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AccessAbility

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Number 154

Governor's Proposed Budget Slashes and Restricts CDPA, Other Critical Services

By Jennifer Watson

My first editorial as Executive Director of STIC is on a topic very near and dear to my heart: Consumer Directed Personal Assistance (CDPA) Services, though I wish I weren't writing about it in this context.

As many of you know, the roots of CDPA can be traced back to the disability rights movement of the 1960s and 1970s, which emphasized self-determination, civil rights and independent living for people with disabilities. Advocates pushed for policies that would allow people to manage their own care with dignity, rather than being institutionalized or relying solely on traditional home care services. Through further advocacy of people with disabilities in NYS, a pilot program was developed and CDPA was officially established in 1995.

As we approach the 30th anniversary of the availability of CDPA services across NYS it's disappointing and disheartening that we are still fighting for Consumer Directed Personal Assistance Services in New York.

The first strike against CDPA came in Governor Hochul's SFY 2025 proposed Executive Budget in the form of a proposal to cut $200 million from the budget by removing the Consumer Directed Personal Assistance (CDPA) program from wage parity, as well as making $200 million in additional "unallocated" cuts to homecare.

Removing CDPA from wage parity would result in the lowest wage and benefit package for CDPA Personal Assistants (PA) in NYC, Long Island and Westchester County since January of 2018. This cut only targets CDPA and not traditional personal care, treating CDPA Personal Assistants like second-class home care workers even though they can do more complex tasks like medication administration, vent, tracheostomy and feeding tube care.

It was unclear until the Governor's 30-day amendments what the additional $200 million in cuts would entail, and it was worse than we thought.

The 30-days amendments included further attacks on CDPA in the form of monumental changes to the program, one being a bill that would eliminate Designated Representatives (DR) in CDPA. DRs have been a part of CDPA since the program's inception, and they take on the responsibilities of the consumer when the consumers themselves are unable to self-direct their own services.

The assault on CDPA hits close to home for me, resonating deeply not just for the hundreds of individuals who rely on STIC as their Fiscal Intermediary for CDPA, and the hundreds of thousands statewide who depend on CDPA to maintain their independence, but also for my son, who participates in the CDPA program.

My son, Kevin, was born in 2011 with very significant disabilities and spent his first three months of life in the NICU. While I would say he was physically well-cared for, it became very apparent very quickly that the doctors overseeing his care saw very little value in him because of his disabilities.

During this time, my husband and I were frequently called to meetings to discuss Kevin's discharge plan. These meetings were actually used to try to convince us that there was no way he could or should leave the hospital. We pushed back.

In turn, they offered us "Comfort Care," which is dramatically different than it sounds. Comfort Care is essentially removing your child from all forms of

INSIDE

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Authorship

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

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support and watching them slowly die. Not very comforting at all. When they realized that collectively we were not going to choose that option, they applied a divide and conquer strategy pushing to see if there was a weak point in either of us in our determination to bring Kevin home. There was not.

It is still terrifying to me the lengths they would go to convince us to leave him behind, but that no effort was focused on finding him a way home. We experienced first-hand how some devalue the lives of people with disabilities.

When it became apparent that we would not succumb to their tactics and we actually believed that Kevin could have a fulfilling life and ours would be better having him in it, they had no choice but to discharge us.

With the support of STIC staff, we enrolled Kevin in the Care at Home Waiver. However, no traditional home care agencies would pick us up for nursing services before we left the hospital, in large part due to Kevin's significant needs. Through our time in the NICU we learned how to take care of Kevin and were eventually discharged from the hospital without services, but with the plan to apply for CDPA through the county.

I'll be honest, I was afraid of taking Kevin home from the hospital without the monitors or the nurses immediately there to deal with any situations that may arise. I was considering CDPA since I had seen it work so well for other people and families, but wasn't sure that it was right for us.

Within three weeks of Kevin coming home, my mother quit her job and took a pay cut so that she could become a Consumer Directed Personal Assistant for him, initially just to give my husband and me a couple of nights of sleep each week. She then moved to days so we could go back to work. Once it was evident that Kevin was home and stable, we were finally able to get a nursing agency to agree to work with us, though we had mixed experiences in the capability and care provided.

Kevin will turn 13 this year and now receives support through a combination of CDPA and private duty nursing from independent nurses. Though his nurses are Licensed Practical Nurses (LPNs), we've had to train most, if not all of them in how to do trach care, use Kevin's feeding pump and other more complex tasks that he needs. Not all that different from how we've trained our CDPA Personal Assistants.

While we have a great team of nurses who work with Kevin now, that hasn't always been the case, and the only constant reliable service provider we've had for Kevin's entire life is his first CDPA Personal Assistant, who also happens to be his grandmother.

With the elimination of Designated Representatives from CDPA, approximately 100,000 people, including Kevin, will lose their CDPA services. This change specifically targets children, people with developmental disabilities, traumatic brain injury, Alzheimer's, and dementia.

One of two things will happen if this actually goes through. People will be forced into more expensive service options like traditional homecare, nursing services or institutionalization. Not to mention losing control of the basic tenets of their lives. Even worse and more likely, people will not be able to get services due to the largest-in-the-nation home care crisis that exists in NYS, along with a lack of nursing home beds, resulting in more frequent emergency room visits, hospitals stays, illness, and death.

The Governor's bill would also make other fundamental and harmful changes to CDPA, including requiring state mandated training for PAs, maximum daily and weekly limits on the hours PAs can work and limiting the number of CDPA Fiscal Intermediaries--like STIC--in a county or managed care plan network.

In recent weeks I've heard many advocates share President Biden's assertion, 'Don't tell me your priorities - show me your budget, and I'll tell you your priorities.'

When the time came for Governor Hochul to tell us what her priorities are, she made it abundantly clear that that people with disabilities who want to control their lives and live with dignity in their own homes were the very least of her concerns.

An Introduction

By John McNulty

I feel a little like the new head football coach at Alabama after Nick Saban; I have enormous shoes to fill, because Ken Dibble's amazing work over decades, along with his deep knowledge and experience, has left an incredible legacy. I can't replace him, but merely succeed him. I have no immediate plans to change the newsletter format with which readers have become familiar, though I'm sure in the course of time there will be some organic evolution. For now, I just want to do my best to meet the high standard that has been set.

I joined STIC this past October, but I've been in its orbit for much longer. I have been blessed with two remarkable children, the younger of which is severely autistic, so she has been receiving services from STIC and other organizations with similar missions for fifteen years. Their wonderful mother took the lead at first dealing with the myriad therapies and appointments and the dizzying alphabet soup of agencies involved; she became far more knowledgeable than I, and indeed made a career of it. Cathy has worked at STIC for several years, currently as a Habilitation Coordinator. I've been doing my best to catch up with her, much more rapidly since I joined the STIC family.

As Ken mentioned last newsletter, I have a background in academia; I spent nearly 20 years as a teacher and researcher, with a specialty in American elections. I've authored or co-authored a number of articles, some of which made a decent splash in the fairly small world of academic political science; indeed, I just observed that recent changes in how voter turnout is affecting electoral outcomes are in concert with a complicated theory for which I helped provide evidence almost thirty years ago. I'm now excited to be doing something a little different; I'm the new Public Policy Specialist at STIC. Producing this newsletter quarterly as Managing Editor will be a large part of my responsibilities, but I'll also be involved in advocacy, policy analysis, and anywhere else I can add value. I'll be following Ken's practice of only signing articles that may generate some controversy (after this first one); as he inimitably put it, so you'll know who to blame. Otherwise, I see no need to see my name in print more than it must be.

It is exciting to be producing my first newsletter; any errors are my responsibility alone, and if correction is necessary it shall appear in the first issue after the error is discovered. I shall strive for continuous improvement, and I look forward to our fruitful correspondence together.

Budget Priorities for Independent Living

There's a lot to say about the governor's proposed budget, more than we have space for in this newsletter. As a summary, however, STIC itemizes below several priorities that we implore the legislature to include in its final budget. Thanks to the New York Association on Independent Living, which originally assembled and composed this agenda for New Yorkers with disabilities.

<u>Independent Living Centers</u>: Increase base funding for Independent Living Centers by $2 million to $18 million, and additionally add ILCs to the human services programs eligible for a cost-of-living-adjustment (A.8437/S.7793).

<u>Health/Medicaid</u>:

- Improve the Medicaid home care program by removing Managed Long Term Care intermediaries and replacing them with accountable care coordination entities as outlined in the Home Care Savings and Reinvestment Act (S.7800/A.8471).
- Increase the wage for home care workers to 150% of New York's regional minimum wage as the Fair Pay for Home Care Act (A.8821/S3189A) does.
- Repeal cuts to eligibility for community-based long-term supports and services in Medicaid advanced by the Medicaid Redesign Team (MRT) II (A.6346/S.328).
- Oppose the Governor's proposed cut of $200 million paid for by removing the Consumer Directed Personal Assistance (CDPA) program from wage parity.
- Oppose another $200 million of unspecified cuts to the home care budget.
- Oppose the elimination of the "prescriber prevails" standard practice, which would jeopardize access to necessary medications.

<u>Housing</u>: Restore the $2 million increase to Access to Home, and add an additional $7 million to allow all regions to benefit from this essential program.

<u>Government Operations</u>: Expand the Office of the Chief Disability Officer (CDO).

- Fund Olmstead Plan creation at $250,000.
- Fund Employment First Initiatives that include all people with disabilities, including the establishment of a small business tax credit (A.4733/S.1555)
- Fund the Interagency Coordinating Council for Services to Persons who are Deaf, Deafblind, or Hard of Hearing within the CBO Office.

<u>Transportation</u>: Mandate that counties expand paratransit service beyond federal Americans with Disabilities Act (ADA) minimums with state-funded support (A.4165/S.4739).

Most of these are at least somewhat self-explanatory; for greater detail on any of the above visit https://ilny.us/advocacy/advocacy-priorities and select the "Budget Disability Priority Agenda" PDF link. They are all important to help thousands of New Yorkers with disabilities live their best lives.

STIC wishes to highlight one action item above that may not be so self-evident, but is critically imperative – the repeal of the proposed cuts to eligibility for community-based long-term services and supports (LTSS)

The 2020-2021 budget adopted a Medicaid Redesign Team proposal which would greatly constrict eligibility for community-based LTSS. Specifically, it raised the eligibility threshold to qualify for LTSS; the federal Maintenance of Effort restrictions for the Medicaid program paused these changes, but we now face imminent implementation of the new eligibility standards on April 1, 2024, and these gravely threaten the viability of home care for a significant percentage of those receiving it, and thereby put many New Yorkers at risk of unemployment, injury, hospitalization, eviction, and institutionalization.

Under the current guidelines, people are eligible for LTSS if they need assistance with any Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL). The new proposed standards, however, mandate that people must require assistance with a minimum of three ADLs to qualify, or if they have a dementia or Alzheimer's diagnosis the requirement diminishes to at least two ADLs.

This will effectively eliminate Level I home care, which provides many people with vital assistance with IADLs such as cooking and cleaning to remain in their homes, but do not require assistance with ADLs. It also sets up a discriminatory eligibility standard which bases eligibility in part on diagnosis. This policy is antithetical to the Master Plan on Aging and the forthcoming Olmstead Plan. STIC urgently recommends the State repeal this destructive policy change and restore the previous eligibility standards, as laid out in A.6346 (Paulin) / S.328 (Rivera).

An Update on Old Business

STIC recently learned, just after going to press for the Winter 2023-2024 issue, that a controversy of long-standing in which STIC was peripherally involved as an advocate for the plaintiff, was quietly settled a few years ago. At the time, STIC was unable to comment at length or with any specificity because we were bound by rules of confidentiality.

We still are, and shall continue to respect that, but given the court settlement, we can now tell the part of the story that is public record. The one-sentence summary: The plaintiff was libeled on social media, and privileged information about him was disclosed; the two defendants were found to have caused damages.

We shall use a pseudonym for the plaintiff so as not to violate his privacy any further; we will call him "Hector Pike." The final settlement that was reached stipulated that the defendants' names should be redacted, so we shan't report them either. Unredacted was the defendants' status as former employees of the Broome Developmental Center (BDC). Hector is an active disability rights volunteer and organizer of long standing who had been a resident of BDC for decades. At some point Hector witnessed BDC employees (identities unknown) abusing another resident (also unknown); he reported what he had seen to the authorities. Mr. Pike subsequently moved out of BDC and got both an apartment and a job.

Some people hostile to Mr. Pike, presumably due to Hector's reporting of malfeasance at BDC, spread verifiably false rumors regarding him on Facebook, the most hurtful of which alleged that Hector was a convicted sex offender. In the series of posts, Mr. Pike's name, address, age, and general physical appearance were disclosed, a clear breach of confidential information and a practice referred to as "doxing." These accusations went viral, and the story reported kept evolving, like a game of Telephone played over the Internet. Newer rumors alleged Hector was charged but not convicted, others suggested he was remanded to BDC by court order because he was incompetent to stand trial for his purported crimes.

The social media accusations were devastating to Mr. Pike, and the humiliations piled up. He was evicted and lost his job. Hector's personal physician discharged him. A local school superintendent sent a letter to all parents advising them of the suspect person – Hector Pike – in their midst. And those are only the tangible damages – imagine how such lies would cause isolation, loneliness, and profound heartache for the accused.

Mr. Pike sought legal remedies available to him. Not many were available; the right to lie is protected under the First Amendment, a necessary evil to protect the higher good – the right to tell the truth. However, two of the people spreading these rumors were employed by BDC and these defendants had disclosed personal information about Hector. This disclosure violated confidentiality guarantees that by law BDC employees were obliged to observe, specifically the NY Mental Hygiene Law, section 33.13. Those employees (and potentially BDC) were subject to civil liability under New York law. Additionally, they were subject to federal liability under the HIPAA statute, which includes both civil and criminal liabilities. The criminal penalty for knowingly and maliciously releasing confidential information under HIPAA can be fines up to $50,000 and incarceration for up to one year.

Hector filed suit in New York alleging violation of the Mental Hygiene Law, section 33.13, and asked for summary judgment, where the judge rules that the evidence of one party is so self-evidently true that formal finding of fact process is unnecessary. (There was another claim referencing the HIPAA federal law, but it was withdrawn.) The defendants made a similar motion, but the judge ruled in favor of Mr. Pike. The defendants were found liable. The only issue remaining was what would be awarded to compensate Mr. Pike for damages. Settlement negotiations required the defendants to pay Hector $6,000 on an agreed-upon schedule.

Why did Hector agree to such a low number? We don't know for certain, but two possible explanations occur to us. First, the defendants are not particularly "deep-pocketed," so pursuing a large dollar amount that could never be received (while racking up legal fees), would be counter-productive. Second, an additional part of the settlement agreement was probably of much greater importance to Mr. Pike.

For that additional part, the defendants each had to enter into the record a formal apology, stipulating to their actions and culpability; that any allegations they made or endorsed on social media were untrue, and that they were wrong to say or even imply otherwise. This would not provide the remunerative financial relief to which Mr. Pike was clearly entitled, nor would it exact the punitive result the defendants richly deserved for their irresponsible malice and cruelty, but it would, once and for all, clear Mr. Pike's name and restore his reputation as best as could be done.

Mr. Pike nevertheless moved to a different part of the state, for a fresh start. We wish him the very best of luck.

We at STIC are pleased that this matter has been resolved, apparently as well as it could have been, but we remain enraged that it happened at all, and that the perpetrators – including others who posted lies but were unfortunately entirely immune from sanction – paid so little a price. Ableism is bad enough, but when it's accompanied by hateful lies, it is extraordinarily toxic. Social media is very powerful and when weaponized, it can hurt deeply at best and ruin lives at worst.

STIC Takes Advocacy Efforts to the Next Level with Voter Voice!

By Lucretia Hesco

STIC is thrilled to announce that we've taken a huge step forward in our advocacy efforts!

STIC now has its own Voter Voice account, allowing us to amplify our advocacy alerts and make our voices heard on critical issues impacting individuals with developmental disabilities.

To grant permission and start receiving our advocacy alerts, please use the QR code to "Sign up for Alerts." Your information will be handled with utmost care and used solely for advocacy-related communications.

Thank you for your ongoing support and commitment to making a positive change together.

Local Businesses Becoming More Accessible

By Susan Hoyt

The Accessibility Advocacy Committee at STIC would like to acknowledge the following businesses for updates to their locations to make them more accessible:

The Kwik Fill gas stations at 1053 Upper Front Street and at 4 West State Street in Binghamton added ramps and handicapped parking spaces. Additionally, many Kwik Fill stations in our area now also offer full service for no additional charge. We do not have a complete list at this time, but two of the full-service stations are at 3408 East Main Street in Endwell and at 411 North Main Street in Vestal. (Please note, these are two different Main Streets.)

The M&T Bank branch at 149-153 Robinson Street has installed automatic doors and offers a lower work station counter for wheelchair access or anyone else who may need it. Thank you for working to be more accessible for people of all abilities!

Disability Groups Protest, U.S. Census Bureau Listens

The U.S. Census Bureau conducts an annual sampling of the U.S. population called the American Community Survey, where they ask about one percent of the U.S. population a lengthy series of detailed questions to collect important and accurate data about the people of the United States while keeping the mandatory decennial census of all U.S. citizens mercifully brief. Among these questions has been several pertaining to disabilities, simple ones like (paraphrasing for brevity) "Are you blind?" "Do you have full use of your limbs", etc., with only Yes or No answers available.

Because the Bureau wants to do their jobs as well as possible, which is praiseworthy, they undertook an initiative to improve the data they collected about disabilities, changing the question wording to elicit ordinal answers such as "No disability," "Some disability," "A great deal of disability," and "Total disability."

This generated a great deal of dismay in the disability community, for two reasons. First, it is our firm stance that any initiative regarding people with disabilities must include the participation of people with the relevant disability or disabilities: the slogan is "Nothing About Us, Without Us." The Census Bureau, however, generated the new questions "in-house," without outside input until they announced the new set of questions and launched the required period of public comment.

Second, and of greater import, it was the judgment of many of the disability groups that the new question would result in fewer people being classified as having a disability, with estimates of the decrease ranging from ten to forty percent. STIC took no official position here, having not made its own assessment, but we did flag some issues for further consideration in our public comment on the matter, available at https://downloads.regulations.gov/USBC-2023-0009-11246/attachment_1.pdf.

To summarize, we suggested that the comparability of the new measure to the old was highly contingent on question

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wording, with specific concern given to the imprecision of the “some” category, which may mean very different things to different people, and in addition that when measuring disability it would be proper and congruent with American tradition to err on the side of too many people with disabilities rather than too few.

The Census Bureau received over twelve thousand comments on the proposed changes, and a large percentage of them were expressing concern about them, if not protesting them altogether. The Bureau listened; on February 6th they announced (https://www.census.gov/newsroom/blogs/director/2024/02/next-steps-on-acs-disability-questions.html) that the new questions would not be used in the 2025 survey, and that they will revisit the questions thoroughly, with greater public and community engagement; i.e., nothing about us without us. We look forward to an improved set of questions later this spring.

Autism Acceptance Month

By Cathy McNulty

April has been designated Autism Acceptance Month. Our daughter Laura, nicknamed Lulu, was diagnosed with autism fifteen years ago now, at age two. Lulu’s father and I were not very aware of autism then, but as Lulu has matured into a feisty teenager, we’ve learned a lot.

For a decade now, during Autism Acceptance Month I put a daily post on Facebook with information and stories about living with autism. This year I thought I would share my usual opening post in this newsletter as well, providing some basic information that I found from various sources, including the CDC website:

In 2023, the CDC reported that approximately 1 in 36 children, or 2.8%, in the U.S. is diagnosed with an autism spectrum disorder (ASD), according to 2020 data. That is a 241% increase over baseline statistics from the year 2000.

Boys are four times more likely to be diagnosed with autism than girls.

Most children were still being diagnosed after age 4, though autism can be reliably diagnosed as early as age 2.

31% of children with ASD have an intellectual disability (intelligence quotient [IQ] <70), 25% are in the borderline range (IQ 71–85), and 44% have IQ scores in the average to above average range (i.e., IQ >85).

Autism affects all ethnic and socioeconomic groups.

Minority groups and other underrepresented populations tend to receive diagnoses later and less often.

Early intervention affords the best opportunity to support healthy development and deliver benefits across the lifespan.

There is no means of medical detection for autism.

Seems scary, right? Well, it is. But I believe that the rates are skyrocketing because of a combination of things: a better understanding of the disorder as well as better tools with which to diagnose autism at an earlier age.

When Lulu was first diagnosed, I personally only knew a few people affected by Autism Spectrum Disorder, and interestingly, they were girls. Today, fifteen short years later, there are far too many with ASD to name here. This truly saddens me, but it also brings a sense of relief. What I mean by that is because of the increasing rates of diagnoses, more attention is given to the disorder, and thus the hope is that funding will go toward additional research and cutting-edge therapies for those affected. It also means that overall, one might find an increased level of patience for children who are melting down, who have quirks, or who stim (making repetitive body movements or noises). This patience was not common at all when I was in elementary or high school.

I know that I sure am glad that Lulu was diagnosed in 2009 rather than even 20 years before that. She does something every day that is amazing, and I couldn't be prouder of her and her peers.

The Heart of STIC: A Reflection on Maria Dibble's Life and the Last 40 Years

(12/22/23)

By Matthew Requa

It's a bittersweet day here at STIC. As we all prepare for the upcoming holiday and are about to take advantage of a well-deserved and extremely generous break until after the New Year, it is Director Maria Dibble's last official day of work at the Southern Tier Independence Center. Her office was nearly empty as I walked in, but she was still boxing up some memories. "How does someone acquire so much stuff in 40 years?" she asked. An unusually bright December sun flooded the now sparse but peaceful space as we headed toward her conference table for a seat so I could ask her a few questions. With her faithful and loving dog Ace by her side, who was just skin and bones when she rescued him from a high-kill shelter in the South, Maria told me a little bit about herself, the history of STIC, and what she envisions for the future.

Maria was a straight-A student when she moved to this area from Long Island. She had planned on being a math major, that is until she took calculus, and thankfully for us and the entire disability community, her passions turned elsewhere. Although Maria grew up in a supportive atmosphere, with her father telling her she could do anything she put her mind to (and of course she eventually did just that), she still experienced discrimination in her youth and even into adulthood. She was incredibly disturbed by the way people with disabilities were treated unjustly and ostracized by society, even parents with their own children. It was this injustice and division that fueled Maria, along with her equally staunch and passionate cohort, Frank Pennisi, to acquire a grant and found the Southern Tier Independence Center. From just four employees and a budget of $100,000, STIC has flourished into a nonprofit powerhouse that employs over 600 people and is a highly regarded and recognized force in the fight for disability rights.

During her tenure at STIC, two programs that Maria said she is most proud of are the CDPA and TBI Waiver Programs. One of the things that has changed the most during her time here is technology and how positive its effects have been on shaping the agency while vastly improving efficiency, communications, and advocacy efforts. For a woman who "grew up in a paper world," this was extremely exciting. One of Maria's most memorable moments was receiving a $10,000 anonymous donation check! As a less than 10-year-old agency at the time, this was a thrilling testament to the work STIC was accomplishing within the community and beyond.

Her advice to the future generation of leaders in this field is to surround yourself with people who are not afraid to tell you when you're wrong, unlike yes-men who are afraid to tell you the truth. And, above all else, always stick to your principles.

Maria's biggest challenge when STIC first opened? At 27 years old, she had never run an organization before. But like her father advised, she put her mind to it, and by visiting other agencies in combination with her drive and strong work ethic, she overcame this lack of knowledge and experience quickly.

In the end, after all of her incredible accomplishments and accolades, she hopes that "we helped people live better lives" and that she "stayed true to her mission by helping people so they could help themselves and be independent." "I know we have" she concluded, and Maria, we all know it too.

Make Remote Access to NY State Public Meetings Permanent

A public hearing was held in New York City last December to solicit public comment on a proposal to make permanent a practice implemented temporarily during the COVID-19 pandemic. Because public gatherings were unsafe and impermissible in the initial months of the pandemic, the decision was made to live-stream all government meetings typically open to the public over the internet; in due course Zoom seemed to more or less corner the market on videoconferencing, so that became the usual medium. With the pandemic being effectively over and the temporary accommodation due to expire, consideration is being given to extending the videoconferencing option indefinitely. One argument being offered is that it will be a kindness to people with mobility challenges or other disabilities who might find it especially difficult to attend a public meeting.

STIC indeed supports making an option to videoconference permanent. The populations we serve would likely disproportionately benefit from the availability of attending meetings for public bodies remotely, but that is not really at the heart of our motivations here. Our philosophy is that we do not want people to be treated *specially*, we want them to be treated *equally*. If equal treatment requires some reasonable accommodations, like ramps and curb cuts, braille on elevator buttons and directional signage, closed captioning and ASL interpreters, *et cetera*, they ought to be provided, but in principle these accommodations are not *just* for people with various disabilities, but for the entire community, so that all may benefit by the full participation of every member of the community in every aspect of community life.

Specific to the question at hand here is whether videoconferencing, which inadvertently became a universal feature of governance, commerce, and education when the COVID-19 pandemic struck, should remain in common practice now that the pandemic has faded to endemic. There are proposals to modify the law to permit people with disabilities to remotely attend these events, but otherwise mandate in-person attendance.

We would support this as the half-loaf it is; it is preferable to disallowing videoconferencing altogether. But we believe a better option is that the law should not single out people with disabilities or require that they seek out special treatment. Who is to say what a sufficient disability is? Would agoraphobia be a good enough reason? How about misanthropy? What if someone is ambulatory, but it requires such effort for whatever reason that she would prefer to attend remotely? We submit it is obvious why it would be preferable that the law not entangle itself in such thorny questions – or thousands more of them.

Rather, if an option to videoconference is offered to *everyone*, it is left to the discretion of the individual whether to attend in person or remotely, and whatever they decide for whatever reason is their own business alone, without any need for individual accommodations to be sought out. This would reflect the core American value that all of us are created equal and should be treated as such.

Budget Advocacy Day 2024

By Matthew Requa

On February 12, 2024, over 20 STIC employees and supporters traveled to the Capitol Building in Albany, NY for Budget Advocacy Day. After a rousing and uplifting rally, we gathered in groups for private meetings with a wide array of assemblymen and senators. Passionately, we advocated for the dire importance of home and community-based services, expanded paratransit, affordable accessible housing, and equitable wages for the disabled population. Even if change doesn't happen right away after our experience in Albany on Monday, the most important thing is that we showed up, spoke our minds, and will continue to fight until those changes come!

The Endicott Rotary Club Welcomes STIC

By Katina Ruffo

We want to thank the Endicott Rotary Club for inviting Katina Ruffo, Senior Navigator, to present on the Southern Tier Independence Center, The Navigator program, and the Caring Majority. The welcoming atmosphere and wonderful lunch were exceptional. A special thank you to Victor Fiori for organizing this presentation and ensuring everything we needed was prepared. Our hope is that our mission spreads throughout the community; having the Rotary Club members in attendance will surely help spread the word about the programs and advocacy that STIC provides. We want to thank Rotary Club for the work they do to provide services to others and to promote integrity, goodwill, and peace though our communities. Our missions are aligned: to advance healthy, lasting change in our communities and bring equality and accessibility to all. Thank you again!

A Lifetime of Faithful Service: Gregory K. "Cy" Jones, 1948-2023

Our dear friend Greg "Cy" Jones sadly passed on December 4th of last year after a brief, unexpected illness. Greg was an attorney who specialized in disability law and was a friend to Centers of Independent Living across New York State. His advocacy was a tremendous resource for STIC over many years.

After serving in private practice for the first stage of his career, he enjoyed a second act in government as Counsel for the NY State Advocate for Persons with Disabilities, and then as Senior Attorney for the Commission on Quality of Care and Advocacy for Persons with Disabilities, before entering a well-earned retirement in 2013. On June 27 of that year, STIC honored Greg for "Lifetime Achievement in Independent Living" in recognition of his many important contributions to disability rights.

Greg was a nationally recognized expert on the Americans with Disabilities Act and traveled far and wide in New York providing advice about compliance with ADA to all who wanted to know, including here at STIC, where we called upon his ADA insights and knowledge often. Even before the ADA passed, Greg vigorously committed himself to improving society for all, but especially for those with disabilities. A bout with polio as an infant left Greg himself with an ambulatory disability, but it hardly slowed him down, as his dedication to improving the world around him for all fueled his spirit. Greg was as generous in his personal life as in his professional one, taking in homeless people and animals and volunteering at his local outreach center in Albany's South End.

Born and raised in Catskill, New York, Greg graduated from high school in 1966 and then earned a bachelor's degree from Clarkson University and a Law degree from St. John's University in Queens. He leaves behind his loving wife, JoAnne, three sons, and two grandchildren, and is also survived by his brother and sister. Greg loved being outdoors and was physically active, enjoying skiing, canoeing, bowling, bike riding, golfing, baseball, frolicking with his dogs, and even skydiving. He also played a mean guitar. RIP.

Prominent Disability Rights Activist Passes: Brooke Ellison, 1978-2024

Dr. Brooke Ellison, a lifelong Long Island resident who enjoyed a brilliant and varied career, passed away on February 4. As a preteen, Brooke was struck by a car walking home from school and sustained severe injuries that resulted in paralysis from the neck down. Undaunted, she became the first person with quadriplegia to graduate from Harvard University, and she did so *magna cum laude*. Her degree was in cognitive neuroscience; she went on to get a master's in public policy from Harvard and then earned a Ph.D. in Sociology from Stony Brook University.

In 2002 Dr. Ellison published the first of two memoirs, *Miracles Happen*, coauthored with her mother Jean Ellison, who went with Brooke to Cambridge and sat aside her in every class, telling the story of her journey from the physically devastating accident to her Harvard degrees. The book was adapted into a TV-movie by Christopher Reeve in 2004, in the last work he did before his passing; the very famous Mr. Reeve (*Superman*) was himself paralyzed, of course. In 2020, Brooke wrote another memoir, *Look Both Ways*, where she revisited her story from a more mature perspective, and also recounted her very active third and fourth decades.

Dr. Ellison joined the faculty of Stony Brook University after graduation and taught various courses in health policy and medical ethics. In part through her connection with Mr. Reeve, she became a prominent activist promoting embryonic stem cell research as a promising potential treatment, or even a cure, for injuries or illnesses affecting the nervous system. She ran for New York State Senate in 2006 against a powerful incumbent in part to promote her views on the issue, and served on a number of institutional boards, including one nonprofit she founded, studying and advancing research on stem cell treatments and equal rights for people with disabilities, as well as maintaining a demanding schedule of speaking engagements worldwide where she told her story offering hope, motivation, and passion for independent living and potential curative therapies.

The cause of death was reported as complications from quadriplegia, thirty-four years after the accident that induced it. How wonderfully she used those thirty-four years, though, and how unfortunate there weren't more. RIP.

Paying Tribute to a Dear Coworker, Daughter, Sister, Wife, Mother and Friend

By Matthew Requa

On October 26th, 2023, just a few days before Halloween, one of her favorite holidays, we all gathered to honor the forever enduring memory of Rachel Bartlow-McHugh. Rachel began her career at STIC at a very early age, fueled by her determination for disability rights and a strong and compassionate heart that embodied not only STIC's mission but also who she truly was at the core: a kind and naturally caring soul who wanted equality and inclusion for everyone. Over long hours and even longer commutes, Rachel cemented her reputation at the agency and among her coworkers as a dedicated, trustworthy, and brilliant person whose presence, light, and warmth will continue to glow and be felt in every corner of the building and our hearts. With an amazing sense of style, humor, elegance, fearlessness, humility and grace, Rachel made everyone she knew feel important, seen, and loved.

There were lots of tears but also plenty of laughter on that overcast autumn day as friends, family, and coworkers reminisced at a podium in front of a beautiful but unassuming custom-built bench with a plaque, thoughtfully placed in our garden in homage to a true trailblazer, rebel, and champion of the marginalized and misunderstood. This bench will provide comfort for someone who needs a rest, or perhaps just a quiet place to sit and reflect on how fleeting life is and that we must live each moment to the fullest, just like our dear Rachel always did.

"Leaves change into red in the fall...sky sunsets also have a shade of red. Lighter or darker its meaning never changes, it only deepens."

~JM Flyer

courts watch

Laufer v Acheson Hotels: Moot

As we forecast in the previous issue of *AccessAbility,* the Justices unanimously dismissed the *Laufer* case as moot. Justice Barrett wrote the controlling opinion, also signed by the Chief Justice and Justices Alito, Sotomayor, Kagan, Gorsuch, and Kavanaugh. Justices Thomas and Jackson each wrote a concurring opinion raising different issues. Justice Jackson's concurrence was focused on a technical distinction between "mootness," or mere dismissal, and "vacatur," which voids the judgments of the lower courts; this distinction is important, but not especially germane to our concerns. Justice Thomas's argument, however, merits greater attention.

Thomas concurred in the judgment, but contended he would rule not on mootness, but on standing. Standing is the necessary condition that legitimizes one's right to sue. Essentially, one must demonstrate that they have suffered some harm, tangible or intangible, by the failure of another party to follow the law; or, if the law itself results in harm or violates an individual's constitutional rights. More informally, one has standing when one either has suffered a loss, or if not, has something to lose. There are more nuances, but this isn't a law journal and I'm not a lawyer, so we'll leave it there.

Were this claim to be rejected on lack of standing grounds as Justice Thomas suggests, there would be grave ramifications for civil rights activists of all stripes. Deborah Laufer was a "tester," apparently self-appointed, of Title III of the Americans with Disabilities Act (ADA), specifically the "Reservation Rule," which mandates that accessibility features, or lack thereof, available in a hotel be provided by the hotel and any third-party offering accommodation. Ms. Laufer sued under this rule over six hundred times when she found websites for hotels that didn't provide the required information. In almost all cases, she would immediately offer a settlement for $10,000, which would almost always be readily taken by the hotels in lieu of extended, costly litigation.

Was Ms. Laufer running a scam? You could say that, perhaps, but it was lawful, and for better or worse she was protecting the rights of people who are disabled under the law, however marginally, because doubtless the hotels revised their websites so they would be in compliance to ensure there would be no further claims. And should it be found that Laufer had no legal standing to sue, it would affect scores of other activists, most of which are more invested in a cause than a racket, who use litigation tactics similar to this to enforce compliance a variety of civil rights mandates on the books.

Since the launch of the civil rights movement in the years after World War II, the judiciary, through litigation, which is necessary for them to act, has been a bulwark against majoritarian inequities enacted or tolerated by other branches of government, including compliance testing such as what Ms. Laufer's activities were. Without standing, litigation cannot happen, and laws cannot be tested in the courts, absent discovering someone to which something very bad did happen that can justify standing to sue under this new regime. So should some activist, or even an entrepreneurial litigant like Ms. Laufer, detect a situation where someone could suffer harm due to non-compliance with the ADA, *or any other law*, they would be powerless to intervene, and would have to watch and wait, perversely hoping that someone suffers an actual harm before they could act. Is that what we want? Is that what *anyone* wants?

AR State Conference NAACP, et al v. AR Board of Apportionment, et al

The answer to that last question seems to be United States Court of Appeals for the Eighth Circuit Judge David Stras, who last November 20th wrote the controlling opinion for the circuit on a three-judge panel, joined by Judge Raymond Gruender, upholding a District Court's opinion, with a spirited dissent from Chief Judge Lavenski Smith. Stras later wrote again for the full body to deny en banc (that is, a hearing before the full roster of active judges) 7-3, with an eleventh judge recusing. CJ Smith again dissented, joined by Judges Steven Colloton and Jane Kelly, on January 30 of this year; Colloton wrote the dissenting opinion for the en banc denial.

Actually, it's worse than the potential Laufer finding urged by the Thomas concurrence; the ruling in this case would not just deny standing to parties not sustaining direct harm, but would deny the right to sue to anyone, with the sole exception of the United States Attorney General!

This case involves the decennial redrawing of district lines after the U.S. Census does their full accounting of the population in every year ending in zero. The Arkansas Constitution provides that a panel consisting of the Governor, the state Attorney General, and the state Secretary of State, collectively the Board of Apportionment, is charged with redrawing the district lines for the two houses of the state legislature. The Arkansas chapter of the NAACP challenged the lines drawn by the Board, noting that in the lower chamber, conveniently comprised of one hundred members/districts, there were only eleven majority-black districts, despite a statewide Black population of sixteen percent. No discriminatory intent was alleged, but the Voting Rights Act (VRA), as revised in 1982, established that discriminatory intent was not a necessary component of a discriminatory effects claim. The "results test," rather, stipulated that anything that can be demonstrated to cause a discriminatory effect, regardless of how it came to be, violates § 2 of the VRA.

For example, imagine an election conducted using a particular type of voting device. All voting devices have a rate of error, where the voter intends to cast a proper ballot but fails and instead casts one that cannot be counted; these lost ballots are commonly called residual votes. The residual vote rate on this device is 3%. But now suppose it came to light that non-white people were three times more likely to err when voting than white people, even controlling for obvious confounds like education, resulting in non-white voters having to cast 109 ballots to have the same electoral impact as 100 white voters. No one intended this; no one even knows how or why this is happening. But the result is discriminatory, and if it can be remedied by using a different voting mechanism, the government must do so.

(Incidentally, this isn't hypothetical – precisely this was found to be true of the Votomatic punch card voting systems made famous in the notorious Florida recounts following the 2000 presidential election. The Votomatics were headed for extinction anyway, but this 2004 finding was one of the last nails in their coffin.)

So, the argument from the NAACP was that the 2020 redistricting had the result of diluting the Black vote, and they offered a redistricting plan of their own that produced a proportionate number of majority-Black districts while matching all of the other merits of the original plan (compactness, joining communities of common interest, avoiding splitting up municipalities unnecessarily, etc.). The question at hand to be adjudicated on its merits was whether the original districting plan was sufficiently unrepresentative to violate the VRA's Section 2; if so, the lines would have to be redrawn. There were complicating factors involved, like was it fair to redraw lines when an election is imminent and campaigning is underway. On the merits, it isn't clear how the case would have been decided.

But the case wasn't decided on the merits. Rather, on February 17th of 2022, U.S. District Court Judge Lee Rudofsky of the Eastern District of Arkansas, ruled, in a lengthy opinion that often seemed apologetic, that, in contravention to decades and decades of precedent, since no "right of private action" was explicitly included in Section 2 of the VRA, that no one other than the Attorney General of the United States could seek legal redress for government action that resulted in discriminatory impact, and dismissed the case on those grounds without prejudice.

Interestingly, in the conclusion to the ruling, Judge Rudofsky all but asks to be reviewed, if not overturned, by a higher court, writing "…the private-right-of-action question is an important one. This Court will not be the last word on it. And this Court is thankful for that. Judges should [acknowledge] that any one of our conclusions might be wrong; [we] are just humans in robes."

As Judge Rudofsky predicted, the case was appealed, amidst unusual attention for a district court ruling. Perhaps contrary to Rudofsky's expectations, however, his ruling was upheld, and Judge Stras, a former clerk of Justice Thomas appointed by President Trump1 off of the Minnesota Supreme Court, was anything but apologetic; if anything, his opinion was combative, snide, and dismissive of the plaintiff's claims. In a torturously literalist reading of the VRA and adjacent statutes and case law, Stras posits that since Section 2 does not explicitly grant a private-right-of-action in its text, then no citizen has any rights at all. He dismisses precedent as irrelevant because he finds his interpretation correct and the hundreds of cases that preceded it wrong, and modified the dismissal of the case to be with prejudice, which means the plaintiff may not re-file suit on this claim; this is a remarkably provocative and gratuitous choice.

Chief Judge Smith's dissent is brief, emphatic, and more than a little incredulous at the controlling decision, citing a dizzying number of precedents that assumed a private right of action, both specifically to the VRA and generally in terms of any of a citizen's foundational natural rights, many of these established as long ago as the Magna Carta. He cites the principle that "where there is a legal right, there must be a legal remedy," and avers that making these rights solely enforceable on the discretion or availability of government actors is antithetical to the sovereignty of a free people.

The opinion and dissent in the denial of en banc largely cover the same ground, including palpable disdain and condescension in Judge Stras's controlling opinion and astonishment at the majority's arrogance and audacity in the dissent. Judge Colloton showed more open contempt for the panel's opinion, essentially asserting that the decision is wrong in virtually every particular, that it defies ample Supreme Court precedent, and it is a demerit on the 8th Circuit that they failed to reject it. He further addressed the expansion of the dismissal to a prejudiced one, noting that it was at the very least procedurally improper and most probably substantially so as well, compounding the already erroneous decision.

Not being a lawyer--but having taught some rudimentary Constitutional law in the past--what occurred to this writer was simply the black letter law of the First Amendment, which, while best known for freedom of religion and speech, includes a final clause: "Congress shall make no law…abridging… the right to petition the Government for a redress of grievances." It is unclear why this went unmentioned both in the opinion and in the dissent, but put simply, if the judiciary is considered a part of the government, filing a suit in defense of one's Constitutional rights is a form of petition, which is sacrosanct. The dissents allude to this briefly but mainly focus on the avalanche of precedent granting private right of action. Stras's two opinions willfully and anti-intellectually avoid it like a toddler ducking and dodging to avoid eating her cauliflower.

Congress passed a law in 1871, intended to criminalize the activities of the newly constituted Ku Klux Klan. It has been revised frequently over the passing years, and it currently is in effect as Section 1983 of Title 42 of the U.S. Code. We shall reprint the operative part of the law below.

Every person who, under color of any statute, ordinance, regulation, custom, or usage, of any State or Territory or the District of Columbia, subjects, or causes to be subjected, any citizen of the United States or other person within the jurisdiction thereof to the deprivation of any rights, privileges, or immunities secured by the Constitution and laws, shall be liable to the party injured in an action at law, suit in equity, or other proper proceeding for redress.

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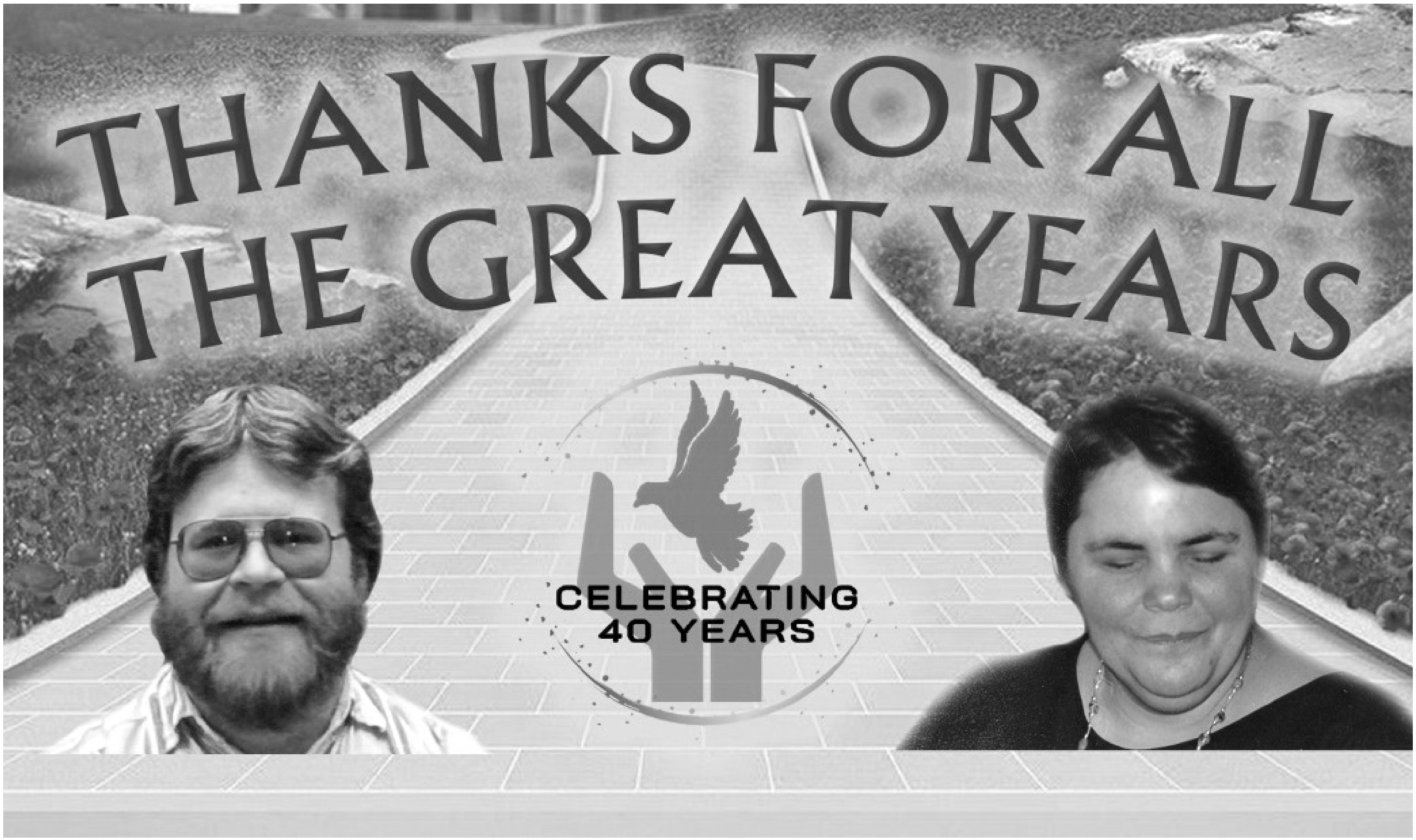
1. Stras's appointment was initially blocked by his home state Senator Al Franken, but when Franken resigned on January 2, 2018, due to allegations of unchivalrous behavior, the White House resubmitted the nomination the next day.

2. It is disquieting that the same judge that writes an opinion for a sub-panel of the court can write the decision to deny reconsideration of that opinion by the full body of the court. At the very least it is a bad look.

Given that, how can anyone seriously contend that a private party cannot sue in defense of their rights?

Between this ruling by a Thomas protégé and Thomas's Laufer concurrence, a hazy shadow of a fairly radical movement in a segment of the legal community is beginning to take shape, using standing restrictions as a fulcrum to roll back much of the civil rights jurisprudence of the Warren Court. We shall be watching this closely.



A Celebration of Legacy: Maria Dibble and Ken Dibble's Retirement Party

By Lucretia Hesco

On Friday, January 26, friends, colleagues, and well-wishers from across the state gathered to celebrate the remarkable careers and contributions of Maria Dibble and Ken Dibble at their retirement party brunch. The event was a heartwarming affair filled with laughter, fond memories, and heartfelt tributes.

Maria Dibble, a co-founder of STIC, has dedicated an incredible 40 years of her life to growing and nurturing STIC into the success it is today. Her unwavering commitment to empowering individuals with disabilities has left an enduring mark on countless lives. Maria's vision and leadership have been instrumental in shaping STIC into a beacon of support and advocacy.

Maria's commitment to STIC will continue beyond her retirement, as she steps into a new role as a board member. In accepting this responsibility, Maria demonstrates her ongoing dedication to STIC and its mission. Her wealth of experience and deep understanding of STIC's values make her an invaluable addition to the board.

Ken Dibble, who has been an integral part of the STIC family for 35 years, is celebrated not only for his longevity but for his multifaceted contributions. Serving in roles such as Chief Information Officer (CIO) and Public Policy Analyst, Ken's expertise and passion have played a crucial role in STIC's development and its ability to make a meaningful impact on the community.

The atmosphere was one of joy and nostalgia, as colleagues reminisced about pivotal moments in STIC's history. The room echoed with applause as Maria and Ken were honored for their dedication, resilience, and the lasting legacy they leave behind.

The retirement party was not just a farewell but a celebration of a dynamic duo whose passion and commitment have shaped the landscape of disability advocacy. As Maria and Ken embark on new adventures, their influence will continue to resonate in the hearts of those who have had the privilege of working alongside them and benefiting from their tireless efforts.

ROD SERLING CENTENNIAL  1924 - 2024

By Todd Fedyshyn and Jennifer Watson

Xscapes at STIC is proud to partner with Assembly Member Donna Lupardo and VisitBinghamton.org to celebrate the Rod Serling Centennial throughout 2024.

As the Greater Binghamton community commemorates Rod Serling's legacy through a centennial celebration, visitors are invited to explore the influence the legendary creator of "The Twilight Zone" had on the city's identity. Through immersive activities, guided tours, and special events, guests will journey through Serling's life and imagination, discovering the parallels between his groundbreaking narratives and the unique spirit of Binghamton.

Serling once said, "Everybody has to have a hometown, Binghamton's mine. In the strangely brittle, terribly sensitive make-up of a human being, there is a need for a place to hang a hat or a kind of geographical womb to crawl back into, or maybe just a place that's familiar because that's where you grew up. When I dig back through memory cells, I get one particularly distinctive feeling – and that's one of warmth, comfort, and well-being. For whatever else I may have had, or lost, or will find – I've still got a hometown. This, nobody's gonna take away from me."

Located in Binghamton, STIC's fully accessible Twilight Zone escape room offers fans of Rod Serling's iconic series an immersive experience like no other. Inspired by the imaginative and thought-provoking narratives of "The Twilight Zone," and Serling's life, this escape room challenges participants to unravel mysteries, solve puzzles, and navigate through mind-bending scenarios—all while paying homage to Serling's legendary storytelling.

What makes this experience even more special is that it serves a dual purpose: celebrating Rod Serling's centennial birthday and contributing to a meaningful cause. All proceeds from this event will go towards supporting STIC's mission to empower people with disabilities to live independently in the community. Click here to learn more about STIC

To book an experience in the Twilight Zone escape room at STIC visit: xscapes-stic.com/index.php/twz/

To learn more about other activities in Binghamton that pay homage to Serling check out: visitbinghamton.org/unique-to-bing/rod-serling/

MEMORANDUM IN OPPOSITION

Editor's note: The governor's 30-day amendments to their budget proposal were issued very near to this newsletter's quarterly deadline. STIC's publishing schedule did not permit us to comprehensively analyze and critique the governor's revised, appalling plan, which represents close to an existential threat to independent living in New York State.

In this issue, therefore, we reprint in its entirety, with permission, a response from the New York Legal Assistance Group, part of the coalition of organizations serving our consumers and the public interest, with which our views are in alignment.

We shall directly address specifics of the budget proposal and the legislature's rejoinder in the next issue; much may be resolved by then, so expect a blend of opinion and reportage.

Gov. Hochul 30-Day Amendments to FY 2025 Budget – HMH New Part H Proposed Restrictions on Eligibility for CDPAP

The New York Legal Assistance Group (NYLAG) opposes this legislation.

NYLAG uses the power of the law to help New Yorkers in need combat economic, racial, and social injustice. We address emerging and urgent legal needs with comprehensive, free civil legal services, impact litigation, policy advocacy, and community education. We aim to disrupt systemic racism by serving clients, whose legal and financial crises are often rooted in racial inequality. Our free legal services include representation of older persons and children and adults with serious illness or disabilities in retaining Medicaid eligibility and accessing Medicaid home care services in order to live safely in their homes and avoid institutionalization.

NYLAG strongly opposes the proposal added in the 30-day Amendments that would harshly restrict access to the Consumer-Directed Personal Assistance Program (CDPAP).

I. Ban on Allowing a Designated Representative (DR) To Direct CDPAP

1. With the severe home care workforce shortage, especially upstate, MLTC plans push members into CDPAP because they simply cannot staff the cases with traditional personal care. It is nearly impossible to staff 24-hour live-in care – and low hour cases as well -- without using CDPAP, even in rural Westchester and Putnam counties, let alone farther upstate. If family cannot serve as Designated Representative (DR) for a person with dementia or other disabilities, these consumers will be left with *no care*. Many will be forced into nursing homes.

2. CDPAP aides may perform skilled tasks, avoiding use of costly Private Duty Nursing and Nursing Homes. Since 1992, when the disability community scored a victory in amending the Nurse Practice Act, CDPAP aides have been able to perform tasks that otherwise only a nurse can be paid to do. NY Education Law § 6908, subd. 1(a)(iii). Thousands of consumers young and old have been able to remain safe at home, with CDPAP aides providing skilled care like NYLAG's clients who need a trusted person to serve as their

Designated Representative (DR):

- Sam, age 31, has Lennox-Gastaut syndrome, a severe form of epilepsy, with chronic obstructive pulmonary disease and other impairments. He is nonverbal and non-ambulatory, but can be fed pureed foods, which he enjoys. He lives with his aging parents who oversee his care. His mother is his 17A guardian and DR. He receives 24 hours/day care - split between private duty nursing and CDPAP -- together providing round-the-clock care with many skilled tasks - suctioning, frequent seizure interventions, administration of medications, nebulizer treatments, oxygen, enemas, chest physical therapy, and pulse readings. They also assist with every activity of daily living (ADL) -- bathing, incontinence care, dressing, transfers and mobility in a wheelchair. Without CDPAP, his MLTC plan must approve a second 12-hour shift of private duty nursing – which is not only expensive but is difficult to staff with the nursing shortage. He would lose trusted longtime CDPAP aides who know how to assist with his complex conditions (at a lower cost than nurses) – or be forced into a nursing home without the loving support of his parents.
- Olga has advanced dementia and depends on a CDPAP aide 12 hours/day while her daughter, who cares for her at night and is her DR, is at work. In addition to assisting with ADLs all day, the aide administers medications, which a traditional personal care aide may not do. Despite her dementia, Olga expresses feeling comfortable and safe in her own home and knows and trusts her daughter and longtime aides.
- Under NYS rules, private duty nurses may not help with Instrumental ADLs (IADL) like shopping, meal preparation, laundry, cleaning. Policy Manual §16.2. (https://www.emedny.org/ProviderManuals/NursingServices/) The plan or State, if fee for service, would have to pay a personal care aide AND a nurse at the same time for those who live alone without family to help. CDPAP aides do it all – saving even more money.

3. Children with severe disabilities depend on CDPAP with their parents serving as unpaid Designated Representatives.

- Anastasia Samoza, with her sister was one of the first children to enroll in CDPAP at age 12. Once she turned 18 she no longer needed a DR, but under the proposed rules she would have been denied CDPAP, making it impossible for her to finish school. Anastasia went on to college and a successful career - gave a primetime Keynote speech during the 2016 Democratic National Convention, was liaison to the Disability Community for the NYC Council and now is a consultant (https://www.tasspeaks.com/).
- Alex, 9 months old, has hydrocephalus, cancer of the optic nerve, and survived COVID-19. Because both of Alex's parents work and care for Alex's sister, after a series of appeals NYLAG filed, Alex was approved for CDPAP services upon showing that the medical services requested were far beyond "normal parental duties." If his parent cannot serve as his DR, his CDPAP would be cut off, and he would require a private duty nurse since he needs medication administration, care of a shunt and port in his chest, and other tasks beyond the personal care scope. One or both of his parents could be forced to quit their jobs.

4. Denying participation in CDPAP for individuals who lack the mental capacity to "direct" their own care is illegal. As a service provided under NYS's State Medicaid plan, CDPAP must be offered statewide to any Medicaid recipient who meets the eligibility criteria. Under the Americans with Disabilities Act, eligibility criteria may not be used that screen out people based on their disability. 28 C. F. R. 35.130(b)(3)(i). Prohibiting an individual with dementia or an Intellectual/Developmental Disability (IDD) from having a DR would deny them CDPAP based on their disability. Allowing a DR is required as a "reasonable accommodation" of their disability.

5. Limiting access to CDPAP would jeopardize enhanced federal funding of $500 million/year under the Community First Choice Option (CFCO). NYS relies on CDPAP, along with personal care as its primary CFCO services since CMS approved NYS's CFCO proposal in 2015. Since then, NYS has drawn down **$3 billion** in the enhanced Six Percent federal match. CFCO services must include supervision, and/or cueing with ADLs, IADLs, and health-related tasks, and must be available to Medicaid recipients who needs a nursing home level of care without regard to the type, nature or severity of disability. 42 U.S.C. 1396n(k)(3)(B), (k)(6)(B). Anyone who needs supervision and cueing with ADLs is likely to need a DR, so banning DRs would illegally deny CFCO services based on the nature of the disability. Banning DRs also violates CFCO requirements for Person-Centered planning, which must include a representative of the individual's choosing. 42 C.F.R § 441.540. (https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html)

6. The MLTC Capitation Model Caused the Growth of CDPAP and Should be Repealed

NYLAG supports the Home Care Savings and Reinvestment Act (S7800/A8470) that would end the perverse incentives that are to blame for rising costs in MLTC. NYS has lacked transparency about data that show the growth in CDPAP as well as MLTC generally is in low-hour cases; MLTC plans reward both personal care agencies (LHCSA) and CDPAP Fiscal Intermediaries (FI) with better rates as a reward for recruiting new members who need low hours of home care. The MLTC plans make a profit on those cases – which are more than 90% of all MLTC cases – because they receive the same monthly premium from the State for each member regardless of how many hours of home care the member needs. Removing the incentive caused by this "capitation model" would likely reduce growth in CDPAP. The State would save money because it would only pay the cost of the few hours of CDPAP care provided in most cases, instead of the high capitation premium.

II. Consumer Protections Must be Enacted if Designated Representatives are Banned

While NYLAG believes that limiting CDPAP to those who can direct their own care would be illegal, if the ban on DRs is enacted, consumer protections are vital. The proposed effective date of the ban on DRs is Oct. 1, 2024 (§§ 14 and 18 of part HH). This date is unrealistic, as the law should require DOH to develop and implement, with stakeholder input, procedures to minimize disruption of care, which would take longer. *Emergency regulations with no public input should NOT be allowed* (§7 of part HH). Procedures must include but are not limited to:

- **Every consumer must be assessed by the plan or local district to determine if the CDPAP aide is performing skilled tasks** beyond the scope of a personal care aide. If so, the plan must authorize private duty nursing services for the same schedule provided in CDPAP. If the plan determines that the aide is not performing any skilled tasks and that services could be provided by a personal care aide, or that a nurse could perform the skilled tasks in a shorter shift, the plan must give **advance written notice of the discontinuance of CDPAP** and the change to personal care and/or private duty nursing. The consumer must have the opportunity to appeal and receive continued CDPAP as "aid continuing" in the meantime.
- **Local districts do not authorize private duty nursing, so DOH must establish a procedure for districts to transfer all CDPAP cases where the aide is providing skilled tasks to the DOH Office that authorizes private duty nursing** to authorize services. The local district must continue CDPAP services until the DOH office has either authorized nursing services or, if DOH decides personal care services would be adequate, then the local district must send advance written notice of discontinuance of CDPAP services to be replaced by personal care services, with the opportunity to appeal with Aid Continuing.
- **CDPAP should not be terminated until the plan or local district have secured adequate staffing of the required personal care or private duty nurses – and until the aides have had time and opportunity to do required training.** Even where a shift from CDPAP to private duty nursing or personal care is not disputed, written notice must be provided to the consumer and the DR of the proposed home care or nursing agency confirming adequate staffing is available, with appeal rights if the consumer cannot verify staffing.
- **Continuity of care when FI's close** -- whether FI's close because of the new contracting requirements or under the proposal to limit the number of FIs in a plan or a county (§2) --protections are needed to ensure continuity of care. Current law only requires the closing FI to give 45-day advance to the consumer with a list of other FI's. SSL §365-f (a)(4-d)(i). It cannot be left up to the consumer to shop around for an FI – they should be given the opportunity to choose one but, if they do not choose by a deadline, they should be assigned. Also, adequate time must be given for aides to go through the paperwork required in the new FI.

III. NYLAG Opposes Mandated Training and Maximum Limits on Hours Worked

NYLAG opposes state-mandated training for CDPAP aides (§7). A hallmark of CDPAP has always been that the consumer or their DR - not an agency or the state - is responsible for recruiting, hiring, training, supervising, and terminating their own staff. This has worked for over 40 years and was the impetus for reforming the Nurse Practice Act in 1992. The DR's ability to train the aides is reviewed by the local Medicaid office or plan as a condition of approving CDPAP. The bill would prevent an aide from working until they have completed a state-mandated training course, removing a core pillar of consumer responsibility and likely to cause a delay in services. Many CDPAP aides perform skilled nursing tasks (see example of Sam on page 1), for which no aide training program exists.

NYLAG opposes setting maximum daily and weekly limits on the hours PAs can work (§ 7, 13). The federal and state overtime limits already impose a practical limit on hours, as many FI's do not allow overtime. Some consumers want or need aides to work overtime, and if the CDPAP FI approves it this should be left to the consumer and the FI. The proposal would authorize DOH to issue emergency regulations – with no public comment – to limit how many hours the aide can work each day and each week, taking more control away from the consumer – and threatening an even more dire workforce shortage.

NYLAG questions the ban on agencies offering home care and CDPAP (§8, 11). Some consumers want or need to combine CDPAP and traditional personal care because of the staffing shortage. This is easier to manage when these two services are managed within the same agency.

NYLAG SUPPORTS the ban on insurance companies operating CDPAP and home care agencies (§3-a). This is a clear conflict of interest and eliminating the practice is a good idea.

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