



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

AccessAbility

Summer 2023
Number 151

So Long, Wild Bill

By Maria Dibble



This newsletter issue is dedicated to the memory of William Bartlow, former employee at STIC, co-founder of our “Haunted Halls of Horror” and subsequently of our Xscapes rooms.

Bill began working at STIC in April of 2010 as a Direct Service Professional, in our Community Habilitation program. The consumers loved working with him and were quite sad when he was promoted to become STIC’s Development Director. He retired on August 31, 2020, though he kept his hand in on some of the Xscapes research even after he left. He was the inspirational force behind the development of our fundraising activities. Driven by a keen intellect, the possession of decades of accrued knowledge (some very obscure) and an ever-present sense of humor, his ideas were ambitious, well-researched and very entertaining.

One day Bill and Todd Fedyshyn came to me with what they thought was a fantastic idea. They said that STIC could put much of its unused space on the lower floor to work earning us money by creating a haunted house, later to be known as the “Haunted Halls of Horror”. Honestly, I thought they were joking at first, because it was, as ideas go, pretty out there for STIC. Bill and Todd had excellent pow-

INSIDE	
Wages of Sin	3
More Money, More Problems .	4
Mental Health: A New Era, or New Errors?	6
Comptroller Slams OPWDD Oversight of Group Homes	7
The Tree of Life	8
Make ‘Em Pay!	8
Courts Watch	9
Bill & Todd’s Excellent Adventure	11
In Memoriam: Judy Heumann	12
Sally Johnston	13
Put on Your Ruby Anniversary Slippers	13
CHEC It Out!	14
Coming Unwound.....	14
Mad Science	15
Don’t Get Scammed	15

ers of persuasion, eventually convincing me to let them go forward with it. They pooled their resources, both having extensive collections of Halloween-related stuff, then built walls and designed the whole maze of attractions themselves. The event was quite successful thanks to their creative, off-the-wall thinking and their love of Halloween.

When we had to stop hosting the event for insurance reasons, Bill and Todd didn’t give up. They had another great idea: What if we used the former Halloween space to create escape rooms? Of course at the time I knew nothing about this new and growing fundraiser, but they educated

AccessAbility

June 2023

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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

Our address is:

AccessAbility

Southern Tier Independence Center

135 E. Frederick Street

Binghamton, NY 13904

Subscriptions

Subscriptions are \$10 per year (4 issues). Subscriptions are voluntary, but very much needed to help cover newsletter production costs. Use the form on the back to subscribe.

Advertisements

AccessAbility prints unclassified ads free for disabled consumers, unless they promote a for-profit business. For-profit businesses can advertise in *AccessAbility*, in Un-classifieds or a display ad, at our regular rates. Ask the editor for information.

Reprints

Any *non-copyrighted* information *originating* in this newsletter may be reprinted without permission. If you want to reprint an article or opinion piece, please credit *AccessAbility* and the author.

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.

and also, I confess, intrigued me because I love fantasy, puzzles, quests and the like. Bill and Todd put their heads together to create another hit for STIC. One has only to walk through our first Xscapes room, "Valley of the Kings", to see evidence of the time, effort and creativity that went into their planning and development. Beautifully choreographed, with innovative and imaginative themes, puzzles and tasks, and Hollywood-quality visuals, it is an immersive adventure that challenges explorers to discover the secrets of the Pharaoh's tomb, and to escape before the time limit expires.

Bill was never happier than when he was researching material for a new Xscapes endeavor, delving deeply into issues, developing sometimes subtle, quite difficult puzzles, urging people to think outside-the-box to find the solutions.

He especially enjoyed working on the "Rod Serling Experience", STIC's Xscapes tribute to the original *Twilight Zone* TV series, I think in part because it allowed him to draw upon his love and enjoyment of Halloween, and some of Serling's stories touching upon the darker sides of people.

As I write this article, I fondly remember our planning meetings for the Haunted Halls of Horror and Xscapes. We laughed a lot, much of it due to Bill's humorous view on things. We brainstormed great ideas, and we worked out the kinks in the events, all while having lots of fun. I used to sometimes feel guilty about just how much fun it was, but Bill taught me that enjoying your work is a good thing, a way to gain strength for the harder times that will inevitably come. We took some outrageous ideas and made them a reality.

I knew Bill long before he started working for STIC, since he was the husband of our then bookkeeper and now Comptroller, Paula Bartlow. I've never forgotten a time when I visited them in their home. We went into the basement and some of us were playing darts. I wanted to try hitting the target (I'm totally blind for those who don't know) and Bill, to be helpful, tapped on it so I'd know where to aim. He didn't move away fast enough and I almost clipped him with the dart. I didn't

though, and we all laughed uproariously, though Bill was more cautious after that.

Bill had his serious side as well. He was a navy veteran, telling us of many experiences he had when posted in Iceland. He abhorred scammers, hating to see people taken advantage of due to their own limitations. He often dug deep into issues to find the truth about a product, service or claim. He was intolerant of those who tried to prey on others, and willingly spoke out against any wrongs he perceived. He absolutely hated what became known as "fake news", always digging for the facts and striving for the truth.

Bill was a complex person, as are all human beings. He could be funny, serious, intellectual and even profound, but perhaps his most defining characteristics were his deep devotion and love for his wife and three children. Nothing could get between him and his family. They treasured their time with him, loving and adoring him as much as he did them. His sudden death on October 6, 2022, was a terrible blow to everyone who knew him, especially his wife and children. No words can soften the grief and sorrow they feel, and I waited a bit before formally memorializing Bill, but I wanted everyone to know what a wonderful father, husband, coworker and friend he was, in addition to being an advocate and a patriot. His memories live in all of those who knew him, thus keeping his spirit alive, still able to touch others with his warmth and personality.

We are dedicating our latest Xscapes room, "Last Pharaoh Standing", to Bill, for it was his inspiration and research that started the creative process behind this last contribution to STIC. It is the sequel to "Valley of the Kings" and is our most progressive and technologically advanced effort to date. It is a grateful tribute to all Bill did for STIC, and to his inspiration, creativity and joyful participation in the development of our agency. We are honored to have known him and thankful that we were a part of his life and he part of ours.



Dedication

Thank you, Bill, for bringing laughter into our lives, for sharing your knowledge and creativity, and for being the kind, caring, thoughtful human being that you were.

William Bartlow

January 31, 1949 –
October 6, 2022

Like a star burning brightly
in the sky,
You brought light and joy
into our lives,
You showed us how to
treasure every moment,
And how to embrace
the chance to learn.
Your love and devotion
to your family
Is beyond the scope of words,
Blazing in their hearts
and minds,
Your light will never dim.
Shining like a beacon
from above,
You touch all who knew
and cared for you,
Timeless memories of
love and friendship,
Forever etched on
our hearts and souls.

— Maria Dibble

Wages of Sin

Most of the harm that Governor Hochul tried to do to homecare in this year's budget process (see *AccessAbility* Spring 2023) was averted, but she and the legislature agreed to changes that will make the worker shortage worse.

Hochul wanted to gradually reduce the difference between the homecare and general minimum wages so that homecare would again become a minimum-wage job. That would have restored the competitive advantage that such jobs, which are easier than providing homecare, had before the historic changes that were made in April 2022.

Advocates pushed extremely hard to stop this and were told they had strong support from most members of the NYS Senate and Assembly. In the end, our legislators preserved the principle that homecare must not be a minimum-wage job. But they capped the differential at \$3/hour, and delayed its rise to that amount for seven years.

Here's what we have now, in upstate NY:

The current homecare minimum wage is \$16.20/hour and the general minimum is \$14.20/hour.

The previously-enacted October 2023 \$1/hour increase for homecare workers is cancelled. Instead, on January 1, 2024, the general minimum will be \$15/hour, and the homecare minimum \$17.55/hour, instead of \$18 as it would have been. In January 2025, the general wage will be \$15.50, the homecare wage \$18.10, with a differential of \$2.60. In January 2026, the general minimum goes to \$16.00, and the personal care minimum to \$18.65, with a differential of \$2.65.

Thereafter, beginning in 2027, both wages will increase annually by a percentage related to the federal Consumer Price Index, but the difference between the general minimum wage and the homecare minimum wage will be capped at \$3/hour when it gets to that point around 2030 or so.

Weeds Alert: The feds don't have just one Consumer Price Index (CPI). NY will use the "CPI-W", which is the "non-seasonally adjusted consumer price index for northeast region urban wage earners and clerical workers," as calculated annually for August through July. It will average the last three CPI-W numbers, and then multiply that percentage by the current minimum wage, and add in the result to make the new annual minimum wage. This will start in January 2027, meaning the last couple of years of high inflation will not be included in the calculation. If we suppose that by that time the averaged CPI-W is 3.4%, then in 2027, the general minimum would go up to \$16.54, the homecare minimum would be \$19.28, and the difference would be \$2.74.

Downstate wages will follow the same pattern, though they will start at a higher number. While the details aren't clear, it seems that most of Hochul's original proposal to adjust the "wage parity" rules was retained. "Wage parity" was a way to enable non-unionized homecare providers to compete in the homecare labor pool with unionized providers, which are plentiful in that region but not upstate. This may mean that non-union downstate homecare workers will get a pay cut, which would drive many of them into other jobs.

It's tempting to say, "That's not so bad; it could have been a lot worse." The second part of that sentence is certainly true. But it's still pretty bad, because what we got a year ago—a homecare minimum wage \$3 above the general minimum—wasn't nearly enough to make a serious dent in the homecare crisis. We can't emphasize strongly enough: Providing homecare is hard work. Not only does it often involve heavy lifting that can cause injuries, but it includes cleaning up things that many people would find pretty unpleasant. On top of that, it requires a great deal of patience, excellent communication skills, and the ability to cheerfully manage difficult behavior from people whose dis-

abilities, such as dementia, traumatic brain injury, and some developmental and mental health disabilities, cause that. It can also be very emotionally draining. The compensation required to recruit people to do this work needs to be closer to 150% of the general minimum wage, as called for in the Fair Pay for Homecare bill which our elected leaders again refused to pass this year. So these changes will increase the homecare shortage, not decrease it.

We were told that most of our legislators strongly supported our issues, and that many of them were working for Fair Pay for Homecare. So how did we end up losing? Two reasons:

First, the big downstate healthcare workers union, “Local 1199”, saw the parity changes as a way to improve their standing, by creating an incentive for more homecare workers to join the union. They signed on to this compromise, and their big lobbying budget has a lot of influence among legislators, especially downstate, including the Senate Majority Leader, Andrea Stewart Cousins, and the Assembly Speaker, Carl Heastie.

Second, rank-and-file legislators seem to be unreasonably terrified of their leadership. If what we were told was true, there were several dozen Fair Pay supporters, and even more people who wanted to keep the \$3/hour differential, in both houses of the legislature. If they had refused to vote for the final budget, we would have lost nothing. Neither Stewart Cousins nor Heastie could have punished all of them, or even most of them, by taking away choice committee assignments or cutting their office budgets, without completely destroying the structure of the legislature. So they wouldn’t have done it, even if they threatened to. Instead, they would have renegotiated the deal to preserve, at least, the \$3 differential, and maybe, over time, added a phased approach to reach that 150% figure. So either we were lied to about the level of support we actually had, or our legislators have no backbones at all. As long as either of those things remains true, we will never win this battle, and advocates will need to look for different strategies.

More Money, More Problems

The final 2023-24 New York State budget is a mixed bag for people with disabilities. The big story, of course, was Hochul’s successful attempt to cut the previously-established growth in the minimum wage for homecare workers (see page 3). Her billion-dollar expansion of mental health services got through largely intact (see page 6). Here are some other notable wins:

Medicaid Buy-In Expansion: We described the Buy-In program in *AccessAbility* Winter 2022-23. It enables people with disabilities to have good jobs with good wages and still get Medicaid to maintain essential long-term services and supports such as homecare. Only people who are rich, or at least have very high salaries, can afford to pay out-of-pocket for homecare for a full lifetime. Medicare does not cover that kind of service; its limited “home health aide” option is not for people who work outside the home or need more than a few hours of service per day. There is no such thing as a standard private health insurance plan, whether employer-provided or purchased through ObamaCare, that covers more than temporary post-acute homecare. Private long-term care insurance is extremely expensive, and the homecare benefit is time-limited, usually no more than a couple of years. There is literally no way for a person who has significant permanent disabilities and is not wealthy to get permanent homecare except via Medicaid. However, under current NY rules, the person must stop working at age 65 and return to poverty in order to keep Medicaid, because the Buy-In has an outdated definition of “working age.” Also, its maximum income of about \$69,000 per year isn’t really enough to support a family, become a homeowner, and save for a comfortable retirement. These problems will be corrected by the 23-24 budget. There will no longer be an age limit for the Buy-In, and the maximum income for a single adult will be \$300,000, with a similar increase in the limit on “resources” or assets. For the first time, people with incomes above 250% of the federal poverty level will have to

pay premiums for Medicaid coverage, but they are capped at no more than 8.5% of income. Also, participants will have to work at least 10 hours per month (up from one hour) to qualify. All this requires federal approval, so it’s not scheduled to take effect before January 1, 2025.

CDPA FIs Remain Stable: Hochul’s attempt to wipe out last year’s agreement to maintain the status quo on the number of Consumer Directed Personal Assistance program Fiscal Intermediaries (like STIC) was rejected by the legislature. This is another big win.

Access to Home: After many, many years of advocacy with no change, the 23-24 budget increases annual funding for this program from \$1 million to \$3 million. This program is used to pay for home modifications for people with disabilities who can’t afford expensive things like ramps or bathroom remodels, and for whom no other source of funding is available. \$1 million doesn’t go very far when a ramp costs \$10,000 or an accessible bathroom is \$25,000. \$3 million will certainly improve the situation, but it’s still not enough to meet the need.

Developmental Disabilities Advocacy and Assistance Program: The budget contains \$2 million to establish a new program to help people with developmental disabilities navigate OPWDD’s complex system and address unfair decisions by that agency and its subcontractors.

These items aren’t exactly what we wanted, but they have some potential benefits:

Managed Care Reform: Hochul’s plan to force all Medicaid managed care plans to rebid their contracts, with extra points for plans that have fewer homecare providers in their networks, was rejected. However, the final budget includes a moratorium on setting up new or expanded plans through March 31, 2027. Meanwhile, plans will be “required to meet certain performance standards” and those deemed “poor performers” by CMS, or which “have an excessive volume of penalties, deficiencies, sanctions or enforcement actions” won’t be eligible for new contracts after that date. We don’t know how many plans might get the axe under these rules, but DOH rarely sanc-

tions plans or enforces their contracts, so this may not be very helpful.

More Information on Managed Care Homecare Wages: There is a dispute as to whether managed care plans are refusing to raise rates for homecare services enough to pay for the higher minimum wage. We at STIC have settled with all the plans we deal with, and our new rates will cover those wages through the end of 2023. We did it by refusing to sign contracts that did not have adequate rates. Most plans certainly did not want to pass along a reasonable portion of their new higher rates to us at first, and had we not held tough (and in one case, threatened a lawsuit) they would not have done so. Many CDPA providers say they still aren't getting adequate rates. We don't know if the plans have really dug in on this or the providers just don't know how to negotiate. More importantly, neither do Hochul or the legislature. The plans have told the NY State Department of Health (DOH) that they pay providers enough to cover the wage increases. The Fair Pay for Homecare bill, which did not pass, would have resolved this issue by requiring direct payments to providers to ensure the wages were paid for, rather than giving the plans discretion on how much to pass on. Instead, Hochul and legislators agreed to "authorize" DOH to require information from both managed care plans and homecare providers on the rates they get and what they pay out, on penalty of fines for late compliance and perjury charges for filing false information. This data won't be made public but DOH must, if it requests the information, send an annual report to the governor and legislature summarizing what it receives. The key term here is "authorized"; DOH is not actually ordered to do this, and may choose not to rather than compile a report that makes managed care plans look even worse than they already do.

COLA: Hochul had proposed a 2.5% cost of living adjustment (COLA) for non-profit providers of "mental hygiene" services (those funded by the Office of People with Developmental Disabilities (OPWDD), the Office of Mental Health (OMH), and the Office of Addiction Services and Supports (OASAS)). Advocates

fought for 8.5%. The compromise figure is 4%, which isn't far below the current projected annual inflation rate. This will help, but it won't all go into higher wages because inflation has increased all of the costs of running those programs, and it won't solve the shortage of Direct Service Professionals (DSPs) in community habilitation programs. It also doesn't affect homecare/personal care/CDPA.

Prescriber Prevails: This perennial greatest hit among NY governors—eliminating the right of those who prescribe medications to have the final say in disputes with Medicaid over coverage of specific medications—was again rejected by the legislature.

"Essential Plan" Expansion: NY's "Essential Plan", a basic health insurance plan funded by Medicaid for people who don't meet the income eligibility requirements for full Medicaid, will have its maximum income limit increased from 200% to 250% of the federal poverty level (this requires federal approval, for which DOH applied in May). A planned expansion to cover undocumented immigrants age 65 and over was delayed to January 2024. Advocates wanted all undocumented immigrants covered. STIC supports health benefits for all documented immigrants who are income-eligible, but we oppose them for people who refuse to get on the record (be "documented") with their requests to come here to work, for asylum or as refugees.

On the downside:

Low-Income Housing: Hochul's ambitious plan to build 800,000 new housing units over ten years was again rejected by the legislature (see *AccessAbility* Spring 2022 for her first try). The plan combined direct funding for support infrastructure like water and sewer lines, tax incentives for housing developers, and targets for adding new units for people with low incomes in most communities across the state. Why did this happen? Legislators representing white middle-class communities didn't want poor people of color living among them. That's not what they said, of course; they talked about "local control" and said they didn't have adequate infrastructure, such as water and

sewer lines, to support higher population density. The latter claim is clear evidence that their motives were bigotry and hatred, because Hochul's plan would have paid for that stuff and the legislators knew it. When people are homeless, even if they start out with no mental health disabilities, the resulting misery and stress are likely to create them. A major increase in housing for low-income people is an essential step in solving NY's mental health crisis. Even if passed, Hochul's plan, which relied on incentives rather than direct funding to get units built, probably wouldn't have achieved all of its goals, but it should have been given a chance.

Nursing Facilities: These institutions have been complaining for years that they are underpaid and can't afford to hire enough staff to keep residents safe. The 23-24 budget gives them a 6.5% increase in their Medicaid rates. This despite the fact that many nursing facility operators use shell companies to skim profits out of Medicaid and transfer them to their own pockets. In 2022 NYS Attorney General Letitia James sued at least three nursing facility operators for doing exactly that. According to Richard Mollot, a nationally-known advocate for residents of nursing facilities, when the facilities sued NY over a Cuomo-era law requiring them either to spend more on direct patient care or return funds to the state, their own court papers showed they would have been required to return \$510 million in 2019—enough to hire 5600 full-time registered nurses.

Interstate Credentials: An effort to allow doctors and nurses who are licensed in other states to quickly be approved to provide services in New York was rejected. This could have helped increase access in border areas that have critical shortages of providers such as psychiatrists.

Independent Living Centers: ILCs, like STIC, did not receive an increase in funding for our general operating grants, even though inflation affects us like everyone else; a failure to keep up with inflation in our funding means our funding was, in fact, cut.

Mental Health: A New Era, or New Errors?

Most of Hochul’s budget proposals to improve services for people with mental health disabilities were passed in April. But even before that, New York City Mayor Eric Adams seemed to have a change of heart concerning his plan to have police round up people who didn’t appear to be taking good care of themselves and force them into hospitals for treatment.

We don’t know how much of that round-up actually took place. An editorial in the *New York Daily News*, published on February 21, 2023, and written by a former community mental health worker who opposed Adams’ plan, described the November 2022 plan as something that Adams was “now seeking” to carry out; it did not describe any roundups actually happening. Neither the police who were supposed to do it, nor the hospitals that were supposed to receive the people, wanted this, and there was massive opposition and very bad press for the Mayor. Adams is sensitive to public relations. The negative media barrage may have led to his about-face.

On March 2, 2023 he announced a new mental health “agenda” that was heavy on community-based supports and services and light on coercion. His proposed initiatives included adding more intensive mobile treatment teams to serve an additional 800 people, expanding a pilot project called B-HEARD that sends mental health professionals instead of police to respond to people in crisis, and building out more mental health “clubhouses.” Also included was a plan to build 8000 new units of permanent supportive housing for people with “serious mental illness.”

Intensive Mobile Treatment is a good model as long as it proceeds on ACT principals (voluntary Assertive Community Treatment), and more permanent supportive housing is also good if it is “low-threshold”—that is, does not require residents to be “sober” or in treatment, or to accept any supports other than rent

subsidies. But we don’t know how these programs will operate.

“Clubhouses” are segregated day programs for people with mental health disabilities, and we are not impressed with this proposal. Walk-in services that can instantly connect people with housing and ongoing supports are what people in crisis need. And when the crisis is resolved, integrated community-based ongoing follow-along services, and help getting jobs, are what people need. Anything a clubhouse can do, good follow-along programs can do better.

B-HEARD (Behavioral Health Emergency Assistance Response Division) is a promising way to get the police out of the business of responding to mental health crises. When allowed to work as it should, and send in peers and professionals with skills in helping people in a calm and friendly manner, it reduces injuries and deaths, and can persuade people to accept effective treatment. However, it rarely operates properly. It relies on 911 operators to decide whether to divert callers to B-HEARD or just call the cops. Operators are supposed to call the police if they think there is a “potential for violence” in the situation. As a result, in the pilot program, over 75% of the time the operator called the police. This is almost the exact opposite of what was supposed to happen—70% of calls being diverted to B-HEARD. This is likely a training problem among the operators, possibly made worse by bigotry or racism when people calling for help are very upset or angry, or don’t sound white. But many times B-HEARD teams couldn’t come when called, so the operator had to call the police instead. That’s due to underfunding; there just aren’t enough teams to meet the need. So overall, only about 16% of crisis calls got diverted.

There’s no question that if B-HEARD could operate at full capacity in concert with well-trained, conscientious 911 (or,

now, 988) operators, it could dramatically increase successful and safe outcomes for people with mental health disabilities in crisis. Adams’ plan to beef up this service would therefore be very welcome, as long as it’s done correctly.

As for what Hochul got done in the budget: We described her plan in detail last time, so we won’t repeat that here. The plan featured expanded community-based services and supports, including more C-PEPs, mobile and ACT teams, intensive post-release follow-along services, and supportive housing, for people with mental health disabilities in the New York City area, with some expansions for the rest of the state. It appears that just about everything she asked for was funded, and that’s very good news, but we still don’t know where the upstate money will go.

There is also an expanded requirement for commercial health insurance that covers inpatient mental health treatment to pay for some types of community-based services. These include mobile crisis intervention, ACT, and critical-time intervention services (CTI). The new law says these services must be covered not only for people who are currently experiencing a crisis or at risk of hospitalization, but for those who are not expected to be able to “manage their primarily psychiatric or substance use related symptoms without de-escalation or intervention.”

Hochul doesn’t seem to have gotten her plan to fine general hospitals \$2000 per day for every day that they don’t reopen mental health beds that were closed during the pandemic. The biggest reason is the ongoing shortage of qualified medical workers, including nurses and aides. Hochul wanted 850 beds reopened more or less immediately; the best projections estimate that about 500 will be back online by the end of this year.

As soon as we find out how all this will shake out in our part of the state, we’ll let you know.

Comptroller Slams OPWDD Oversight of Group Homes

NY State Comptroller Thomas DiNapoli generated lots of press coverage in April with his audit of the COVID-19 pandemic response of the state's Office of People with Developmental Disabilities (OPWDD). He accused the agency of issuing pandemic guidance only to eight state-operated ICFs (Intermediate Care Facilities), and not to over 6900 other group homes operated or funded by OPWDD. He also accused OPWDD of refusing to cooperate with his audit.

The audit came in the wake of revelations that Americans with developmental disabilities who lived in group homes died of COVID at a much higher rate than those who lived in ordinary homes (*AccessAbility* Winter 2022-23), and that OPWDD group homes, unlike nursing facilities, were not prioritized to receive PPE during the pandemic (*AccessAbility* Fall 2021).

There followed a public urination match between OPWDD and the Comptroller over the report. OPWDD claims its "uncooperative" behavior was primarily because the agency was scrambling to respond to the pandemic and it prioritized those efforts over the Comptroller's requests and cited the difficulty of developing "custom reports" demanded by the Comptroller. The Comptroller's Office responded that they told OPWDD to provide whatever standard reports they already had that matched at least some of what they were requesting.

The Comptroller's criticism concerning guidance issued only to eight state-operated ICFs refers to a single document (called an "annex") that OPWDD generated to comply with a specific regulation governing the operation of its own ICFs. OPWDD claimed that this document was derived from, and summarized, many earlier documents that had been sent to all group homes. The report lacks evidence that the facilities that did not receive the "annex" did not get the

same information from OPWDD in other forms. The Comptroller responded that it still would have been "helpful" for other facilities to have all of this information in one centralized place.

The Comptroller criticized OPWDD for not having pandemic-specific guidance already available prior to March 2020, in part because the federal Center for Disease Control had advised "community administrators who serve vulnerable populations" in 2017 to plan for such events. OPWDD responded that its plans covered various emergencies, including "hypothetical" pandemics, but that the COVID-19 pandemic "presented many unparalleled circumstances that could not have been reasonably foreseen." In turn, the Comptroller accused OPWDD officials of being "defensive" and failing to "acknowledge a potential lesson learned."

The report creates the impression that bad blood was generated between OPWDD employees and the Comptroller's auditors early in the audit process, and the situation deteriorated from there. We can well imagine that OPWDD's people, drowning in cases of illness and death while facing unprecedented staff shortages, felt harried and harassed by auditors demanding information.

As a result, this report fails to effectively inform the public about what really happened in the group homes operated and funded by OPWDD during the pandemic. Its focus on the argument that developed between the two agencies (17 out of its 42 pages) obscures the issues.

The Comptroller's press release stated that "DiNapoli's audit found OPWDD did not provide consistent guidance to some 6,929 group homes across the state during the first wave of the deadly pandemic." The media took this to mean that OPWDD had exhibited a bizarre level of favoritism toward its own facilities while seriously neglecting its responsibilities to the other facilities under its supervision. In fact, the audit did not really find out anything about 6,929 group homes. The auditors visited only 16 group homes, which were not chosen as a statistically valid random sample. The report itself states, "The results from our review of selected homes were not, and cannot be,

projected to the entire population of OPWDD-certified homes."

That doesn't mean OPWDD should be let off the hook for its performance. The agency's claim that the events of 2020-2022 could not have been predicted is bogus. Public health experts had been predicting for decades the likelihood of a devastating pandemic. The CDC designed a scenario in 2017 that eerily described most of what happened with COVID, and urged, at the time, that serious planning for a pandemic should immediately be undertaken by all health-related service providers. In fact, the outlines of the COVID pandemic pretty well followed the events of the 1918 influenza pandemic, an event which has been well-studied for over 100 years. Anyone who took a serious interest in this topic could have predicted most of what happened in 2020 and beyond. In fact, they did. It's the politicians and public health administrators who didn't take a serious interest—and that was a fundamental and reckless failure to do their jobs.

However, given OPWDD's dependence on segregated congregate residential settings, it's unlikely that much could have been done to reduce the infection and death rate. The most important lesson that needs to be learned here is simply this: When there's a virulent and deadly disease on the march, congregate settings become death traps. OPWDD could have quadrupled its pay rates for DSPs and there would not have been enough of them to keep people safe in those conditions, because so many of them would have themselves become ill and/or died. They could have had a three-year stockpile of PPE and it would have made no difference.

What we as a society have to understand is that we have backed ourselves into a corner with our reliance on institutional settings—even small ones—to support the people who are most vulnerable to infectious disease, those who are elderly and/or have disabilities. The good news is, we can fix this. It's not like we haven't made these kinds of mistakes before. We learned, for example, in the mid-20th century that air pollution was sickening and

killing people at an accelerating rate, and we took measures to reverse course and clean up the atmosphere. This is what we have to do with housing for people with disabilities. We have to shut down these congregate settings and provide supports for people to live in their own homes. If we do that, I guarantee that when the next pandemic comes—and it will—

fewer of them will die even though their disabilities and related health conditions put them at higher risk. And if we as a society don't cynically throw up our hands and write them off because of that higher risk, as we did this time, there will also be a fantastic side-effect: they'll be able to live better lives.

Make 'Em Pay!

This spring the Biden Administration announced that it wants to change several Medicaid rules in order to address problems that people have with getting a broad range of Medicaid services.

Two "Notices of Proposed Rule-Making" (NoPRMs) were issued by CMS, the federal Centers for Medicare and Medicaid Services. One mostly addresses Medicaid "fee for service" programs, and the other mostly concerns Medicaid managed care. Both primarily are aimed at states' failure to ensure that the rates paid to providers of Medicaid services are "sufficient to enlist enough providers so that [Medicaid] ...services are available ... at least to the extent that such care and services are available to the general population in the geographic area," a legal requirement codified at section 1902(a)(30)(A) of the Social Security Act.

As we've reported (*AccessAbility* Spring and Summer 2015), nearly a decade ago some US Supreme Court decisions made it impossible for Medicaid service recipients or providers to sue states under that rule in order to force them to pay adequate rates. Instead, the Supremes said it was up to CMS to develop its own enforcement measures. That's what CMS wants to do now.

There are a lot of details in these proposals, and they don't all squarely address the rate issue, but some of these ideas, if they are adopted, could make a big dent in the problem.

First, it's a big win that CMS has acknowledged that in many places, not enough providers of acute medical services accept Medicaid patients because the rates the states pay them are too low, and that the homecare worker shortage is mostly due to low wages resulting from low provider rates. Although other factors may also affect this situation, CMS has made it clear that inadequate rates are a major roadblock to access to Medicaid services.

One of their solutions for the worker shortage is to require at least 80% of payments received by homecare service providers to go to compensation—wages and benefits—for homecare workers. One of the ideas to address the "not-enough-providers" problem is to strongly encourage states to set fee-for-service rates to at least 80% of Medicare rates for the same types of services. And CMS wants to require states to set timely appointment standards for providers of certain common medical services as another way to both increase access and collect performance data.

CMS also wants to leverage consumer and provider advocates by strengthening requirements that states not only have advisory groups "on paper" but actually use them when making decisions about rates. If these groups identify problems, they want to require states to respond in meaningful ways. When it comes to managed care, they want to go farther than that: If the groups provide substantial data to show that, for example, lots of people can't get enough personal care services, the state must respond with a corrective action plan to solve the problem, and it must send quarterly progress reports to CMS, which would closely monitor them.

CMS's plans don't go far enough in some areas, but they do acknowledge that might be the case, and they are asking for input supporting even broader measures.

For example, they want to apply the 80% worker compensation rule only to homecare-like programs, such as Personal Care (including CDPA in NY) and Home Health Aide services. They want to exclude habilitation services because the program costs may be higher, especially for facility-based programs such as site-based Day Habilitation due to the cost of maintaining those facilities. At STIC, we think 80% would work for CDPA-style homecare, which has very low overhead (we actually do better than that). For habilitation, though, the costs are indeed higher for supervisors and related requirements that OPWDD currently doesn't pay enough for. We think CMS should set a 75% requirement for compensation for DSPs and their immediate supervisors, and should also specifically require states to ensure that the rates are high enough to



The Tree of Life

By Maria Dibble

Many poems and memorable words have been written to describe trees, but perhaps their most important aspect is the symbol they represent to us. Bill Bartlow was an avid gardener and arborist, and in his memory the people who loved, worked with and respected him purchased 212 trees, enough to plant an entire grove, through "Trees for a Change". They are located in a US national forest in northern California.

To me, trees are the embodiment of strength, endurance, perseverance and longevity. What more fitting memorial can there be than that bestowed upon us by mother nature, whose spirit lives on throughout time, nurturing the earth, the environment and our souls? Rest in peace my friend, for the beauty you created in your art, poetry and humor, resides forever in every tree, flower and blade of grass that sprouts in the birth of spring; flourishes in the sunlight of summer; rests in the splendor of autumn; slumbers in the cold of winter; then revives again to gift us another year of blossoming spirit and the pure essence of life.

cover all of the time that DSPs and their supervisors spend in activities that OP-WDD requires, such as writing notes, receiving training and supervision, and developing service plans, and not just time in “face-to-face” direct service provision. If the state doesn’t comply with that rule, then provider agencies should not be penalized. Also, this percentage should apply equally to all forms of habilitation services, whether site-based or not. That would encourage providers to downsize and close segregated programs and expand community habilitation instead.

CMS only wants states to look at whether their Medicaid rates match at least 80% of Medicare rates for the same services if a state asks permission to reduce or “restructure” rates. We think states should be required to analyze all of their rates in this way at least once every three years.

CMS only wants to apply these new rules to homecare that is funded by “waiver” programs. They are excluding so-called “State Plan” personal care because, they say, it is not commonly used. We beg to differ; about a third of the people in our CDDA program are in that category.

We’ll be conveying our views on all of these issues, and more, to CMS about the time you read this. You should send your own thoughts to them as well. There is already a lot of opposition among providers to the 80% compensation requirement, and CMS needs your support.

There are many details in these proposals, and CMS’s explanations are wordy and sometimes redundant, but please don’t be daunted. It’s easy to submit comments (which are due on July 1).

Go to this site to read the proposed fee-for-service rule and submit comments:

<https://www.regulations.gov/document/CMS-2023-0070-0001>

Go here for the managed care rule:

<https://www.regulations.gov/document/CMS-2023-0071-0001>

Both of those pages have a button near the top-left corner labeled “Comment.” When you click that, you can type in your comments right there, upload a document, or both.

Ciaramella v Zucker: Teeth at last!

Now known as *Ciaramella v McDonald* (we have a different state health commissioner), this case concerned NY’s Medicaid coverage limits for dentures and related dental procedures. Dental coverage is optional for states under federal Medicaid law, but if a state decides to include it, then the law requires the state to pay for all “medically necessary” dental services and procedures. NY did not do that. For example, it refused to replace dentures that were not at least eight years old for any reason—including the fact that they never fit correctly—except changes to the patient’s mouth that made them “un-serviceable”; refused to cover root canals and crowns on back teeth unless the teeth could not be pulled; and refused to pay for implants at all. A lawyer for the Legal Aid Society, which filed the suit in 2018, told *The New York Times* that Medicaid’s dental coverage was “structured to pull your teeth rather than save them.”

We covered this class-action suit back then (*AccessAbility* Fall 2018), so we won’t repeat the details of Ciaramella’s situation or those of other members of the class. Suffice it to say there are many examples of how failure to replace defective, broken or lost dentures promptly, repair rather than pull severely damaged teeth, and apply dental implants in some situations, can cause deterioration in the physical or psychological health of human beings, especially if they have other conditions that put them at further risk. While not settled, the suit had motivated the NY State Department of Health (DOH) to make some changes in its policy for coverage of dentures, effective November 12, 2018, and pre-approve Ciaramella to receive replacements. Ciaramella remained on record as a plaintiff until his death in 2020.

This was not sufficient for the Legal Aid Society; they added new plaintiffs to challenge the implant and root canal/crown policies, and the case continued. DOH agreed to provide a root canal to another plaintiff in 2019 but did not revise its policies concerning that procedure. This pattern

continued, with various plaintiffs dying or being culled by DOH settlements, after which new plaintiffs were added and the complaint was modified, while the parties simultaneously entered mediation. Eventually, it seems, everybody just got tired.

On May 1, 2023 a settlement was announced. DOH did not admit any wrongdoing but agreed to implement new policies for Medicaid dental coverage. They take effect in August. DOH is required to send letters to all adults who are “enrolled” in the Medicaid dental program, as well as to county social services departments and Medicaid managed care plans to tell them about the new rules; publish the new rules on the state’s Medicaid billing website, eMedNY; and present a live webinar to county social services departments, managed care plans, and dentists who take Medicaid, to explain the changes. This level of mandated publicity is quite remarkable.

The new policies had not been published at press time, so we can’t tell you more. If you have Medicaid and a dentist, look for those letters in the mail.

Perez v Sturgis Public Schools: Money for nothing

We reported this case in *AccessAbility* Winter 2022-23. Miguel Perez, a deaf student, attended the Sturgis Public Schools in Michigan. While there, he was given a classroom aide who did not understand sign language, and he was not provided with an interpreter. Despite this, he was awarded good grades and listed on honor rolls until suddenly, in his senior year, he was told his school performance did not qualify him for a high school diploma and he would only receive a certificate of completion. This was devastating news for him, and his parents, who had assumed all along that he was doing fine.

They followed the complaint resolution procedure under the Individuals with Disabilities Education Act (IDEA), which led to a hearing before an administrative law judge (ALJ). Before the hearing could take place, the district settled with the Perez

family, agreeing to send him to a school for the deaf for remedial education, and to pay for any appropriate post-secondary education, sign language classes, and attorney fees. Perez then sued the district in federal court under the Americans with Disabilities Act (ADA), seeking cash compensation for emotional distress. Such compensation is not available under IDEA.

The dispute revolved around IDEA's provision that people can't sue schools under other laws under some circumstances until they "exhaust" IDEA's own procedures, which in this case would have involved proceeding with the ALJ hearing and then, perhaps, appealing to the state education department. The federal judge said this requirement applied in Perez's case, and the Sixth Circuit Court of Appeals agreed, landing Perez before the Supremes.

On March 21, 2023, the Supreme Court issued a unanimous decision, authored by Justice Gorsuch, that sided with Perez. The decision lays out an extremely obvious argument.

IDEA says that "Nothing" in that law prevents somebody from suing a school district for relief under other laws if IDEA cannot itself provide that relief. That's really all anybody needed to know for this case. The meaning of "nothing" is extremely clear. But to nail down the point, Gorsuch explained that this rule is presented in two paragraphs. The first one has the "nothing" part, and the second one has the "unless the relief is actually available under IDEA" part.

Gorsuch also felt he had to explain that when different sections of IDEA use the words "relief" and "remedies" they mean the same thing, which, he said, would be apparent to any ordinary reader—except, apparently, school district lawyers and some federal judges. He demolished those lawyers' claim that a previous Supreme Court decision had decided this issue in their favor by simply stating that, no, it had not; it had, in fact, explicitly stated that it was *not* deciding this issue. And finally, he shot down the school district's attempt to get him to reinterpret the text of the law to enforce what it claimed was the intent of Congress to route all complaints

and requests for relief through administrative law judges and state education departments because they are the real "experts." He said that if Congress had intended to say that, it would have written that into the law. Quoting another Supreme Court decision, he said, "we cannot replace the actual text with speculation as to Congress' intent." Honestly. I can't make this stuff up.

In this case, a very right-wing judge's insistence on enforcing only the actual text of a law worked in favor of a progressive cause—the civil rights of students with disabilities. These cases don't always work out that way, but they would if progressives insist on that kind of writing in the bills they support, only work with lawyers to draft bills who will write them that way, and oppose all bills that don't contain such writing even if they appear to promote their interests.

That's going to be important for Perez as well. The Supremes did not consider a major aspect of the case—whether the ADA can, in fact, deliver the compensation he asked for. They sent that issue back to the lower court to resolve. What the eventual outcome will be is not clear at all. The argument will probably hinge on how likely it was that the school district could have predicted that "serious emotional disturbance" would result from its cruel deception of Perez over his entire public school career (see *Cummings v Premier Rehab Keller* in *Access-Ability* Summer 2022). Ambiguous language may very well defeat him there.

Laufer v Acheson Hotels: Test Fight

Laufer is a self-proclaimed "ADA tester" who sued a hotel in Maine in federal court because its website didn't provide information on whether it was accessible or not, nor did 13 generic hotel booking websites. At issue is whether she had standing to sue because she did not intend to actually stay at the hotel.

The federal court ruled against her, and the case went to the First Circuit Court of Appeals, which ruled for her. The hotel has appealed the case to the US Supreme Court, which will probably hear arguments this fall.

This is one of the best-written federal court decisions I've ever read. The judge, O. Rogerie Thompson, rendered some really complicated material in a friendly, down-home manner that anyone can understand (you can read it here: https://scholar.google.com/scholar_case?case=3355103331574540058&hl=en&as_sdt=6&as_vis=1&oi=scholar). I could easily have reprinted it here, but it would have taken up the entire newsletter. So you'll just have to bear with my poor summary.

The federal Department of Justice (DOJ) has an ADA regulation, known as the "reservations rule," that says hotels must "with respect to reservations made by any means ... [i]dentify and describe accessible features in the hotels and guest rooms offered through its reservations service in enough detail to reasonably permit individuals with disabilities to assess independently whether a given hotel or guest room meets his or her accessibility needs." The regulation also applies to "third parties" that book reservations for hotels (such as Expedia). So while Laufer complained about a website, this is not a case about whether the ADA covers websites.

Whether a person has "standing" to sue depends on if s/he has alleged that she experienced a real or "concrete" injury. At this stage of the proceedings, the court assumes the allegations are true and only considers whether there is enough information provided to show a real injury.

The US Supreme Court has long held that civil rights "testers" have standing to sue when the things they test violate civil rights laws, even when the tester has no intention of actually using that thing. This goes back to at least the 1980s, when it became common to test landlords by having a black person and a white person call to ask about an apartment to see if they would tell the black person "no vacancies" but tell the white person, "Sure! Come on down!" Whether or not the black tester really wanted an apartment made no difference, because she still experienced the pain and humiliation of being discriminated against in that very phone call. She, in fact, sustained a "concrete injury."

The Supreme Court has also, at least until recently, ruled that denial of information

to which a person is legally entitled can also be a concrete injury.

A monkey wrench was thrown into the works by a 2022 Supreme Court decision known as *TransUnion*. Some consumers accused a credit union of failing to report some required information in the prescribed format. The Supremes ruled against them because, they said, the credit union did not actually fail to provide the information; it just didn't do it in a specific way. That should have been enough, but the decision's author, Justice Kavanaugh, felt compelled to go further and express a non-binding opinion: "Moreover," he wrote, the plaintiffs "identified no 'downstream consequences' from failing to receive the required information" and an "informational injury that causes no adverse effects" isn't enough to provide standing to sue.

That is something new. The hotel claimed that this remark is "*dicta*." *Dicta* refers to language in a Supreme Court decision that is not part of the essential chain of logic that led to that decision, but that may indicate how the Court would rule in future cases. Lower court judges are expected to think carefully about *dicta*, though they don't necessarily have to treat it as binding. Supreme Court justices also make off-handed remarks when writing decisions that no one is expected to take seriously, but the distinction between *dicta* and a mere aside is fuzzy.

Here's where we get into dangerous territory. Thompson doesn't believe this brief statement is *dicta* because it doesn't address why a lot of Supreme Court precedents, which say the mere fact that you didn't get information the law says you should get is enough for a lawsuit, should be discarded. Real *dicta* usually includes more detail along those lines. Still, Kavanaugh could come back with this adverse effects business in this case. Thompson also says that shouldn't matter because Laufer was likely injured emotionally, and suffered a loss of dignity, in the same way that black housing testers who are told "no vacancy" are, so she actually did experience adverse consequences. However, here Thompson is conflating the standing issue with issues of fact. Her earlier use of the housing tester example

to explain emotional or "dignitary" harm may not be relevant when determining standing. Courts are only supposed to consider the information that is presented to them, and not make assumptions about things that may have happened to plaintiffs that they themselves did not report. If Laufer's complaint, which we have not seen, doesn't clearly assert some sort of suffering or harm as a result of not getting the information she should have gotten, then she would not meet Kavanaugh's new requirement if he chooses to push it.

There are other potential pitfalls here. The hotel says Laufer could have just called them on the phone to get the information she needed. That sort of thing has long been thought to meet the ADA's requirement to offer "alternate" accommodations when a standard feature can't be made accessible. Some recent ADA cases have leaned more heavily on its language indicating that denying a person with a disability the same experience a nondisabled person would have, or requiring them to do something more, or different, from what a nondisabled person would have to do in order to get the full benefit of a service, is illegal discrimination. However, Kavanaugh is pretty skeptical about the ADA as a whole; he doesn't believe that the notion that intentional disability discrimination even exists is "deeply rooted in this nation's history and tradition," a bogus prerequisite to establish federal civil rights that was just invented by right-wingers a few decades ago and most recently used in the 2022 *Dobbs* case to wipe out abortion rights (see *AccessAbility* Fall 2018). Kavanaugh might be in the mood to take on the entire ADA here.

As Thompson pointed out, nobody had raised the argument that the reservations rule wasn't well-grounded in the law or that DOJ went too far in issuing it at the time she was considering the case, so theoretically the Supremes shouldn't even address that point. However, another longstanding precedent that is now under the gun may change that calculus: the Supreme Court's *Chevron* ruling that when things get complicated, federal courts should give great deference to guidance from federal agencies as "subject matter experts." In recent years, as

far-right politicians have seen some of their more nasty initiatives derailed by federal regulations, various right-wing Supremes have begun chirping about how maybe *Chevron* wasn't such a good idea. There's a case on their docket, *Loper Bright Enterprises v Raimondo*, that



Bill & Todd's Excellent Adventure

By Todd Fedyshyn

As I sat down to write this and started to reflect on my time together with Bill, I was overcome with joyful bliss as I thought of the memories from over a decade of sitting next to that amazing gentlemen daily at STIC. Bill was more than just my co-worker; he was my dear friend, and we shared many great moments together as we developed fundraising efforts for STIC. Bill was without a doubt the most intelligent person I have ever met and had the pleasure to learn from. Some days, as we sat in our office together, I couldn't believe the knowledge this man shared with me. As we developed our approach to different projects, I could always count on Bill having a binder of printed material ready to be reviewed for creative planning. He was always thinking of ways to share ideas and his vision with others and gave to everyone around him, including sharing his mind with telemarketers. In closing, the best thing I can say is that I consider myself blessed to have had an opportunity to spend time with this man and he will be forever in my thoughts and heart. Miss you, my friend – Love, Todd

takes on that very issue, and it will likely be decided around the same time as the *Laufer* case. The Justices surely will have *Raimondo* on their minds as they think about *Laufer*, and they could go so far as to declare the reservations rule unconstitutional. The fact that the ADA expressly permits alternate accommodations, in apparent conflict with claims that the law requires disabled and nondisabled people to have the same experiences, could be fertile ground for such a decision.

Stay tuned.

Fields v Annucci: Heinous Acts

New York State’s HALT (Humane Alternatives to Long-Term solitary confinement) Act, passed in 2021, was intended to sharply reduce the use of that practice in state prisons. This is because there is a broad consensus among mental health professionals and many prison officials that extended stays in solitary confinement can, all by themselves, cause mental illness, as well as exacerbate any such pre-existing condition.

The Act contains some pretty big loopholes (see *AccessAbility* Summer 2021), but it also says solitary confinement may only be used with people who committed one or more of seven very specific highly dangerous or harmful acts, and “only if those acts are so heinous or destructive” that letting the person remain in the general prison population would impose a “significant risk of imminent serious physical injury” and an “unreasonable risk” to facility security.

The Acting Commissioner of the NY State Department of Corrections and Community Supervision (DOCCS), Anthony Annucci, responded by issuing guidance that automatically defined any behavior listed in “Tier III,” the highest level of the department’s disciplinary categories, as meeting that definition. For example, “unhygienic act” is a Tier III offense that includes spitting on the floor. But neither spitting nor other unhygienic acts are among the list of seven, and even if they were, they would not meet the “heinous or destructive” test. Yet Annucci’s employees continue to put people in the hole for spitting and similar minor offenses.

HALT also places limits on how long someone who met those criteria can be held in old-style solitary or “keeplock” confinement, meaning 23 hours a day in a small cell, but they don’t apply to the use of special restricted settings called “Residential Rehabilitation Units” (RRUs).

Unfortunately, the two plaintiffs in this case, Fuquan Fields and Luis Garcia, aren’t attractive examples of the unfairness of Annucci’s policies. Fields, who has mental illness, threatened suicide and was placed in a restraint chair while waiting for a mental health professional to come see him. He said he needed to use the bathroom. The guards denied his request. After two hours, he opened his pants and urinated on the floor. He was charged with an unhygienic act, “lewd conduct” (also not on the list of seven) and “assault on staff,” which might be on the list depending on how serious the injury (potential or actual) was. However, after appeal the assault charge was dismissed, but he was still sentenced to 120 days in solitary. Garcia, who was in an OMH Residential Mental Health Unit at the prison, threw an “unknown brown feces smelling liquid” at two guards. He was convicted of two counts each of assault on staff and unhygienic acts. There was no written determination that his actions, while disgusting, were truly heinous or destructive, as required by HALT. He got 730 days. Although the lawyers also allege that DOCCS is regularly violating the duration limits for solitary confinement, it’s not clear that these plaintiffs, who were placed in RRUs, were mistreated in that way.

We wish the lawyers had found some better plaintiffs, but this is a class-action suit representing all NYS prison inmates whose treatment violated HALT. It was filed in Albany County Supreme Court in April, and it has a long road ahead.

Even if Annucci loses, it’s unclear whether any resulting orders to change his behavior will be enforced. He announced plans to retire in June, but it’s not clear that his deputy, Daniel F. Martuscello, has a better attitude about this. We’ll let you know what happens.

In Memoriam: Judy Heumann

(from a press release)

Judith “Judy” Heumann—regarded as “the mother” of the disability rights movement—passed away in Washington, DC on March 4, 2023. Judy was at the forefront of major disability rights demonstrations, helped spearhead the passage of disability rights legislation, founded national and international disability advocacy organizations, held senior federal government positions, co-authored her memoir, *Being Heumann*, and its Young Adult version, *Rolling Warrior*, and was featured in the Oscar-nominated documentary film, *Crip Camp: A Disability Revolution*.

Born in 1947 in Philadelphia and raised in Brooklyn, NY, Judy contracted polio at age two. Her doctor advised her parents to institutionalize her when it was clear that she would never be able to walk. When Judy tried to go to kindergarten, the principal blocked her family from entering the school, labeling her a “fire hazard.” Her mother fought back and demanded that Judy have access to a classroom. She attended a special school, high school, Long Island University, and the University of California, Berkeley, earning a Master’s in Public Health.

In the 1970s, Heumann attended Camp Jened, a summer camp for people with disabilities in the Catskills, and she later returned there as a counselor. Several of the leaders of the disability rights movement also were at Camp Jened, which was the focus of the documentary *Crip Camp*.

During the same decade, the New York City Board of Education refused to give Judy a teaching license because they feared she could not help evacuate students or herself in case of fire. She sued, becoming the first teacher in the state to use a wheelchair. Continuing her fight for civil rights, Judy helped lead a protest that shut down traffic in Manhattan against Richard Nixon’s veto of the 1972 Rehabilitation Act, and she launched a 26-day sit-in at a federal building in San Francisco to get Section 504 of the revived Rehabilitation Act enforced. Judy was instrumental in developing and implementing national disability rights legislation, in-

cluding Section 504, the Individuals with Disabilities Education Act, the Americans with Disabilities Act (ADA), the Rehabilitation Act, and the UN Convention on the Rights of Persons with Disabilities.

She helped found the Berkeley Center for Independent Living, the Independent Living Movement, and the World Institute on Disability. She also served on the boards of the American Association of People with Disabilities, the Disability Rights Education and Defense Fund, Human Rights Watch, and several others.

From 1993 to 2001, Judy was the Assistant Secretary of the Office of Special Education and Rehabilitation Services in the Clinton Administration. From 2002 to 2006, she was the first Advisor on Disability and Development at the World Bank. From 2010 to 2017, she was the first Special Advisor for International Disability Rights at the US State Department.

“Some people say that what I did changed the world,” she wrote, “But really, I simply refused to accept what I was told about who I could be. And I was willing to make a fuss about it.”

Sally Johnston

(from NYSILC)

Sally Johnston, a celebrated disability advocate in New York State, died in May 2023.

Her accomplishments were many, but her advancement of Consumer Directed Personal Assistance (CDPA) stands out. In the early 1990s, Sally persuaded a contingent from Syracuse, including the Onondaga County executive and others from the Local Department of Social Services, to visit New York City and examine this new model of community-based support. Together they worked to bring a demonstration program to Syracuse and Onondaga County.

While the program in New York City had been for individuals with a high degree of management capacity, Sally envisioned a CDPA program that could be implemented statewide and allowed a new level of consumer, one who needed more in the way of support from their Fiscal Intermediary (FI). This change forever altered the program and led to the type of FI that most people, particularly those upstate, utilize today.

Later, she worked to bring the collective of FIs operating around the state together under

one umbrella, an organization that was officially founded in 2000 and named the Consumer Directed Personal Assistance Association of NYS (CDPAANYS). The association now serves as the only statewide resource on CDPA, advancing the program for both FIs and consumers.

In 1988, Sally received the Ralph E. Kharas Award for Distinctive Service in Civil Liberties from the Central New York Chapter of the New York Civil Liberties Union. In 2022, she was inducted into the New York State Disability Rights Hall of Fame.

In recognition of Sally’s pioneering work, CDPAANYS created The Sally Johnston Advocacy Award, given each year to an individual whose advocacy on behalf of CDPA was critical for the success of the program and its grounding philosophy of independence and control.

Sally retired in 2020. That same year, Access-CNY established the Sally Johnston Advocacy Center to honor the contributions that she made in advancing disability rights in Central New York. The Center is not only a remembrance of Sally’s 40 years of advocacy work but also a promise to continue her work and constantly strive towards equality.



STIC NEWS



Put on Your Ruby Anniversary Slippers

By Maria Dibble

Four decades have flown by since I assumed my position as Executive Director of Southern Tier Independence Center (STIC), and it has been quite the journey.

We are marking this milestone with an anniversary celebration on June 22, from 12:30 to 4:30, at STIC’s offices located at 135 East Frederick St. in Binghamton. Please use the rear entrance.

The event theme will be loosely based on the Wizard of Oz, since my co-founder (Frank Pennisi) and I have always been big fans of the movie. In fact, we named much of our paperwork forms after various characters; thus we have the Dorothy form (intake) Toto Form (quarterly activ-

ity log) and so on, including the “No Place Like Home” Form (reporting on people leaving nursing homes or other institutions. A bit silly perhaps, but it helps to make the paperwork more palatable.

The event will be an open house, with many activities for adults and children. We’ll be showing the Wizard of Oz movie for visitors’ enjoyment as they perhaps munch popcorn while they watch.

There will be face painting, outdoor activities, a wheelchair obstacle course for any visitors to try navigating while in a chair, and more. Spin the game wheel for a small prize, while listening to some live music. Visit a selfie station and take a picture with some interesting background themes. Check out a sample Xscapes room and learn about this fun and challenging fundraising activity.

All of STIC’s departments will have displays about their services, and it will be



an opportunity to meet our staff and learn more about what we do.

Stop by and celebrate with us, relax and have some fun, have a bite to eat or a cool drink, on a hopefully warm and sunny summer afternoon. Admission is free, though we are selling some of the food to raise money for STIC.



CHEC It Out!

By Lucretia Hesco

ATTENTION! STIC has a new Coalition: The Community Habilitation Equity Coalition (CHEC)

Mission: To advocate for equity in Community Habilitation billing and rates, in order to achieve a living wage for Direct Service Professionals (DSPs).

(DSPs provide daily care, services and supports to people with intellectual and developmental disabilities 24 hours a day, 7 days a week. These services make an immeasurable impact on a person's ability to live safely in their home, to manage their healthcare and finances, to have a fulfilling community life, and to maintain meaningful personal relationships. Working as a DSP is a rewarding yet challenging job, which requires ongoing training and a high level of responsibility and skill. Despite their critical role in the lives of people with disabilities, many DSPs earn minimum wage. These are not minimum wage jobs.

The DSP workforce is in a dire state which has only been decimated by the pandemic. We are in a full blown DSP workforce emergency due to many factors, including annual cost of living increases that are insufficient in supporting the rise in minimum wage, and years of cuts and underfunding by NYS. There are staff shortages statewide and it is becoming much more difficult to attract and retain quality staff. Without the ability to find and keep people in these important roles, people with disabilities face a loss of these essential services.

STIC has formally organized the Community Habilitation Equity Coalition (CHEC) to advocate for equity in Community Habilitation billing and rates in order to achieve a living wage for DSPs. By achieving equity with such services as OPWDD Supported Employment billing and rates, Comm. Hab can be a stronger and even more vital service than it already is and would allow us to pay a living wage to attract quality DSPs to a career in the field.

The Coalition will be composed of families, community provider agencies, Care Coordination Organizations, DSPs and, most importantly, people with intellectual and developmental disabilities (I/DD).

It is only a matter of time before people with disabilities and their families completely lose access to their options and resources required to remain in their home and community without significant investment and innovative solutions to solve the DSP workforce emergency.

CHEC will meet in person (with Zoom available, as well) the last Thursday of each month at STIC's office. Please join us. **Together, we can make a difference!**

Coming Unwound

By Chad Eldred

During the COVID-19 pandemic, New York's Medicaid program played a critical role in ensuring that vulnerable populations had access to healthcare services. The state implemented several emergency measures to expand coverage and increase access to care, including the deployment of telehealth services, the relaxation of certain eligibility requirements, and continuous coverage for public health insurance enrollees without the need to renew.

As the public health emergency (PHE) begins to unwind, New York is expected to continue to prioritize Medicaid coverage and access to healthcare services. However, the state may face challenges in sustaining the emergency measures that were implemented during the pandemic, particularly as federal funding begins to expire.

One of the consequences of the PHE unwind that New Yorkers will face is the renewal of public health insurance coverage. Public health insurances include Medicaid, Child Health Plus and the New York State Essential Plan. During the PHE, renewals for those enrolled in these coverages were suspended. Health coverage was automatically extended in 12 month increments based on the initial coverage date. As a consequence of the PHE unwind, automatic extensions will now stop and recipients of public coverage will resume renewing on an annual basis.

The renewal process has already begun. Notifications are currently being sent out from the New York State of Health (NYSOH) insurance marketplace along with local social services offices where some individuals still receive Medicaid coverage. These notifications, along with subsequent renewals, will continue for everyone enrolled in public health coverage over the course of the next year until all accounts have been renewed. This process can consist of income and household updates and may include any number of additional pieces of information.

Eligibility will be updated to reflect this new information. For some this may mean continued coverage in their current plan, for others this could result in a new eligibility altogether and could necessitate the selection of a new insurance plan.

For some this renewal process is a return to something familiar as they may have renewed annually in the past. For others, such as those who enrolled during the pandemic and had never had public coverage prior, these are new waters. In order to make this process smooth and seamless there are a few things that a person can do:

- 1. Watch your mail.** Coverage renewal notices will be sent to all of those who need to renew in advance of their coverage expiration date. Do not ignore notices that are sent from the New York State of Health insurance marketplace or notices from your local social services department. For those who have elected paperless options through the New York State of Health, pay equal attention to email notifications. These

Mad Science

By Lucretia Hesco

Bill Bartlow was Halloween personified. Thus, it only makes sense that October was Bill's favorite time of year. It was during October that his love for Halloween ignited like a thousand flickering jack-o-lanterns, similar to the ones he donated for use at STIC's Haunted Halls of Horror. With intense passion, he (and Todd) transformed STIC's basement into a haunted haven. Every corner became a stage for his creativity. From elaborately decorated rooms to meticulously crafted costumes, Bill turned Halloween into

an unforgettable spectacle (and fundraiser for STIC). His infectious enthusiasm drew us in and together we celebrated the magic of Halloween hosted by our very own Mad Scientist, Bill.

I am grateful for the privilege of knowing Bill. His quick wit and clever comebacks brought an element of fun to meetings...he never ceased to amuse us. Bill brought abundant laughter, camaraderie and of course, the merriment of Halloween into our workplace. His legacy will guide us to foster our own creative spirits, to never take life too seriously, cherish the power of laughter and *celebrate* the magic of Halloween throughout the year.



notices will provide critical information such as important deadlines and renewal procedures.

2. Contact a Navigator or Facilitated Enroller. Navigators and facilitated enrollers are professionals who receive ongoing training in the health enrollment process. The training includes the renewal process for public health insurances. While navigators can address questions regarding the NYSOH marketplace, facilitated enrollers have similar expertise regarding enrollment and renewal for those with Medicaid coverage through their local social services office. Navigators and facilitated enrollers can help with the process or related questions.

3. Update your contact information. If you have moved since the pandemic began or changed your contact information it is important to update the information through the NYSOH portal or with your local county social services office. Crucial notices will be sent to whatever address you currently have on file with NYS or your local social services office. In order to ensure that notices reach you, make sure that the information is up to date. NYSOH navigators can assist you with this process if you are unsure as to whether your information is up to date.

Following these steps will go a long way towards ensuring that the renewal obliga-

tion is met and preserving coverage continuity. Resources are available to support individuals and families through this process. If you have questions about any of this, please contact me at the Southern Tier Independence Center. My number is 607-724-2111 ext. 352. STIC has a team of navigators and enrollers that would be happy to answer questions and assist with the renewal process.

Don't Get Scammed

(from a press release)

New York Attorney General Letitia James and Acting Department of Health Commissioner Dr. James McDonald warned about a new scam targeting New Yorkers enrolled in public health insurance programs and provided important tips to protect consumers. James and McDonald are urging people to be vigilant in light of reports of scammers deceptively calling people and asking them to pay hundreds of dollars to maintain their health insurance.

"It is despicable that scammers are trying to exploit New Yorkers' need for quality health insurance and uncertainty over ongoing Medicaid coverage," James said. "The best tool consumers and families have to combat scams is knowledge, and that is why I am committed to raising this issue. I urge everyone to follow our im-

portant tips, and anyone impacted by this scam to contact my office immediately."

"These schemes are maliciously preying on public health insurance enrollees as they navigate the return of renewals for the first time in three years," said McDonald. "Such actions are downright criminal, and I ask all New Yorkers to read these guidelines and help protect each other from this fraudulent abuse."

Additionally, James and McDonald provided the following tips:

- No one can ever charge you a fee to renew your health insurance in Medicaid, Child Health Plus, or the Essential Plan.

- Government agencies will never threaten you, demand you pay money, or ask for credit information, in a text message or phone call.

- Report suspected fraud.

- Call the New York State of Health's Customer Service Center at **1-855-355-5777**. TTY users should call **1-800-662-1220**.

- Call your county's Medicaid office at the phone number listed here: www.health.ny.gov/health_care/medicaid/ldss.htm

- Contact the Office of the Attorney General's (OAG) Health Care Helpline at 1-800-428-9071 or the NY State Department of Financial Services' Consumer Hotline at 1-800-342-3736.



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

NON-PROFIT ORGANIZATION
 U.S. POSTAGE
PAID
 BINGHAMTON, NEW YORK
 PERMIT NO. 126

135 E. Frederick St.
 Binghamton, NY 13904
 (607) 724-2111

Toll Free (877) 722-9150
 email: stic@stic-cil.org

RETURN SERVICE REQUESTED

Free Access Is Not Free

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.

- | | |
|--|--|
| <input type="checkbox"/> Individual \$5 | <input type="checkbox"/> Contributing \$100 |
| <input type="checkbox"/> Supporting \$25 | <input type="checkbox"/> Complimentary \$_____ |
| <input type="checkbox"/> Patron \$50 | <input type="checkbox"/> Newsletter Subscription \$10/year |

MAIL TO: Southern Tier Independence Center, Inc.
135 E. Frederick St.
Binghamton, NY 13904

Name _____
 Address _____
 City _____ State ____ Zip _____
 Phone _____

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

EXECUTIVE DIRECTOR
 Maria Dibble

ASSISTANT DIRECTOR
 Jennifer Watson

ACCESSIBILITY SERVICES: TBD

NHTD RESOURCE CENTER:

ADA SERVICES: TBD

Ellen Rury Belynda Raminger

BEHAVIORAL CONSULTING:

Kay Hogan Pamela Lounsberry

Yasmin Van Veronica Wallen

NY CONNECTS: Amy Friot

Rachel Schwartz Michelle Stimak

PEER COUNSELING:

EC-FACE: Karen Roseman Leigh Tiesi

Richard Farruggio Lisa Fornillo

EDUCATION SERVICES: Nadia Hedrington

Danny Cullen Robert Deemie Susan Link

HABILITATION SERVICES: Kendra Kellam

PERSONAL ASSISTANCE SERVICES:

Daniel Schwartz Alexa Conklin

Susan Hoyt Jillian Kaufman

Catherine McNulty Lucretia Hesco

Katina Ruffo Alicia Richards

Katie Trainor-Leounis

PSYCHOTHERAPY: Kelsie Seyler

HEALTH EXCHANGE NAVIGATORS:

SA-FACE: Shannon Smith Tara Ayres

Alicia Bouseman Casey Flanders

SELF DETERMINATION FI: Rhonda White

Michelle O'Hare Yvonne Scheiner

SUPPORTED EMPLOYMENT:

Loretta Sayles Chad Eldred Joy Stalker

Michelle Dunda Hannah Hickox

Theresa Kircher Patricia Lanzo

Isaac Normile

Brittany Pritchard Brittaney Carey

SYSTEMS ADVOCACY: Susan Ruff

HOUSING SERVICES: Nancy Huston

TBI RESOURCE CENTER:

Matthew Lee Eileen O'Brien

Valerie Soderstrom Ellen Rury

INTERPRETER SERVICES: Stacy Seachrist

OPEN DOORS (MFP): Marcy Donahue

Cortney Medovich Heather Quigley

George Buchanon Teresa Shoemaker

TECHNOLOGY SERVICES: Lucas Stone