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AccessAbility

Summer 2025
Number 159

In Opposition to the Medical Aid in Dying (MAID) Bill

by Jennifer Watson

STIC strongly opposes the legislation A.136/S.138, which would legalize physician-assisted suicide in New York State, and we are deeply chagrined that the Assembly and Senate have both passed the bill by narrow margins. While intended to offer compassionate options to individuals facing terminal illness, this legislation presents substantial and well-documented risks for people with disabilities and other vulnerable populations and lacks sufficient safeguards to prevent misuse and harm.

The disability community has long experienced systemic discrimination in healthcare, housing, education, and broader societal attitudes. Legalizing assisted suicide, even under seemingly narrow conditions, sets a dangerous precedent by reinforcing the notion that some lives, particularly those involving long-term care, dependency, or high-cost support, may be less worth preserving. This undermines efforts toward equity, inclusion, and equal access to care.

The "six months to live" criterion, which this legislation uses to define eligibility, is both arbitrary and medically unreliable. Prognoses are often wrong, sometimes by months or even years, especially for people with chronic illnesses or complex disabilities. Using such a vague benchmark as a gateway to life-ending medication places people at unnecessary risk and erodes the foundation of ethical medical care. It opens the door to ending lives not because death is imminent, but because care is inadequate, expensive, or simply inconvenient to others.

I experienced this firsthand. My son was born with a significant disability and spent months in the NICU. During that time, we were repeatedly pressured by doctors to end his life. They insisted he wouldn't survive his first year and certainly not beyond that. They urged us to sign Do Not Resuscitate orders and told us it would be better for both him and for us to "let him go." They even employed strategies to try to divide my husband and me on the issue, hoping that if one of us agreed, the other would follow. It wasn't until we made it absolutely clear that we would not back down that they finally began working towards discharging us.

INSIDE

That child deemed too burdensome to keep alive, just turned fourteen this June. He is deeply loved, well cared for, and an integral part of our family. His life is not an exception or a statement—it's a real life, with its share of ups and downs, hard days and happy ones, challenges, and milestones. It reflects what should be true for everyone: that every life is worthwhile, regardless of disability or diagnosis.

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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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People with disabilities are disproportionately vulnerable to coercion and abuse, particularly in settings where they rely on others for care and decision-making. Research and lived experience consistently show that rates of abuse among disabled individuals far exceed those of the general population. In the absence of strong and enforceable safeguards, assisted suicide laws open the door for life-ending decisions to be shaped not by informed, voluntary consent, but by subtle or overt pressure from caregivers, family members, physicians, or even financial constraints.

This concern is not theoretical—it is reflected in real-world data from Oregon, where physician-assisted suicide has been legal since 1997 under a law that closely mirrors the proposal now on the governor's desk in New York. Over 25 years of reporting, the percentage of individuals accessing assisted suicide who had private health insurance declined sharply from 65% to just 20%, while reliance on public insurance coverage, Medicare or Medicaid, rose to 80% by 2022. During the same period, the number of individuals citing fear of being a burden to family or caregivers as a reason for seeking assisted death increased from 30% to 46%.

These trends suggest a shift from purely medical motivations toward psychosocial and economic pressures, which disproportionately affect people with disabilities, who often face the need for high-cost, yet largely inaccessible, long-term support services.

At STIC, many of our staff and community members can speak from personal experience about how they or their loved ones have been treated by physicians and healthcare systems as if their lives were less valuable. These are not isolated incidents; they reflect a pervasive, systemic bias that devalues the lives of people with disabilities. Allowing physician-assisted suicide in such an environment compounds the risks, especially when decisions are made under duress, or due to a lack of access to adequate care and support.

In some documented cases, insurance providers have denied coverage for life-sustaining treatment while approving payment for assisted death, further underscoring the ethical risks of introducing this option in systems that already fail to equitably support disabled people.

Mental health screening practices in existing assisted suicide frameworks raise additional concerns. A study published in the New England Journal of Medicine found that 20% of Oregon patients who pursued physician-assisted suicide exhibited symptoms of depression. Despite this, data from Oregon shows that psychiatric referrals have dropped significantly—from 28% of cases in the early years of the law to just 1% in 2022. At the same time, the average length of the doctor-patient relationship prior to prescribing life-ending medication has declined from 18 weeks in 2010 to just 5 weeks in 2022.

This raises multiple concerns about whether physicians have sufficient time to understand a patient's full circumstances and assess the true drivers of their request. It also highlights a deeper, systemic issue: the ongoing lack of accessible, adequate mental health services, particularly for people with disabilities and others who already face barriers to care. In this context, legalizing assisted suicide without first addressing the state's mental health and long-term service gaps risks substituting death for the support people are unable to obtain.

This disparate valuation of life that assisted suicide implies has an insidious effect. Assisted suicide purports to be a measure of compassion in only the gravest of terminal cases, where one expects to survive only days or hours longer, suffering until the end. We share in the compassion for such people. Everywhere this has been tried, however, the practice expands in a classic, "slippery slope" fashion to include people with non-terminal physical conditions, with mental illnesses or cognitive decline, or even no condition at all beyond depression, old age, general ennui, or a mere desire to avoid the inevitable debility time inflicts on all of us.

For these reasons, STIC implores New York Governor Kathy Hochul to veto MAID; the veto pen is the last line of defense preventing premature deaths of New Yorkers.

The Callous Boondoggle of Involuntary Commitment

Governor Hochul has been proactive and constructive in her mental health policy during her tenure. In cooperation with the Legislature, the Governor has invested readily and deeply in a variety of initiatives that have been helpful in addressing the mental health crisis. We salute that.

However, there were several high-profile tragedies in 2024 in which mental instability played a part, mainly in the New York City subways, to which the Governor felt obliged to respond in some fashion. In her 2025 State of the State address, she introduced a plan to expand means to commit people suspected to have a mental health condition to institutions involuntarily, and then held the budget hostage until the Legislature acceded to her demands.

STIC believes this is a terrible development, and we urge the measures to be repealed or dramatically amended. While couched as a sympathetic and caring measure towards individuals that are unable to care for themselves, the policy prescription belies the sentiment. "Communal well-being and safety" here means the forced removal of anyone who might tend to make pedestrians, commuters, consumers, or business patrons feel uncomfortable. This ensures the clear consciences of the many by abusing the freedoms and civil rights of a vulnerable few.

Constitutionally, this infringes on the right of habeas corpus, according to which the government must demonstrate just cause for detaining someone. Judging to have a mental health condition so severe that they must be incarcerated for their own safety ought to be a rather high bar – this initiative lowers it.

Out of sight may mean out of mind, but that just papers over the problem by locking away vulnerable people. Involuntary commitment does nothing to solve the mental health crisis. We still face a critical shortage in mental health professionals and facilities. People seeking mental health care on their own initiative are routinely turned away from CPEP after brief, stabilizing stays, for lack of space and unavailability of providers. How much will this situation worsen when we start bringing people into these overtaxed agencies in against their will? We're about to find out.

This is a transparently political and cynical attempt to appear as if one is solving an intractable problem by literally hiding it, moving free people, perhaps difficult ones, from the streets to a place behind walls. It will create an adversarial relationship between those assumed to be mentally ill and the police, if not authority in general. Vulnerable people will flee and hide from police, for fear of losing their freedom despite committing no crime. When such flight is observed, it would inevitably induce the police to pursue, with all the potential bad endings in which such chases can end.

Speaking plainly, much of the concern about "mental health" is more precisely a concern about homelessness. The solution to homelessness, however, is not to round people up unwillingly and send them for treatment from caregivers who aren't present in facilities that don't exist. This is a recipe for unintended consequences, just about all of them bad.

There are no silver bullets to solve this problem, no shortcuts—it requires sustained investment and hard work. We must start by strengthening community-based mental health services, which are more effective, more humane, and less costly than institutional care. Inpatient treatment should be reserved for only the most acute situations, while the majority of people can and should receive support in their own communities. This includes expanding programs like Peer Bridgers and INSETs, which help individuals engage with person-centered support, rebuild their lives, and stay connected to services over time. We also need to invest in facilities for those who seek treatment and raise wages for mental health professionals so we can ensure access to timely, quality care. We also need structural improvements, including the mandated use of Incident Review Panels to investigate critical events, identify real system gaps, and develop effective and humane solutions.

Solutions should not be confined to the arena of health care. If homelessness is a concern – and it is – then let's build more affordable housing – another statewide crisis – and address NIMBY zoning restrictions that result in people having nowhere to go. Invest in outreach programs that offers those in need to voluntarily get sufficient nutrition, job training or retraining, and affordable health care, physical as well as mental. These are not easy answers, but they are ones that will work. And with the avalanche of social spending cuts imminent on the federal level, state investment is more important than ever; New York must step up to preserve our way of life.

We lament that this expansion to involuntary commitment was bullied into place by Governor Hochul, and we hope that its ineffectiveness will be made manifest soon, before grave harm befalls many. Then we can focus our efforts on finding benevolent, real solutions to the growing mental health needs in our communities, such as the voluntary, community-based services that have proven effective elsewhere.

STIC's Stance on Mental Health

Southern Tier Independence Center (STIC) strongly opposes the expansion of involuntary mental health treatment in New York State. Instead, we advocate for a mental health system that prioritizes voluntary, peer-led, community-based support over coercive interventions.

Recent legislative proposals seek to broaden the criteria for involuntary psychiatric commitments and forced outpatient treatment. While proponents claim these measures enhance public safety, evidence suggests they increase trauma, worsen health outcomes, and impose higher costs on the state. Rather than expanding restrictive interventions, resources should be directed toward strengthening voluntary, community-based mental health programs that address the root causes of crises.

Expanding involuntary commitments undermines individual rights and disproportionately affects marginalized populations, particularly people of color and individuals experiencing poverty. This reflects a systemic failure to support those most in need. Coercive interventions fail to address critical factors such as housing instability, food insecurity, substance use, and inadequate access to health and mental health care.

New York must address critical gaps in the community-based mental health system. The Olmstead decision mandates that people with disabilities, including those with mental illnesses, receive services in the most integrated setting appropriate to their needs—reinforcing the necessity of strengthening community-based care. Furthermore, the Department of Financial Services (DFS) has already acknowledged that "at present, there is not provider sufficiency" in community-based behavioral health services. This underscores the urgent need to invest in voluntary, effective interventions rather than involuntary alternatives.

To create a more effective and person-centered mental health system, New York State must take the following steps:

- Reject policies that expand involuntary commitments and instead prioritize voluntary, community-based solutions that promote dignity, autonomy, and long-term stability. Funding in the SFY 2025-26 NYS Budget must be restricted solely to enhance voluntary service packages and not to the expansion of involuntary treatment.
- Implement Incident Review Panels to analyze systemic failures and improve future crisis responses, ensuring better outcomes for individuals in mental health emergencies. Incident review panels are currently authorized by Mental Hygiene Law § 31.37, but they have never been implemented.
- Increase funding for housing initiatives by strengthening the Empire State Supportive Housing Initiative (ESSHI) and expanding Housing First programs, providing individuals with a stable foundation for recovery and independence.
  - Enhance the base ESSHI rate to $34,000 per year, as the Governor's proposed enhancement is insufficient.
  - Expand Housing First programs by adding 750 more Housing First units statewide.
- Fund eight INSET teams in regions that currently do not offer

this pivotal service, at an annual cost of $4 million. These peer-to-peer, person-centered outreach and engagement teams have proven highly effective in connecting with individuals experiencing severe mental illness. Notably, nearly half of those served by INSET teams are or have been homeless.

- Fund seven Peer Bridger teams at an annual cost of $3 million. Since 1994, Peer Bridgers have helped thousands of individuals to successfully transition from state hospitals to the community. Peer Bridger teams should be routinely offered as a part of successful hospital discharge plans that prevent high numbers of avoidable relapses and repeat readmissions.
- Expand Assertive Community Treatment (ACT) and Forensic ACT to improve access to intensive, evidence-based community services, reducing hospitalization and incarceration rates for individuals with serious mental illness.
- Support mental health clinicians and providers by implementing a 7.8% inflation adjustment to address staffing shortages and improve overall service delivery, ensuring individuals receive timely and effective supports and services.

Expanding voluntary services is the only path to a more just and effective mental health system that truly meets the needs of New Yorkers. We urge legislative action to prioritize sustainable mental health investments and reject ineffective, coercive interventions that harm rather than heal.

A Tone-Deaf Spending Cut

As we are all aware, the second Trump Administration and a pliant Congress has targeted domestic health programs for draconian spending cuts as window dressing to counterbalance the budget-busting extension of the tax cuts enacted in the first Trump Administration. The Department of Health and Human Services (HHS) has proposed especially jaw-dropping cuts.

Here's just one program targeted by HHS to be zeroed out: The Center for Disease Control and Prevention's (CDC) Early Hearing Detection and Intervention Program (EHDI). Since its establishment in 1999 by Congress, the EHDI program has played a critical role in ensuring that newborns and infants are screened for hearing loss early in life and receive timely intervention services if necessary. Hearing loss is one of the most common birth conditions, and without early detection and support, it can severely hinder a child's development — particularly in language, communication, and social skills.

Before EHDI programs, the average age of identification of a child with hearing loss was over three years, or thirty-six months, of age. Since EHDI was implemented, the average age of identification is three months of age. Early access to language/communication is critical to meeting

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later development milestones and ultimately future earning potential of the child. EHDI has successfully built and supported a national infrastructure that allows for consistent, statewide newborn hearing screening and follow-up care.

Eliminating this program would set back the progress we have made as a country with a simple, near-costless screening. It would (naturally) disproportionately affect underserved communities, reduce access to critical services, and ultimately lead to higher long-term educational and social costs. The American Academy of Audiology (AAA) — the largest organization of, by, and for audiologists — has expressed its strong opposition to any efforts to eliminate or reduce funding for EHDI.

This is not a costly program, particularly since all the start-up expenses were incurred long ago, and it pays for itself multiple times over by preventing easily avoidable developmental delays. That is speaking strictly in terms of dollars and cents; more importantly, this simple, cheap means of early intervention enables priceless, irreplaceable flourishing in our most precious resource, our children. One could make the case that this sort of thing is why we have government in the first place.

This is but one egregious example of the lunatic "Ready, shoot, aim" approach the new Administration has taken in its manic hunt for "waste, fraud, and abuse." There's surely plenty of that to be found, but burning down buildings because one dislikes the wallpaper is not prudence, but madness.

Disability and Survival Under Fire

by JL Bonner

I've been following the work of the Sameer Project in Gaza for well over a year now. The grassroots project, founded by four Palestinians in the diaspora, strives to provide access to the necessities for life made scarce by the conflict. Organizers on the ground work to locate, secure, and distribute aid throughout the enclave, as families and communities struggle to survive over twenty months of bombardment, displacement, and trauma. The Sameer Project organizes critically needed encampments and distribution points for water, meals, shelter, and medical aid throughout Gaza.

One campaign of the Sameer Project holds extra relevance for our community: the Refaat Alareer Camp (RAC). Named for the famed Palestinian poet, writer, professor, and activist who was killed in December 2023, the RAC was set up with the specific mission of supporting disabled people and families. As the camp's fundraising page - where organizers document the activities and spending for the encampment - explains, "This first encampment will serve some of the most vulnerable families: highrisk [*sic*] perinatal and neonatal females, children with physical or mental disabilities, adults with special needs and mobility issues, war injuries and chronic diseases." In Gaza, survival is constantly under threat. For those with disabilities, this threat is even greater, making efforts like that of the Sameer Project's a critical lifeline as disabled people struggle for life and dignity under fire.

Terrible tales abound of disabled people being harmed in Gaza, leaving surviving family members and communities in agonizing grief. These stories haunt me as I consider disability in a global lens. Muhammed Bhar's mother recounted to the Middle East Eye how her son with developmental disabilities was slain by military dogs in their family home fell under attack, recalling that "Muhammed could not speak or say any word, but out of horror, he was screaming at the dogs, sometimes saying [...] 'Khalas ya habibi' [enough, my dear]. I don't know how he uttered these words; we had never heard him speak before." Duaa Al-Hweihi's father shared also with the Middle East Eye how he was unable to rescue his thirty-four year-old daughter with cerebral palsy as she was immobilized in their displacement tent in an UNRWA school after the school was raided and the tents set ablaze. Recalling his horror and helplessness as he watched the tent Duaa was trapped in burn, he said, "I couldn't scream; there was no one to talk to. Who could I talk to? The tanks that didn't stop firing?" Yousef Aljamal, the Gaza coordinator for the American Friends Service Committee, interviewed disabled people and their families in Gaza for a piece published in Al-Jazeera News in November 2024. After recounting their stories, he wrote, "Everyone I talked to was dealing with extreme hardship and unable to get the care they needed. But even under the most extreme conditions, the lengths that people were willing to go to protect their loved ones are astounding." In such an uncertain world where all support systems have been disrupted, everyday people with and without disabilities in Gaza unceasingly support and protect each other.

The RAC provides not only a space for disabled people in Gaza to try to survive in dignity and relative security, but also the network of care that people with disabilities have been robbed of. The encampment staffs its own medical clinic on site that treats and monitors individuals with chronic illnesses and disabilities, and also helps to fund travel to one of the remaining partially operating hospitals in Gaza for those who cannot afford transportation. With the cost of medicine skyrocketing as it becomes increasingly scarce, the RAC purchases medications and treatments, and, as life under displacement makes hygiene and sanitation herculean tasks, the camp provides cleaning and personal health support, and even services like haircuts. New families joining the camp have often lost their shelter and belongings, so those in need are given tents, mattresses (including medical mattresses), blankets, and emergency cash stipends. While accessibility devices of all types are scarce as existing supplies dwindle or are destroyed, camp staff are still able to source devices like the occasional wheelchair for some of those who are in critical need. The project employs teachers who provide the education that has been interrupted for young people in Gaza, in addition to speech and physical therapists to work with those who have lost access to such critical supports. The camp regularly organizes events to support mental health, particularly for traumatized children. Children in Gaza already faced incredibly high rates of mental health struggles (a 2022 report finds 80% with depression and over half reporting suicidal ideation) and now having experienced the last twenty months, events like music classes and sports provide a rare escape. As humanitarian aid into the region remains stymied, the project regularly provides as much clean water and nutritious food as it can acquire. The updates, financial accounts, and photo documentation published to the project's fundraising page make clear the tremendous efforts supporting the humanity, agency, and dignity of Gaza's disabled community.

In addition to the day-to-day struggles that organizers and residents of the Refaat Alareer Camp work to overcome, the camp demonstrated its ability to launch emergency action in April 2025 when the area they operated in became an active combat zone. Displacement and forced evacuation are a horrifying ordeal for all who experience it, but especially so for the escalating number of those with disabilities from traumatic injuries. Alaa Arafat, an English teacher in Gaza, writes for We Are Not Numbers specifically on the issues of disability and displacement, focusing on the large number of Gazans who have lost limbs over the last two years (including the largest population of child amputees per inhabitants globally per UNICEF data) or previously. Arafat writes, "In this small spot of land, able limbs have themselves become a precious treasure," going on to detail the compounding effects of disability under displacements that demand constant mobility to dodge danger. Project organizers for the Refaat Alareer Camp state plainly that, "We were the lucky ones. The lucky ones that had the means, strength, and logistical support to evacuate to safety." The camp organizers cannily secured both trucks and extremely scarce fuel to evacuate disabled residents. In the new emergency encampment they inaugurated in a safer place, they reestablished critical services and quickly organized an activity day for the terrified, disoriented children. When the immediate danger abated, they returned to the camp's original location and resumed their work.

I cannot help but see myself and my loved ones and colleagues in the faces and stories of suffering people in Gaza, regardless of the distance and experiences that separate us. As the Refaat Alareer Camp works to receive and support new families, even more names, faces, and stories fill my daily thoughts. On April 17, organizers shared that following the emergency evacuation they were still welcoming displaced families. Hassan - a fourteen-year-old in one of these newly arrived families - was hit in his head and chest with shrapnel and then discharged from the overstressed hospital shortly after surgery. The organizers write that, "Hassan is already excited to start classes with Miss Iman despite the shrapnel in one of his eyes." Earlier that month, on April 5, the project announced the arrival of two new families, including one family with two nonverbal children, in addition to another young child and a month-old infant. The two nonverbal children have at long last resumed speech therapy and physiotherapy, and all have better access to nutrition and standard medical care. Rajaa and her family were run over by a tank, which killed her husband and two sons; she and her two surviving children sustained severe injuries. Now, they have access to the physical rehabilitation and mental health services they require. The need in Gaza far surpasses what the Sameer Project and programs like it can provide. Simply looking online at various fundraising efforts or reading accounts of struggles with disability in the enclave shows how many individuals, families, and communities are trying desperately to survive with disabilities both new and old. With no clear end to the horrors in sight, every effort to help disabled people survive in these circumstances is critical. The Refaat Alareer Camp has dedicated its existence to this struggle, declaring, "Our mission is to serve the most vulnerable population, to give them hope, to give them a future, to preserve their lives." As I work alongside everyone at STIC here in Binghamton, and alongside ILCs across New York and the United States, I see echoes of this mission in everything we do in support of, and as, disabled people engaged in struggles for accessibility, dignity, and humanity.

JL Bonner is the Support Specialist in STIC's CDPAP Department and has a M.A. in History from Binghamton University. Hyperlinks for sources on all underlined text above can be found at https://stic-cil.org/newsletter/AccessAbility_Summer2025_WEB.html#Bonner.

Disability Employment: Increasing Income and Savings for the Future

by Laurie Schaller

Like many states, New York has taken steps to increase wages for employees. The next step is to ensure that everyone, including people with disabilities, is working to their fullest ability. For individuals who receive SSI and/or SSDI benefits, there are work supports and financial tools that can help a person earn and save more income while maintaining health care benefits and supports like Medicaid, Medicaid Waiver, and Medicare.

Working may bring added costs. A person may need a reliable, modified vehicle, more physical therapy, or assistive technology beyond what an employer, vocational rehabilitation or the Department of Labor will provide. These expenses may qualify as Impairment Related Work Expenses. A Plan for Achieving Self- Support is another option that can help a person pay for training, education, reliable transportation and tools related to a work goal. A person who has a disability may also use their ABLE account (or 529A) to save for Qualified Disability Expenses (QDEs) including basic living expenses, work related expenses, and retirement. Most state ABLE plans offer investment options too.

ABLE investment growth is not taxable and does not impact means-tested benefits now or in the future. This is important for those who have a disability and may need means-tested benefits in the future. For example, savings from 401(k) or 403(b) accounts may impact means-tested benefits now, taking someone over a countable resource limit. More importantly, when 401(k) or 403(b) funds are disbursed in the future, they may be taxable, and funds are countable income that may impact benefits. ABLE disbursements do not impact benefits when used to pay for QDEs.

Filing income taxes is essential for people with disabilities who work, especially for SSI beneficiaries. Filing taxes builds a person's earnings record and may lead to future SSDI, retirement benefits, and Medicare benefits. Whether a person receives a W-2, a 1099, or is self-employed, it is important that they file income taxes.

Tax credits can further support financial goals. The Earned Income Tax Credit (EITC) may increase a person's income tax refund. A person who deposits earned income into their ABLE account may be eligible for the Saver's Tax Credit, which could reduce income taxes. These tax credits boost income and savings. Call 211, or 311 if you live in New York City, to find a free tax preparation site near you.

A person who has a disability that began before age 26 is ABLE eligible. On 1/1/2026, the ABLE age of eligibility expands to include people who have a disability that began before age 46. A person does not need to be receiving disability benefits to be ABLE eligible. An ABLE account may be opened at any age.

More people than ever can take advantage of ABLE to build a path toward employment, independence, and long-term financial wellness. The combination of working, using work supports, filing taxes, and opening an ABLE account can be part of a strategy for a stronger financial future. Visit the ABLE National Resource Center to learn more.

Laurie Schaller is Financial Empowerment Manager and Subject Matter Expert at the National Disability Institute. Hyperlinks for more information on all underlined terms can be found at https://stic-cil.org/newsletter/AccessAbility_Summer2025_WEB.html#Schaller.

STIC Launches Sexual Education Advocacy Committee

by Robert Deemie

Conversations about sexual activity and sexual health for people with disabilities may be, at best, a difficult topic to discuss. As society has been progressing towards a brighter future, what was once a taboo topic is now an inalienable human right. The mission of the Sexual Education Advocacy (SEA) Committee is to educate and advocate for the sexual rights of the disability community.

A main goal of SEA is dismantling barriers that stigmatize sexual autonomy for anyone with a disability. We also seek to educate allies and the community at-large to best serve people with disabilities, including parents and guardians of those with disabilities, as well as caregivers and service providers.

Our goal is to change the way those without disabilities view the disability community, especially with regard to their sexuality. One example is defining consent, and how consent is applied to people with disabilities. Consent is about respect and dignity; just as everyone must have the right to say "no," everyone ought to have the right to say "yes." Policies that restrict that freedom, despite any good intentions, infringe on that right.

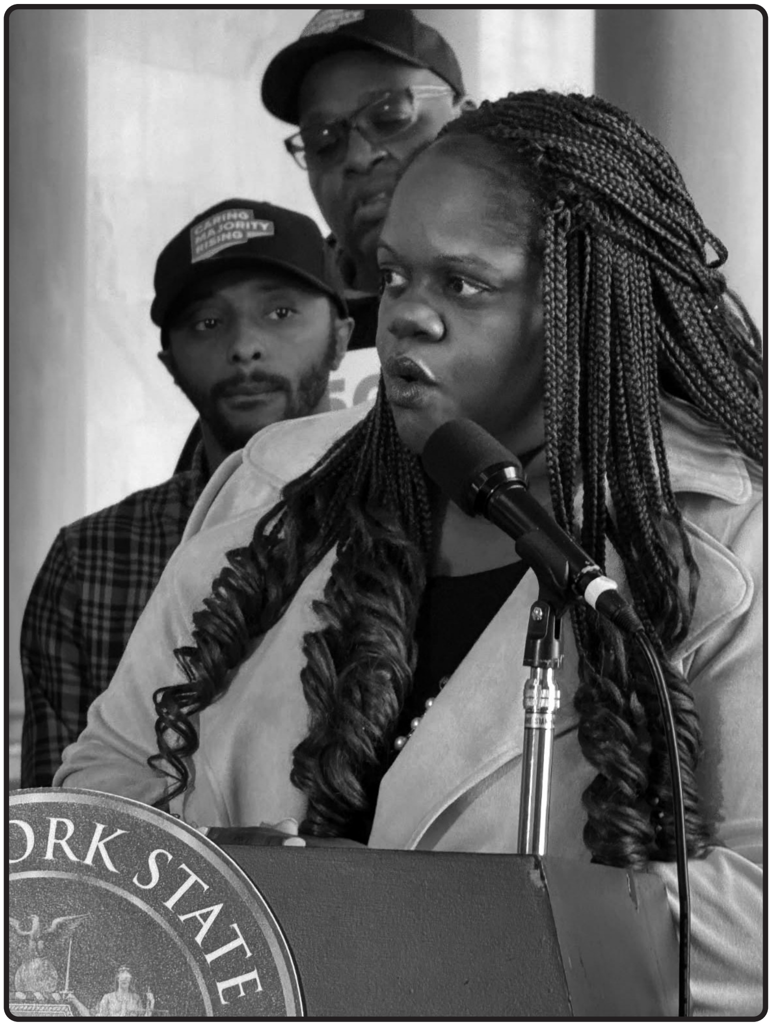
If you would like to know more about our work, or how to help, please contact Chair Robert Deemie; robertd@stic-cil.org.

STIC fights for CDPAP in Albany

STIC has been very active advocating for the protection and preservation of the Consumer Directed Personal Assistance Program, or CDPAP, most specifically from the failing single Fiscal Intermediary (FI) scheme currently unfolding exactly as forecast – calamitously. We have been in constant contact with several legislators in the Southern Tier and have sought meetings with the governor and legislative leadership. We have launched multiple campaigns to deluge lawmakers with emails and phone calls urging them to support various legislative measures, both to ameliorate the effect of the transition to the single FI, and (even better, but less likely) to extricate CDPA from the shambolic process altogether.

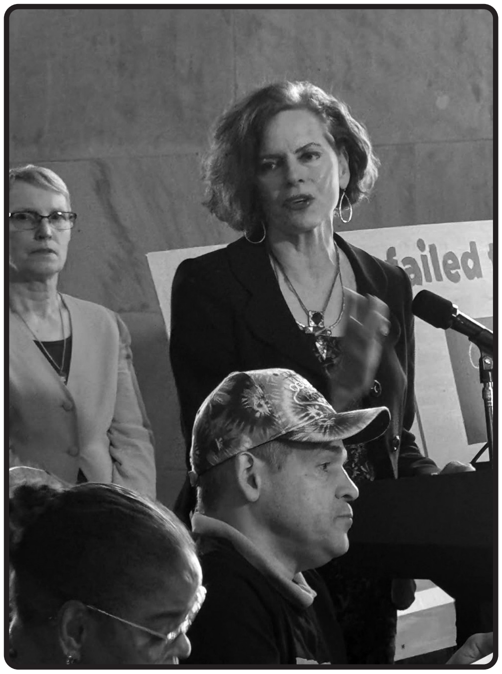
Just to recap, CDPAP is a wonderful system created by disability advocates, including several Centers for Independent Living (CILs) such as STIC, almost thirty years ago, that allowed people with disabilities who needed assistants the ability to hire, train (and fire) their own staff. The "back end" of the employment – things like payroll, tax withholding, employment screens, etc. – was handled by organizations formerly known as Fiscal Intermediaries. Initially, the CIL's and a handful of other non-profits served as FIs, and costs stayed manageable as the program grew. In 2012 New York launched "managed care," which invited for-profit agencies to serve as FIs as well, which, as it became clear the bonanza of Medicaid dollars to be had, they did in a mad rush. Costs skyrocketed, and anecdotal tales indicated that some of the for-profit agencies were bad actors. Instead of exercising oversight and disciplining or removing the bad actors, the governor decided to eliminate all the FIs and inaugurate a new monopoly FI for the whole state, and to do the transition in under one year. This immediately was recognized as a recipe for disaster, and so STIC has been advocating for corrective measures as this disaster has unfolded painfully in plain sight.

There have been several bills introduced, some successfully, that have sought to solve some of the problems created by this DOGEian transition. One is that New York CILs have been made subcontractors under the single FI, although what exactly that means is still undefined. It does give us the capacity to maintain some minimum level of service for consumers and employees that has been otherwise unavailable. The latest measure STIC and its allies have been advocating for is a bill (the latest iteration being S7954/A8355) that would restore the ILCs as full,



coequal FIs, and permit others to petition the Department of Health to serve as an FI as well; in other words, to provide the basic oversight of CDPAP that was needed in the first place instead of a convoluted consolidation doomed to fail.

Delegations from STIC have been traveling to Albany almost every Tuesday for over two months. Additionally, STIC participated in Disability Awareness events on May 8 and May 20 advocating for these bills and many others, and we were represented on May 28 when a major rally for the restoration bill cited above took place. We shall stalwartly continue our advocacy for our communities as we must.



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COURTS WATCH

A.J.T. v. Osseo Area Schools: **Defining the standard of "reasonable"**

This case comes to us from the Minneapolis suburbs, where a student, AJT ("Ava"), with a profound disability moved and sought reasonable accommodations for her rare form of epilepsy that causes daily seizures and impairs her cognitive and physical functioning. Specifically, she sought additional schooling after normal hours of instruction, since the seizures most frequently occur in the morning, up to the standard number of hours per day. The school district cited logistical problems in providing the extensive after-hours instruction and made several counterproposals seeking to address Ava's concerns. Consensus could not be reached so Ava, through her parents A.T and G.T., sought relief, first through the Minnesota Department of Education, and eventually through the federal courts, citing the Rehabilitation Act of 1973 (specifically, Section 504) and the Americans with Disabilities Act of 1990 (ADA). There has been ample jurisprudence on these laws; it has been established that they "live and die together, as the enforcement, remedies, and rights are the same under both," as cited by the panel for the Eighth Circuit Court (spanning Minnesota, Iowa, Missouri, Arkansas, Nebraska, and North and South Dakota). The chief "circuit split" and the question before the Supreme Court is whether the precedent set for the Eighth Circuit in Monahan v. Nebraska in 1982 is the proper interpretation of the relevant federal laws. Monahan specifies that a school district is not liable merely for statutory non-compliance, but must demonstrate that there was wrongful intent, by demonstrating "bad faith or gross misjudgment." Importantly, this is not the standard nationwide; it has been adopted by some Circuits but not others, and it falls to the Supreme Court to resolve the question.

The Court has not ruled as of this newsletter's deadline; oral arguments were held at the end of April. They made a minor splash in national news, not for the substance of the question but for the unusually combative tenor of the proceedings. Respondent's counsel accused Petitioner's counsel directly of lying, violating unwritten but firm rules of decorum, and drawing a pointed rebuke from the bench via Justice Gorsuch.

The question at hand is the standard by which a school district can be adjudicated to be out of compliance with ADA and 504. The Monahan standard basically decrees the school district in compliance, so long as it makes a good faith effort to provide a free and appropriate public education, which Respondent (the school district) demonstrates it did. Petitioner (A.J.T) argues that Monahan establishes a second, more stringent standard before injunctive relief can be granted, for which the relevant statutes do not allow; rather, the same standard of "appropriateness" as applies in all ADA/504 cases should apply here as well.

The Court is expected to deliver a ruling in June; we shall report on it in the Fall newsletter.

Bowling Night

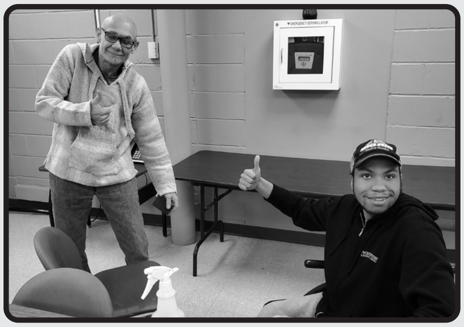
by Matthew Requa

We had such a blast at our Staff and Consumer Bowling Night on Friday, May 9th at Ripics Carousel Lanes! There were some gutter balls, but plenty of gut laughs, strikes, and cheering one another on. Thank you so much to Ripics for always being so accommodating to our agency and for helping us create an evening of wonderful memories.

Cleaning Day

by Matthew Requa

Cleaning Day 2025 was a sweeping success! Many hands make light work as they say, and our hardworking and dedicated staff was happy to pitch in and get things gleaming and organized, in addition to being given time to clean and organize their own personal office space. As a reward, they were treated to a delicious lunch of Nirchi's pizza, including thoughtful gluten-free and vegan options.



Trivia Night

by Matthew Requa

Our STIC Trivia Night fundraiser on Friday, April 11th at My Uncle's Place was a fun, memorable, and successful evening! Thank you so much to Uncle's for hosting us and providing scrumptious free food. And thank you to all of our generous sponsors and knowledgeable teams who all came together in a spirit of gentle competition and a passion to help STIC further its mission. We can't wait for next year!

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THANK YOU!

Southern Tier Independence Center

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