woman in her 60s who, on a cold Christmas Eve, was hanging around an elevated subway sta-

tion. She had refused to talk to any BronxWorks people for five years. She had sores all over her legs, they were swollen to the point that she couldn’t put on socks, and one foot was bare. As the *Times* reported, “She screamed when the police arrived, but she got in the ambulance.”

Under the program hospitals are supposed to keep people long enough for them to achieve a stable recovery process, often involving medication, and then be discharged to permanent housing with supports. Mitchell Katz, the city’s public hospital chief, told the *Times*, “Nothing about a seven-to-14-day hospitalization is going to change the arc of the life of somebody who’s homeless and has schizophrenia.” This woman was in the Manhattan Psychi-

atric Center for about five months, where she went from very sick and very resistant, to physical health and a strong desire for continued support. In June she moved into permanent supportive housing.

Another person, Mazou Mounkaila, who had been homeless for ten years, was found sleeping under an overpass on a night when the wind chill reached -4 degrees. The workers told him he had to go either to a shelter or a hospital. He refused. The workers brought in the police who, Mounkaila said, "To my surprise, they handcuff me." He then spent 104 days in Jacobi Medical Center in the Bronx, receiving treatment for schizophrenia. There were things he liked about his new situation: getting regular meals and showers, and being reunited with his daughter, whom he hadn't seen for eight years. But he was forcibly medicated, and toward the end of his stay in the hospital, he said, "I'm like in prison." A month or so later, "he moved into an apartment-style shelter run by BronxWorks, which is working to find him supportive housing." He says he takes his medication, "not because he thinks he needs it, but because he says BronxWorks would be upset if he stopped. Life is good. This place is better than living in the streets."

The *Times* reported that of the nine people BronxWorks has hospitalized, 5 are in permanent housing, or shortly will be. Three are still in hospitals or nursing facilities. One is on the street because the city hospital he was taken to, "Lincoln Medical Center, discharged him the same day, without notifying BronxWorks," in violation of the mayor's policy.

We're sure things don't always go so well; indeed, they didn't for that last BronxWorks client. Jordan Neely, who, famously, was choked to death by a bystander on May 1, 2023 when he started ranting in the New York City subway, was on a so-called "watch list" of about 50 or 60 homeless people with mental illness that is maintained jointly by the city and service providers, including BronxWorks and the Bowery Residents' Committee, which has the city contract for mental health outreach in the subways, but apparently he didn't benefit from the new program. Earlier in the year he'd been jailed briefly for punching an elderly woman in the face, then released to a residential

treatment center. He was able to walk away from that center two weeks later. When outreach workers found him in March they took him to a shelter for one night, and when they saw him again in April, according to the *Times*, "at an end-of-the-line station in Coney Island, Mr. Neely, wearing dirty clothes riddled with burn holes, exposed himself and urinated inside a subway car." The workers called the cops, who merely threw him out of the subway station. That's clearly not the way the program is supposed to work.

In July, *Politico* reported that a hotline that the New York City police are supposed to call to get advice on whether to force someone into a hospital wasn't being used. The hotline is staffed by 30 psychiatrists, social workers, "and other medical professionals employed by" NYC Health + Hospitals, the city's public health system, but its use by police is voluntary. As of July 10, the hotline, which opened on January 31, had received zero calls. On the other hand, the *Times* story didn't say anything about police acting on their own to pick up people; they only did so when called by a service provider that had already decided that hospitalization was necessary. That doesn't mean it isn't happening, of course; we just aren't aware of any reports about it so far.

But what most of the people involved seem to agree on is that the key is time. Given enough time and consistent follow-along support, people who have been living in horrendous conditions for years, for no fault of their own, are finally getting the effective help they need, and they are feeling better. It's also quite clear that, at least in the beginning stages, this is not a backwards-looking effort to lock people up permanently in institutions. It's simply a recognition that people with serious mental health issues sometimes need to be kept safe and in intensive treatment long enough for permanent benefits to take hold, and long enough to learn how to trust in their own ability to take care of themselves effectively and get help when they need it, and while that is not a long time in terms of their total lifespan, it's not necessarily a short time either.

STIC has taken the position that people should not be forced into a hospital or similar setting against their will, even if it's clear that they will be better off if they

are. This is a problematic view to endorse. We've done it in the name of our dedication to civil rights. But it's possible to look at this in terms of our commitment to people's right to informed choice as well. For years we campaigned against those who claimed that various people with intellectual disabilities had "chosen" to live in segregated settings, when the truth was, that even if they had actually been asked their opinions, they had never had any experience of true freedom and autonomy and had no way of knowing what they would really prefer. Providers in the developmental disability field are now coming to realize that their role is to give people a variety of experiences so they can learn to make decisions based on real knowledge, rather than be influenced by the wishes of those around them. Choice is not enough; choice, to be meaningful, must be informed choice. This is equally true for people who, due to mental illness, simply cannot assemble a true picture of reality. Making choices based on irrational fears is also not informed choice.

It's true that many such people have had very unpleasant experiences in institutional settings, or have been betrayed by those who promised to continue to help them, and those events may also inform their choices. Yet, to be traumatized by one's experiences is to be damaged, and often that damage is to the ability to reason, or see a better way. We may be at the dawn of a new realization among mental health providers that their role is to stay in the game with the people they serve, closely, continuously, and indefinitely, until they know that, this time, they will not be abused or abandoned, that there truly is light at the end of the tunnel, and that there is no way that a few months in a well-run and compassionate controlled setting, with eventual return to the community with supports guaranteed, can be worse than a decade on the freezing streets.

Meanwhile, some members of Congress have proposed a new Medicaid Home and Community Based Services (HCBS) program for adults with "serious mental illness." It's similar to the so-called "State Plan HCBS" option. It would offer a pretty full range of services, including peer support, supported employment, intensive case management, assertive community

treatment, mobile crisis intervention, and housing-related services (not housing subsidies but counseling, advisement, and advocacy services to enable people to find, and keep, permanent housing). Recipients would have to have a “serious mental illness” but could not be excluded because they have any other disability, including intellectual or developmental disabilities or substance use disorder. It would offer an enhanced FMAP (“federal medical assistance percentage”; that is, the percentage of the total cost that is paid by the feds) of up to 25% on top of the standard FMAP the state already gets for Medicaid services (not to exceed 100%, of course). However, it would require people to need assistance with at least two Activities of Daily Living (ADLs such as bathing, dressing, using the toilet, moving around, or eating), or at least one ADL and one Instrumental Activity of Daily Living (IADLs, such as cooking, cleaning, shopping, etc.) This is too restrictive, since many people with serious mental illness can handle all of their ADLs themselves but need a lot of help with IADLs. It’s not a bad idea if that issue could be corrected.

The bill, the “Strengthening Medicaid for Serious Mental Illness Act,” was introduced in the Senate by Kirsten Gillibrand (D-NY) in June and referred to the Senate Finance Committee. A House version, introduced by Dan Goldman (D-NY), with Jerry Nadler (D-NY) as a co-sponsor, was sent to the Committee on Energy and Commerce’s Subcommittee on Health. Prospects for passage are unknown. If it becomes law, NY’s elected officials would have to be persuaded to opt into the program. NY already has an HCBS program for people with mental illness known as “HARPs” (Health and Recovery Plans). It’s authorized under the State Plan HCBS Medicaid option mentioned above, and includes peer support, psychosocial rehab, short and long-term crisis intervention, educational supports, employment supports, self-directed services (including community habilitation), and non-Medicaid transportation. Unfortunately, NY has failed to roll this service out to very many people. It’s unclear if state officials would add another, similar program, to the state’s Medicaid Plan, or if they’d actually provide the services if they did.

Early Voting Access Assessed Early

Disability Rights NY and the Brennan Center for Justice published a report in August that found that nearly all early voting sites in upstate New York had one or more accessibility problems. They sent surveyors to 179 early voting sites in 57 counties (they excluded New York City because it alone has 140 early voting sites and there wasn’t enough funding to include them).

Most of the problems related to parking, and most of those were mere lack of signage, though in some cases the accessible parking spaces didn’t have access aisles, which would make them unusable for people with vans whose lifts are on the side. A few other common issues included: ballot-marking devices (BMDs) did not have privacy screening or enough space around them for a person in a wheelchair to maneuver, doors did not have accessible hardware, and parking lots and walkways were not “solid, firm, and slip-resistant.” All of these issues but the last one could have been easily fixed, at least temporarily, if anyone had bothered.

Much less frequent were problems with BMDs not being available because the poll workers didn’t know how to set them up, or because they were broken and the workers didn’t know how to get them fixed. In a few cases, the poll workers didn’t even know what they were. Several poll workers were rather ignorant about the whole concept of accessible voting machines. They insisted they were only for disabled voters to use (not true under NY law), and one insisted they were only for people who were deaf or hard-of-hearing. A poll worker told a surveyor that the BMDs were only available on Election Day, and not during early voting.

This is an old story, and it keeps getting repeated primarily because no law requires the state Board of Elections (BOE) to crack down on county Boards when they don’t fulfill their duties to ensure that polling places are fully accessible and poll workers are well-trained. The local Boards don’t do that at least in part because they don’t have much of a budget for monitoring polling places or training

workers. Another reason is that some local Board members have cozy relations with the operators of some inaccessible voting sites and refuse to move those sites, which receive a fee from the Board. Workers need to use BMDs themselves, frequently, to stay “in practice” and ensure that they know how to set them up and troubleshoot them. Getting a few hours of training six months before a voting day won’t accomplish that. And BMDs would be more reliable if they weren’t so absurdly complicated—a matter of poor design.

The report’s authors made recommendations to the legislature and the state BOE. Curbside voting should be available, and so should more money for local Boards, and the state BOE should have legal authority to enforce the rules. Something may, or may not, come out of that.

The big take-away from this is that most problems with accessibility at early voting sites are extremely minor and should not prevent most disabled people from voting. *Please* don’t assume you’re going to have a problem and stay away from the polls. As we’ve said before, accessible voting is a very good thing, but voting is far too important a duty to abandon merely because it’s not fully accessible. We need every eligible voter to vote in every election to prevent our self-governance traditions from being destroyed by right-wing demagogues and fanatics, and that means **you** need to vote, even if you have to bring somebody along to help you.



Tenant Rights and Wrongs

The NY State Office of People with Developmental Disabilities (OPWDD), the NY Office of Mental Health (OMH), and the NY Office of Addiction Services and Supports (OASAS) operate, or fund, more-or-less “community based” housing for people with disabilities. But the three agencies treat residents of those programs very differently when it comes to tenant rights.

Federal Medicaid law requires that any residential program that is provided, or could be provided, under several so-called “Home and Community Based Services” (HCBS) options must guarantee the residents certain tenant rights. Most impor-

tantly, there must be a lease or similar agreement that guarantees the resident the same rights that ordinary lease agreements do for nondisabled renters. In New York, state law allows tenants to sue landlords over illegal evictions, which should mean that this protection also applies to HCBS recipients in NY.

As we reported (*AccessAbility* Spring 2023), the state submitted a final HCBS Transition Plan to the feds last fall that contained the ludicrous claim that OMH supportive housing programs are not subject to the HCBS “Settings Rule.” But federal Medicaid managed care regulations issued in 2016 made it clear that any Medicaid-funded program that *could* be provided under a Medicaid HCBS authority is subject to the rules. The rules apply to any “provider owned or operated housing” facility where any supports beyond a rental subsidy are provided. Supportive housing programs for people with mental illness in NY all include services besides rental assistance, such as ongoing monitoring, peer counseling, and supported employment, and most of them receive at least some Medicaid funding. Anyone in such a program should have a lease-like rental agreement that protects them from unfair or sudden eviction. But the NY Focus website reported in July 2022 that people living in those programs have been evicted without notice, finding their belongings thrown out on the street, and some judges have ruled, like the OMH employees who wrote the above-mentioned section of the Transition Plan, that supportive housing is “residential treatment” not subject to either federal or state law that guarantees tenant rights. As Focus reported this past July, this is continuing even though both OMH and OASAS recently issued improved guidance to supportive housing providers emphasizing tenant rights.

Meanwhile, OPWDD took a different approach. The agency says NY landlord-tenant laws don’t apply to their certified community-based residential programs (IRAs and Family Care), but they agree that the HCBS Settings Rule requires that residents have signed agreements that confer the same rights and responsibilities as those laws do for ordinary leases. OPWDD regulations also require that when a housing provider wants a resident to move out, it must work with the resident and his/her

Care Manager to ensure a safe transition, and must continue to provide services until the person is ready to move. OPWDD released a new Administrative Directive Memorandum (ADM), along with a template that providers can use to create their own occupancy agreements, that does a very good job of describing and enforcing all the HCBS Settings requirements.

It says housing providers can’t require residents to have a job or take part in any of the provider’s programs. It will be interesting to see how providers will respond. Many of them base staffing on the expectation that everybody who lives in “the house” will be out of “the house” during weekday daytime hours. DSP wages being what they are, it will be tough for providers to hire more workers to support people who prefer to stay home during the day. Residents also have the right, under the Settings rules, to support for individual recreation and activities in places of their choice. That’s another staffing issue for group homes that have relied on van rides and movie outings. The ADM also says group homes can’t restrict access to visitors or food at any time under “house rules”; any such restrictions must be part of an approved individual service plan, and only if they are the least restrictive way to address a serious and imminent health or safety issue. People’s rights can’t be limited due to stereotypical beliefs about what a person with an intellectual disability “might” do; limits must be based on objective evidence about what the person is *likely* to do, and only applied after supports, including supportive decision-making, have been provided, and failed, to address any issues before restrictions are applied.

Lastly, on the topic of the Statewide Transition Plan, we’ve heard through the grapevine that state officials have said the federal Centers for Medicare and Medicaid Services (CMS) was not at all enthusiastic about granting NY an extension for full compliance with all of the Settings Rules, which was due by March 17, 2023. However, we couldn’t find any public statement about CMS’s response to the state’s request for a delay until July 2024 on the NYS Department of Health website. As we’ve reported, the primary reason given for this requested delay was “workforce issues,” that is, the inability of the not-for-profit agencies that deliver most HCB services to hire enough direct support workers. This is due to the

state’s refusal to pay adequate rates to those providers, a problem that the recently enacted 2023-24 state budget did not correct.

Access to the Interwebz

On August 3, the federal Department of Justice (DOJ) published proposed new rules on accessibility requirements for websites and apps developed or operated by “public entities” covered under Title II of the Americans with Disabilities Act (ADA). Public entities include state and local governments, and anything owned or operated by them, such as schools and universities, libraries, and hospitals. We’ve been waiting for this for a very long time.

We’ve also been hoping for rules for Title III “public accommodations”—stores, businesses, and venues open to the general public—but they aren’t in this proposal. Several years ago, DOJ published a regulatory agenda that included web access rules for both Title II and Title III, but later announced that the rules would be issued separately. We think this means we’ll eventually see a proposal for Title III, though we don’t know when, but it could look a lot like this one.

DOJ will require all HTML content (stuff not in so-called “conventional electronic documents”) to be accessible as described by the WCAG 2.1 Level AA standards. WCAG stands for Web Content Accessibility Guidelines, and version 2.1 is the latest version. WCAG has three levels: A is the absolute minimum to enable reasonable accessibility. AAA is the highest level, but also the most difficult to follow. AA is the “just right” option and should deliver an almost completely accessible experience in nearly all cases. This includes ensuring that any disabled person, including one who uses screen-reader software, can find and use all of the HTML text and controls on a website, and requiring both live and pre-recorded captions for current audio content, and audio description for current video content. The rules apply to websites accessed in a browser, and to phone apps provided or used by public entities to conduct public business.

Public entities serving populations of 50,000 or more will have to be in compliance two years after the final date of the rule. Smaller entities will have three years to comply.

DOJ won't require 100% accessibility for everything on all public entity websites; they believe that will be too difficult, time-consuming, and expensive. The focus is on HTML content (text that's "just there" on most websites, and not contained in separate documents); items and information that are current; and information and features that are required to enable citizens to successfully interact. Everything else would be subject to limited exceptions, as follows:

Archived web content: This is text, documents, and audio or video files that are "exclusively for reference, research, or recordkeeping," that are stored in archive locations, and are not altered once stored. The ADA and Section 504 of the Rehabilitation Act require accessible versions upon request; the new rule just won't require them to be made accessible all at once.

Pre-existing "conventional" electronic documents: This includes word processor, spreadsheet, and presentation documents (as in Microsoft's Word, Excel, and PowerPoint), PDF files, and database files. DOJ says too many of these already exist to reasonably expect public entities to make them all accessible at once. But any new files for the general public going forward will have to be accessible, and, importantly, any documents that are essential for people to do business with a public entity will also have to be made accessible, such as PDF fillable forms.

Other "web content": If a public entity posts information on a third-party website,

such as Facebook, Instagram, Twitter, etc., then that information—and by inference, that website—must be accessible. If a public entity contracts with a third-party to host information on a website that is outside the public entity's site, that information, and website, must be accessible. If a third party is hired to produce content for the public entity's website, it must be accessible. However, if other people can post documents to a government website (such as comments on a proposed rule like this one), there'll be no requirement that those documents be accessible. (On the federal government's regulations.gov site, most such comments are indeed accessible anyway).

Course content: For public schools, colleges, and universities, any course-specific content that is accessed from password-protected user accounts would only have to be made accessible if the school is made aware that a particular disabled student needs it. For public primary and secondary schools, if they operate a "portal" where students and parents can obtain important information, again through a password-protected account, the portal itself would have to be accessible, but any student- or parent-specific information on the portal would only have to be accessible if the school knows a disabled person needs it to be. All HTML information available to the general public on these schools' websites and apps would have to be accessible.

"Individual" documents: Sometimes governments transmit individual documents

(for example, a receipt if you pay your taxes online, a bill from a municipal power company, or medical records in a public hospital's patient portal) via the web. If such information is in conventional electronic documents, individualized for a specific person, and behind a password-protected account, then DOJ would not require public entities to make them accessible all at once. If a disabled person needs and requests an accessible version of any such document, it must be provided promptly. DOJ is concerned about the time, expense, and difficulty of making all such documents accessible, but they are seeking comment on how this should be approached. We think it's pretty common to have an option to convert documents like these to HTML (which DOJ says must be accessible in all cases). For example, I can use Microsoft Word to save the document I'm typing right now as a "web page," which means HTML. So we don't really think there's much difficulty here, and that's what we'll tell them when we submit our comments.

You can submit comments too, and we hope you will. As proposed federal rules go, this one is pretty short (216 double-spaced pages, nearly all of which is explanatory material and not the actual rule itself). Go to this page: <https://www.regulations.gov/document/DOJ-CRT-2023-0007-0001/comment>. You can type in comments or upload a file, and you can read comments already submitted. The deadline for comments is October 4, 2023, a Wednesday.

courts watch

Health & Hospital Corp. v Talevski: A sigh of relief

Last seen in *AccessAbility's* Winter 2022-23 edition, this case concerns whether a resident of a government-owned nursing facility who was mistreated can sue for damages under federal Medicaid law. The short answer is "YES!", as stated in a 7-2 Supreme Court decision in June.

This is a decided victory for those who think individuals should be able to sue to enforce the Medicaid law. Since the Supremes had been narrowing that ability for well over 20 years, many people worried they would take the bait offered by

Health & Hospital Corporation (HHC), an entity of Indiana's Marion County government. HHC asked the court to say that all previous cases that let individuals sue governments under federal so-called "Spending Clause" legislation like the Medicaid law were wrongly decided. Possibly fortunately for Talevski and the rest of us, HHC inexplicably failed to offer a full list of reasons why the Court should do so. So the Court ruled only on the factually disputable arguments that HHC did present. Justice Thomas, as might be expected, was persuaded that the request was proper based on evidence not pre-

sented to the court, and wrote a lengthy dissent about it, but nobody else agreed with him. Justice Alito agreed with most of the majority decision but still would have ruled against Talevski on one point, in agreement with the Biden Department of Justice, which was decidedly not our friend in this case.

Those two dissenting opinions should raise a caution flag for those who believe this issue is definitively settled, but I don't have the space to explain that fully. Here are the basics:

Talevski was drugged into near catatonia without medical justification by the nursing facility, despite a Medicaid law provision outlawing that, and then was transferred to another facility without his consent, also illegal. The law had "ad-

ministrative remedies” that let residents file grievances, and Talevski used them to eventually overcome the resistance of the private company that was hired to run the facility and force them to stop drugging him and trying to transfer him. However, lawyers were hired to achieve this, and doctors were also paid to wean him off the drugs in a different facility, incurring costs which were not recoverable under the administrative remedies. (Due to said catatonia, he was unable to give consent, and just before the Supremes took the case, he died, but his wife continued to seek repayment for those costs.)

By convention, the Medicaid law is deemed to be allowed by the Constitution’s “spending clause.” In short, the Tenth Amendment of the Constitution won’t let Congress dictate to the states except as explicitly permitted by that document’s “enumerated powers.” Those powers, of course, were written in the 1780s and do not contemplate such things as government health insurance. So in order for Congress to tell states how to run their Medicaid programs, it uses tit-for-tat deals: Congress offers money to states, and in return, states consent to follow Congress’s rules. Some people, like Justice Thomas, think citizens can never sue states or subordinate government entities to enforce provisions in such laws, or collect damages, because the deal between the feds and the states is just a “contract,” which only the feds can enforce, by terminating it and/or demanding repayment of funds (to themselves, not Medicaid recipients).

After the Civil War, Congress passed a civil rights law that included “Section 1983,” which says that any person under the jurisdiction of the US can sue in federal court for redress if any person acting in the name of a government entity violates any federal law that results in the person being harmed. (Having to spend money to solve a problem created by such a violation is a form of harm.) Note that this means that people can only use Section 1983 to sue a nursing facility operator or owner for violating Medicaid law if it is a government entity, and most are not. But this decision has wider reach, allowing, for example, homecare recipients to sue state governments for harm resulting from failure to deliver services.

In 1980 the Supremes ruled that Section 1983 can be used for such suits only if the law very clearly establishes “rights” for “individuals,” and does not preclude Section 1983 as a remedy either explicitly (“you can’t do that”) or by establishing “administrative remedies” to resolve complaints that would be “incompatible” with Section 1983.

In 1987 Congress passed the Federal Nursing Home Reform Act (FNHRA), a new section of the Medicaid law, and the one under which Talevski sued. It indeed says residents have “rights” to not be overdrugged or transferred without their consent and does not specifically say Section 1983 can’t be used. While it contains extensive “administrative remedies,” they don’t enable injured people to recover costs, and it explicitly says that nothing in those remedies is intended to preclude access to other remedies available under other laws.

Most of the Justices agreed with the opinion’s author, Ketanji Brown Jackson, that rights are clearly present in the law and Section 1983 can be used to sue for damages. (“Any law” means “any law,” spending clause or not.) Justices Barrett, Alito, and Thomas each had different views on what species of weeds are growing in the “incompatible” briar patch, though Barrett didn’t dispute the results, and Thomas didn’t think they should get off the “spending clause” fairway (“spending clause” acts by Congress don’t carry any force of law at all and can’t create “rights” even if they say they do; they are contracts, only enforceable under their internal terms).

Justice Gorsuch, while agreeing with the majority, briefly regretted that HHC did not offer enough evidence to support deeper review of Thomas’s points about the Tenth Amendment and “spending clause” laws. He did not say what position he might take if given the opportunity for such a review, thereby inviting another case along these lines in the future.

In any case, it doesn’t look like there would be more than three Justices on the current Court who would be inclined to backtrack on the basic premise that Section 1983 applies to all violations of federal laws by government actors unless those laws clearly preclude its use. Another reason to vote in every national

election, because they control who gets to appoint Supreme Court Justices.

NY v Centers Health Care: Say, how many crooked nursing facilities are there, anyway?

This is another in a series of suits filed by New York State Attorney General Letitia James against nursing facility operators for diverting Medicaid funds into their own pockets and providing substandard care as a result.

As we’ve reported, nursing facility owners often complain that they don’t get enough money from Medicaid and Medicare, and that’s why they are understaffed and frequently neglect, injure, and even kill their residents. In this past budget cycle, they convinced Governor Hochul and legislative leaders that these lies are true and got a 6.5% increase in their Medicaid rates.

The facilities themselves also went to court to enforce their position, suing NY in April for its 2021 law (never implemented due to the pandemic) that imposed minimum staffing requirements and other rules to force them to spend more of the funds they receive on direct resident care and services. Although their complaint repeats the lie that they don’t get enough Medicaid money to cover their costs, they also make a plausible argument that the law attempts to control how the facilities use Medicare funds, which are not under the authority of the state.

But James sees the lies for what they are, and she continues to bring them before the public.

Centers Health Care is a huge regional corporation that operates nursing facilities, hospitals and homecare agencies in the north-eastern US (you may have seen its recent ads on TV). Four of its nursing facilities, in New York City, Westchester County, and Buffalo, are the targets of her suit.

James’s June 28, 2023, complaint accuses them of diverting Medicaid funds into “fraudulent” real-estate transactions. As we’ve described before, the company separates ownership of facility operations and buildings into two companies, both owned and controlled by Centers Health Care. The two companies then operate in a “landlord-tenant” relationship. The “landlord” side charges the “tenant”

side massively-inflated rents, which cut into the funds available for direct services provided by the “tenant,” and flow into the pockets of the “landlord,” which has no obligations to serve or protect the health or safety of anyone. Another charge concerns fraudulent “third party transactions,” in which Medicaid funds get diverted from direct services to other purposes through companies ostensibly owned by “third parties,” though their owners are actually the same people who own the “tenant” and “landlord” companies. Few details of these transactions were provided in James’s complaint, but a common version of this is to create “administrative services” companies to provide non-medical services at the facility. These companies can then hire executives at exorbitant salaries, and/or bleed off funds directly to the owners. James also says Centers Health Care diverted more than \$2 million to “no-show” jobs for friends and relatives of the owners, and overall misdirected more than \$83 million over the past ten years.

These alleged crimes don’t differ much from those James charged against other nursing facility operators in four other lawsuits over the past year. Nor are the consequences—a long trail of neglect, abuse, injuries, and death resulting from inadequate numbers of poorly-trained staff—that has been reported from these facilities. Certainly the owners should be made to answer for their crimes. But our elected officials should also answer for their placid handover of even more Medicaid money to them this past spring, much of which will now pay for legal fees—especially after they refused to ensure Medicaid-funded homecare workers can make a decent wage.

Disability Rights Mississippi v Fitch: A vote for truth

This is another victory for objective truth over right-wing paranoia. Mississippi recently passed a state law to outlaw so-called “ballot harvesting.” This negative term refers to a common practice of “get out the vote” organizers, who collect absentee ballots filled out by voters and either mail them or deliver them to a local dropoff location. Right-wing politicians have called this a form of “fraud,”

implying, or stating outright, that the organizers either coerce voters into filling out the ballots in a certain way, or simply fill them out themselves. To date, nobody who makes these claims has produced any credible evidence that this actually happens in more than a handful of isolated instances, if at all. That’s also the case in MS, where a federal judge inquired about it.

Lynn Fitch, one of the defendants in this case, is MS Attorney General; the other defendants are state and local government officials who have jurisdiction over elections. Judge Henry Wingate presided over the federal district court where the case was heard. He asked the defendants for any evidence of a “ballot harvesting problem” in the state. There was no response.

The reason for that is because there was no such problem, in MS or anywhere else in the US. Right-wing politicians pass laws like this not because they genuinely believe there is a danger of fraud, but because they believe that “get out the vote” campaigns result in more people of color, and poor people, including those with disabilities, voting, and they think most of those votes will favor progressive candidates. That notion has also not been proven, though it could well be true.

The law contains a limited list of who can “collect and transmit a ballot”: election officials, postal service workers, other authorized government officials, common carriers (freight haulers and companies like FedEx), and, for disabled voters, “a family member, household member, or caregiver of the person to whom the ballot was mailed.” MS lets disabled voters vote by mail.

The judge issued a temporary restraining order on July 25, barring the new law from taking effect, for a simple reason: federal voting rights law says that a disabled voter can get help to vote from ***anybody they choose***, without restriction. The judge noted that “caregiver” might cover this, but the MS law doesn’t define the term, and at least some definitions of “caregiver” are too restrictive, referring to people who provide a “broad range” of assistance to people with whom they have a “personal relationship.” In fact, ***any*** restricted definition of who can help a disabled voter conflicts with federal

law, and federal law, under the Constitution, trumps state law. Although the injunction is temporary, we don’t see how it could be overturned on appeal.

D.P. v Palm Beach School Board: Stop copping out

In this case the US Department of Justice (DOJ) went on record as believing that Title II of the Americans with Disabilities Act governs the behavior of school districts with regard to disabled students, and that using “school resource officers” to control them violates that law. DOJ issued a “statement of interest” in the case, which is in federal district court in Florida, in June.

The Palm Beach schools have been routinely calling the police to have primary and secondary students with disabilities handcuffed and hauled away for “psychiatric evaluation” in response to behavioral “episodes.” The teachers who made these calls ignored best practices for students like D. P., whose disabilities, such as autism, can affect behavior; they did not try to understand what causes the undesirable behaviors or find less restrictive ways to keep them from occurring.

It’s an old story, repeated in many places across the country. Teachers and school officials have been trying to get out from under federal mandates to educate students with disabilities, including those with behavioral issues, for decades. A common strategy is to get them removed from their classrooms, using tactics ranging from deliberately ignoring early signs of potential behavioral outbursts to actually deliberately triggering them.

This Florida case is of interest to us for two reasons: First, DOJ is asserting that Title II, which governs state and local governments, requires school districts to provide reasonable accommodations to students with disabilities, up to and including truly effective behavioral response plans, instead of calling the cops on them. Second, New York State recently enacted regulations that mostly prohibit the use of physical restraints on disabled students, but include a specific exception for school cops who handcuff them and haul them away (see page 3). The NY State Education Department and Board of Regents should study this case carefully; they are now on notice that this exception is likely a violation of federal law.

The Queen of All Our Hearts

By Maria Dibble

It is with profound sadness that I must report that our newest Controller, Rachel Bartlow McHugh, passed away unexpectedly on June 28, 2023.

Rachel has been a long-time employee of STIC off-and-on from when she was a teenager helping out in our Interpreter Services program. She came back to us as Office Manager, Fiscal Manager, then Fiscal Director and on to her final role of Controller, which was to begin in July. If her name sounds familiar, it's likely because her father Bill Bartlow worked at STIC and passed away last October, and her mother recently retired from STIC after 35 years as our Controller.

Shock waves reverberated through STIC at her sudden passing. Only 51 years old, she had many plans and dreams, and aspirations that guided the direction of her life, now forever denied her, as well as her family, coworkers and friends at STIC.

Her loss has left a gaping hole in the culture of this organization. I can't put into words all that she gave to our agency, to our consumers, even to the stranger on the street. She was extremely generous in spirit and action, and she had a wonderful sense of humor and a contagious laugh.

No STICnic will be quite the same. Rachel approached them as she did everything in life, with humor, perfection and great zeal! I remember her competing with another coworker in a pie eating contest. The week leading up to the picnic she would challenge her coworker to monumental feats of pie eating, assuring him that she'd be the

champ! Well, no matter who won, she was always STIC's champion!

I know she would not want us to shed tears, to mourn overlong or to plunge into grief, but I'm sorry, my friend, all who knew you are grieving, and will likely never truly reconcile your loss to the world. As it often is, cancer was the vile thief that stole you from our lives, but it couldn't steal our memories, and we are sharing some of them in this newsletter. You are probably looking down at us and marveling at "all the fuss", and you are likely thinking, "Hey, this is no biggie." But it is huge! Work just isn't the same without you, and I fear it will never be again.



COMMUNITY HABILITATION EQUITY COALITION

CHEC



EQUITY IS A NECESSITY. INVEST IN THE COMMUNITY HAB WORKFORCE NOW!



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.

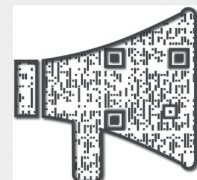
Please Join Us!

CHEC MEETS THE LAST THURSDAY OF EVERY MONTH, 12P, VIA ZOOM AND IN PERSON AT STIC

SOUTHERN TIER INDEPENDENCE CENTER

135 E. Frederick St.
Binghamton, NY
13904

OR JOIN VIA ZOOM



To Rachel with Love

By Maria Dibble

A rift has been torn in the fabric of STIC,
That no seamstress or weaver can mend,
Lost yesterdays seen through the gap,
The memories, the actions, the love,
The dreams of a better tomorrow.
Hope has taken wing and has flown far away,
Carrying her possibilities on its back,
Leaving emptiness and loneliness in its wake,
Promises and dreams ruthlessly stolen,
Depriving the world of her gifts.
Gusts of emotion blow through our souls,
Storms of tears flowing with pain
Sadness and sorrow flooding our senses,
Hours and days drowned by waves of grief.
But she'd want us to rejoice and to live for today,
To learn from her life and the examples she set.
To celebrate her successes with gusto and joy,
To share in the glory that was her life on earth.
So in honor of Rachel
I pledge to move on
With a laugh and a smile,
As she'd wish me to do,
To raise a glass to her life
And all she achieved
And to never forget her
For as long as I live.
Thank you for sharing your life with us, Rachel. It was way too short, but it was quite a ride!



Cheery Bomb

By Lucretia Hesco

In a world full of monotony, Rachel burst onto the scene like a firework, leaving a trail of laughter and vivid memories. Rachel had a fashion sense that was uniquely her own. Her wardrobe was a canvas of bold colors, and daring patterns. Rachel always managed to make a statement, leaving everyone in awe of her fearless style. Rachel had a laugh that could fill a room and charisma that drew people in. She had the uncanny ability to turn the mundane into a hilarious anecdote, making even the dullest moments memorable. Her magnetic presence created such a fun atmosphere, and STIC's hallways seem incredibly empty without her here. Rachel was truly one of those people that are just as beautiful on the inside as they are on the outside. Her willingness to lend an ear, offer advice or share her genuine smile brought people closer together. Rachel embodied a spirit of kindness and generosity that touched the lives of so many. As we say goodbye to Rachel, we remember the countless memories she left behind. Her larger-than-life personality, impeccable style, love for football and unmatched sense of humor will forever be etched in our hearts and the hallways at STIC. Rachel's spirit will continue to inspire us to live life with passion, style and a whole lot of laughter.

Sister-Cousin

By Emillie Stone

I was hired by Rachel almost 9 years ago now. In that time, she became so much more to me than just a manager—she was a mentor, a role model, a friend, and as my husband so eloquently explained to her once, “like a sister-cousin”. If you were fortunate enough to have known her, then you already know all that I’m going to say. That she was the human embodiment of warmth and absolutely, positively lit up the room (pardon the trite phrase, but it’s true). That she was thoughtful and kind, she could (and would) make anyone feel welcome. That she was an amazing story teller; she was so good in fact that often times I found myself thinking that her retelling was probably funnier than the actual event. That she was incredibly knowledgeable; and not just about work related things, I even learned from Rachel how to tell when Easter falls each year. That she had a wonderful sense of humor. That she had impeccable style and taste and man, could she do make-up like nobody’s business.

Losing Rachel has been utterly devastating for me and for so many others who knew and loved her. I don’t believe in stages of grief anymore as it feels more like being caught in a whirlpool of denial, sadness, and anger. I don’t think acceptance will ever materialize for me because I cannot imagine ever accepting that someone so wonderful is no longer here. I hope that you will join me in a campaign to keep Rachel’s spirit alive by acts of simple



kindness: smiling at a stranger, welcoming a new coworker, telling someone their hair looks nice. Find the humor in things and laugh. And just be unabashedly and unapologetically YOU. It's how Rachel lived and I think it's how she would want us to live.

Rachel's Humor

By Sue Ruff

Rachel put up 2 different signs in all the bathroom stalls or walls on soft purple paper. Some of the signs have faded, many have not. But they remind us of her sense of humor.

First:

DON'T FLUSH:

A STOP sign picture on left and a picture of a talking toilet with a megaphone on the right. The list of things to not flush was typed below:

- Tampons
- Maxi Pads
- Paper Towels
- Drug and Alcohol Paraphernalia
- Cellphones (it's easier to just take the call)

- Love Letters
- Food (we have a break room, you don't need to eat in here)
- Purses
- Legos (really any toys)
- Dentures
- Money (STIC takes donations)
- Hopes
- Goldfish (alive or dead)
- Diapers
- Make-up (remember you don't need it—you are beautiful!)
- Jewelry
- Dreams (they can always come true)
- Panty Hose or Knickers
- Your Ex (*Sorry!*)

And the second sign, taped near the toilets, printed in fancy cursive print:

*sprinkles
are for
cupcakes
not for toilet seat
THANK YOU*

Sue was holding a bake sale fundraiser for Southern Tier ADAPT and she writes: I was so honored when Rachel bid up the price of a cake she had no intention of even eating.

It was great support for ADAPT and it got many people involved in the drama of who would win. And it also got others into the kitchen to buy other items that day. That's just how she was, she'd be generous and supportive, while making it so much fun that others couldn't help but join in.

Miss Sue Misses You

By Sue Hoyt

Rachel always called me Miss Sue. I would come in many mornings and she would be walking down the hallway and with a huge smile say, "Good morning Miss Sue!" It would brighten my morning!

No matter the topic, the moment we passed in the hall, or being together at a meeting, I was always greeted with her smile and "Miss Sue." She would say, "Hello Miss Sue." or "Hi Miss Sue."; "So....Miss Sue."; "Guess What Miss Sue?"; "We have a problem Miss Sue!"; "Oh Miss Suuuue..."

I so miss her, I miss her smile, I miss her laugh and humor, and I especially miss hearing "Good Morning Miss Sue."

And yes, I cried while writing this.



STIC NEWS



Forty Years On

By Maria Dibble

STIC held our 40th Anniversary celebration in June, and it was a tremendous success.

In the morning, we had a brunch for invited guests, where STIC was praised and recognized for our achievements over the four decades by a variety of speakers, including Senator Lea Webb. We had proclamations from Assembly Members Donna Lupardo and Joseph Angelino from the NYS Legislature, declaring a special day in our name and acknowledging our many accomplishments. Other speakers included Lindsay Miller, Executive Director of the New York Association on Independent Living (of which STIC is an active member), current Board President Charles Kramer, and former Board member Karl Wokan.

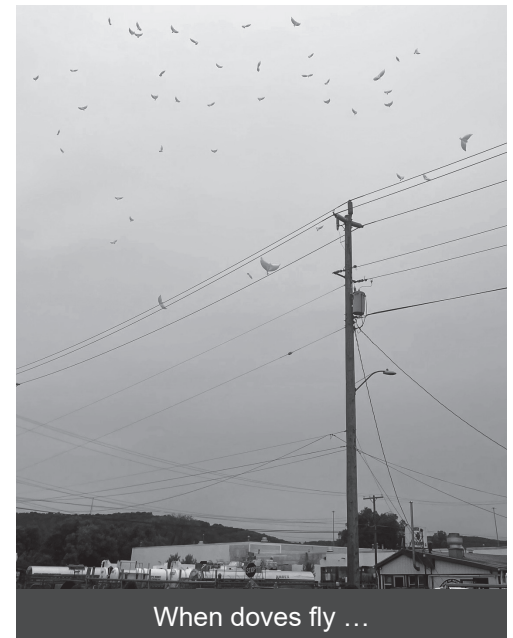
At the brunch, I announced my retirement from STIC at the end of this year, and in-

troduced Jennifer Watson (current Assistant Director) as my replacement.

Once the speeches and announcements were done, we released 40 biodegradable dove balloons into the air, symbolizing freedom and independence, two of the pillars of our philosophy. One of the balloons landed on a wire, hesitated and then took off again, almost like a real bird. It was quite a lot of fun and a fitting finale for the morning ceremonies.

In the afternoon we were open to the public, with many displays, food, games and activities, as well as live music by RnR.

Many old and new friends dropped by to congratulate us on achieving 40 years and for all of the successes we've had over this period of time. People remembered rallies in support of issues like the ADA, demonstrations in Albany to protest homecare cuts and urge the establishment of the Consumer Directed Personal Assistance



When doves fly ...

Program, marches down Court Street as Barrier Busters to demand curb cuts and accessibility, and so much more. Visitors spoke warmly of STIC, thanked us for the assistance we'd provided to them and/or their families, and for being here when they needed us. It was a very moving day, as a steady crowd of people came through our



Jennifer Watson and Maria Dibble accept donations

doors all afternoon, until sadly, the memorable day came to an end. My thanks go out to all who stopped by, or called or emailed their well-wishes, and for helping to make STIC the organization we've become.

Let's Get to Work!

By Hannah Hickox

Despite unemployment rates returning to pre-COVID levels this summer, there are still over 384,000 New Yorkers who are unemployed and looking for work. For those with disabilities, the unemployment rate in NY is still TRIPLE that of the general population. STIC has been assisting the residents of Broome, Tioga, and Chenango counties to achieve their goals of obtaining meaningful employment for nearly 30 years. We provide supported employment services to people with disabilities under contract with the New York State Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) and the Office for People with Developmental Disabilities (OPWDD). By means of these funding sources anyone with a disability such as a mental illness, visual or hearing impairment, intellectual, developmental or other related disability may be eligible to receive supported employment services at STIC. STIC currently offers three unique employment programs designed to meet the needs of anyone, regardless of how much prior work experience they have. Beginning in 2024, STIC will launch a fourth employment services program.

OPWDD Programs offered at STIC

Through the Office for People with Developmental Disabilities (OPWDD), STIC offers an Employment Training Program (ETP), Community Based Pre-Vocational Services and Extended Supported Employment ("SEMP") services.

The Employment Training Program is a time-limited form of intensive support that is designed for individuals who are ready to work, but have limited experience or who are unsure about what kind of work they would like to do. In this program, participants will begin with an interactive assessment period. Then a participant will be assisted to negotiate a paid internship with an employer where they can learn and gain experience. Typically, these internships are 6-12 months. During the internship, the participant's wages are paid by the state funding source, not the employer. In exchange, employers agree to hire the participant as a regular employee upon successful completion of the internship period and benefit greatly from hiring someone who is already trained and have experience in the position.

The Extended Supported Employment program is designed to support individuals who are already working to maintain their employment long term and/or advance their career. The service is focused on supporting continual skill and career development. On and off-site coaching services provided at least twice per month are combined with periodic work performance evaluations to help participants be successful in maintaining long term employment. Extended employment services may remain in place for as long as a person wishes to receive them.

The Community Based Pre-Vocational Services program is STIC's newest program, launching in early 2024. This program is designed to help individuals who are interested in working someday. Community Based Pre-Vocational services will provide participants with the opportunity to explore their interests and develop the necessary skills to enter the competitive workforce. A combination of classroom-style learning and hands on work experiences in the community allows participants to develop skills like taking direction, effective communication, professionalism, time management and more, all while finding out first-hand what kinds of work they enjoy and what accommodations they may require.

ACCES-VR Services offered at STIC

STIC offers Intensive Supported Employ-

ment and Extended Supported Employment services through ACCES-VR.

The Intensive Supported Employment program is designed to support individuals who are ready to enter the competitive workforce and need support to obtain, maintain, or advance in a job. Participants can receive services both on and off the worksite that will focus on interviewing skills, resume building, increasing work skills and independence, facilitating relationships, and developing natural supports in the workplace. The primary goal for Intensive Supported Employment is to help participants become stable in a job for at least 90 days.

The Extended Supported Employment program is designed to support individuals who are stable in their positions and who are looking to maintain or advance in their careers. Similar to the OPWDD Extended service, participants will receive on and off-site coaching at least twice per month combined with monthly check-ins with their direct supervisor. Participants may remain in extended services for as long as they feel the need to receive these supports to successfully maintain their long-term employment.



STIC is now accepting new referrals in all four programs. To learn more, visit our website: www.stic-cil.org, or contact STIC's Employment Director, Hannah Hickox, by phone at 607-742-2111 ext. 228 or by email at hannahh@stic-cil.org.

STIC is hiring! If you are a human services professional looking for a career in providing employment services, check out our posting on Indeed or visit our website for more details. Send your resume to apply@stic-cil.org.

Xscapes Bucks Holiday Gifts

By Todd Fedyshyn

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. It's the gift that keeps on giving, while supporting STIC's mission in our community and the individuals we serve.

To purchase, please call (607) 760-3322 or email info@xscapes-stic.com. Xscapes

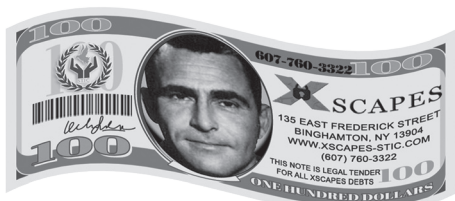
bucks come with a holiday certificate. This will be mailed to you, or your family as requested during your purchase.

Xscapes is also a great team building option for your business associates. We also often see school functions or camp outings use Xscapes for amazing community outings. 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 and food you can bring with you to make your overall experience spectacular here at Xscapes.

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

We also 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.



Hunger Games

By Sue Ruff

“Need food stamps in New York? Come back in a few months. Counties across the state are blowing past deadlines to process SNAP applications, documents show.”

The May 21 headline from the Albany *Times-Union* and New York Focus told the story of the long delays for tens of thousands of New Yorkers, who have had SNAP benefits delayed for months past the federal requirement of 30 days. A temporary boost to SNAP benefits put in place during the COVID-19 pandemic, known as emergency allotments, ended nationwide after February, 2023. “In December of last year, the latest month for which New York Focus has data, the state’s 57 county social services offices outside New York City were illegally late in processing more than 11,000 food stamp claims — or one out of three open applications.” Each county administers their own process and there have been severe shortages of workers at many

DSS offices. This results in large backloads of applications. Applicants come because they have lost jobs, have medical or other debts piling up, or are trying to pay increasing rent and transportation costs. Many want to make sure their children aren’t hungry. Nearly 63% of applicants in Broome County wait past the 30 day limit, according to the *Times-Union* article. That’s the second highest “wait rate” in the state. County DSS offices with reduced staff also have to handle Medicaid renewals.

Applications are hard to do, especially for those who have trouble with reading and writing. At the Family Enrichment Network in Johnson City, a Nutrition and Outreach Education Program (NOEP) worker helps people with the applications. Their website says, “SNAP is our nation’s first line of defense against hunger – stretching the monthly food budgets of all who meet program guidelines.” This is a very busy worker, we have heard.

<https://familyenrichment.org/nutrition-outreach-education-program-pg.html>

What do you do if you aren’t eligible for SNAP because you make a little too much money, but struggle due to the other costs of living and taking care of a family? What do you do if you need food that is low-

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sugar, low-salt, or dairy or gluten free? You have lost your apartment and have no refrigerator or stove or microwave? You need transportation assistance? We hear about a range of barriers.

The Food Bank of the Southern Tier and the Broome County Food Council report that the numbers of people who come to various food sites has never been higher. To help people access food, they partnered with Binghamton University’s Geography Department to create an online site that locates food pantries, free meals, and other resources. Here is their link to their food map, a video locator, and a printable list of food access sites and times.


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

Their site will be updated as we move into fall.

The Broome County Public Library, Friends of the Broome County Public Library, the Rural Health Network and CHOW have created a produce pantry for the community. One can find fresh fruits and vegetables here at 185 Court Street. The food is free.

EMERGENCY FOOD

ACCESS MAP





<https://bit.ly/BC-EFAM>



This newsletter is also available online, at:
<https://stic-cil.org/index.php/accessibility/>

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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.

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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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