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AccessAbility

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Leadership in Health Care, Past & Present

By Jennifer Watson

The world lost a true champion of health care and social justice when Jim Tallon passed away on July 9, 2024. He was one of the most influential figures in shaping health care policy in New York State. Tallon served in the NYS Assembly from 1975 to 1994, representing the Binghamton area. His tenure was marked by a deep commitment to public service and a particular focus on health care reform and accessibility. He was a strong ally of STIC and independent living, especially in the early days of our organization during his time in the Assembly.

As the chair of the Health Committee from 1988 to 1993, Tallon played a pivotal role in crafting and advocating for policies that significantly expanded access to health care. He was instrumental in the development of the New York State Medicaid program, including development of Child Health Plus and eventually Family Health Plus. Tallon's leadership helped secure funding and support for providers across the state, ensuring that all New Yorkers had access to necessary medical services.

After his legislative career, Tallon remained prominent in health care policy as the president of the United Hospital Fund (UHF), a nonprofit organization dedicated to improving health care in New York. Under his leadership, UHF became a critical voice in health policy discussions, particularly in areas such as Medicaid reform, health care delivery systems, and the expansion of health insurance coverage.

Jim Tallon's contributions helped New York build a more equitable and accessible health care system, ensuring that millions of New Yorkers, including those with disabilities, had the resources and support needed to live successfully in their communities. His legacy is one of compassion, commitment, and an unwavering belief in the right to health care for all.

Sadly, in the very year of Jim Tallon's passing, New York State faces significant challenges under the leadership of Governor Hochul, as she continues her attempt to dismantle the Consumer Directed Personal Assistance (CDPA) program. A proposal forced through the Budget process by the Governor will consolidate CDPA under a single statewide Fiscal Intermediary (FI) – there are currently hundreds – with an unrealistic target date of April 2025. In an irresponsible attempt to support this misguided decision, Hochul, with deliberate malice, mischaracterized the CDPA program as a "racket." She alleges CDPA spending is rife with fraud and abuse, despite her own Medicaid Inspector General finding no evidence of this. STIC itself was subject to an OMIG audit for our CDPA program four years ago and not a single unjustified expenditure was discovered. Furthermore, consumers who use the program must first go through a state mandated eligibility assessment process. While we agree there are issues in the program that need to be addressed, mostly stemming from the transition to managed care in 2012, the state can address them without resorting to this extreme single-FI scheme, which will not solve any problems but only create new ones. Had the state performed diligent oversight, measured, effective corrections could be made with a "scalpel." But the hasty transition to a single statewide FI is closer to a paper shredder, and rather than solving problems with the CDPA program, will likely turn the whole program to pulp. There are only two winners here: the large corporation that wins the single FI contract, and the SEIU 1199 union that plans to unionize that corporation's newly

INSIDE

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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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conscripted workforce; together, they will pick up the pieces to their own advantage, against the manifest interest of the citizens of New York who rely on CDPA to maintain their independence.

The CDPA program was created by people with disabilities and is a lifeline for hundreds of thousands of people, allowing them to hire and manage their own personal care assistants. The program not only promotes independence and dignity but also aligns with the broader principles of disability rights and independent living.

It's clear from the recently released Request for Proposals (RFP) for the single statewide fiscal intermediary that the state does not remotely understand how the program actually operates. Ironically, despite the Governor's claims of fraud and abuse in the CDPA program, she intends to hand over a $40 billion contract to an out of state corporation without oversight from the NYS Comptroller. The final budget language specifically states that the contract for the single CDPA statewide FI does not require review by the NYS Comptroller. No justification for excluding the Comptroller's review is offered; conspiracy theories abound.

Jim Tallon

In another recent attempt to harm CDPA, the state ignored required procedures and directed Medicaid managed care plans that contract with CDPA Fiscal Intermediaries to change their funding mechanisms to FIs, causing drastic funding cuts. The cuts will broadly result in FIs not being funded to meet state mandated requirements, including even a minimum wage for homecare workers.

The attacks on the CDPA Program by state leadership not only harm the lives of people who rely on the program, but also represent a significant step backward in the fight for disability rights. The CDPA program was designed by people with disabilities to provide autonomy and choice, reinforcing their right to make decisions about their own care—just as non-disabled people do. The pointless, careless destabilization of the CDPA program undermines these principles and will either force people into institutional "care" or leave them with no care at all. This will have a devastating impact on a homecare workforce that is already in crisis. Much of the growth of CDPA can be attributed to the fact that it is the only way many people are able to receive homecare, due to lack of availability of homecare workers and nurses via established channels. This is true particularly in rural areas where traditional personal care and home care services are unavailable and public transportation is impractical.

STIC and other advocates have repeatedly asked to be included in discussions about these radical changes to CDPA with the Governor, her staff, and the Department of Health. We have been resolutely ignored. This is unwise. Our community created, nurtured, and avail ourselves of the CDPA program, so we understand how to ensure it continues to function as intended.

Moving forward, the principles of disability rights and independent living remain central to policy discussions regarding the CDPA program. Jim Tallon's legacy reminds us of the importance of creating and maintaining systems that support and empower all individuals, ensuring that everyone has the opportunity to live with dignity, autonomy, and independence.

On the Highway

By Sue Ruff

Last week I drove to an appointment a few hours east. Nice day to travel – sunny, clear skies, light traffic. I noticed, however, that people traveling west on the highway were encountering LONG traffic jams, miles long, probably caused by road repairs or maybe, accidents. It is hard to be in a miles-long bottleneck, with hundreds trying to merge into one lane and no forward progress. I wondered about the travelers. What if you had a baby in the back seat who hated car seats and your car was stuck in this jam? What if your gas tank or electric charge was getting low? What if your body was regretting that extra burrito you had for dinner? And what if the next exit or rest stop was still many miles away?

In the last newsletter Jen Watson and John McNulty wrote about the budget issues affecting the Consumer Directed Personal Assistance Program (CDPAP): https://stic-cil.org/newsletter/AccessAbility_Summer2024_WEB.html#heart

There are at least 250,000 people in NY who use CDPAP as their means of having long term services and supports (LTSS) in their own homes. Many have families; some don't. But all have staff that helps them maintain their freedom and independence. And all fear institutionalization.

The state's plan to move all these people into one Fiscal Intermediary (FI) to handle the administration of the program has also generated legitimate fear. In other states that tried that, it was an epic failure (and they had fewer people using CDPA in those states).

The state released an RFP for organizations to apply to be the one FI. They offered the opportunity to ask questions. Here is a link to the 104 pages of questions and in many instances, unclear or obtuse answers: https://www.health.ny.gov/funding/rfp/20524/qanda.pdf

The Independent Living Centers who have been FIs for decades are still unsure of how we will function as sub-contractors in the new system, and that wasn't made clear in the RFP questions and answers, either.

On the highway to independence, freedom, and long-term services and supports, we have encountered traffic jams in the past. It is very hard to find and keep personal assistants, for example, and that leaves people stuck in parking lots off one of the exits they have been required to take in order to qualify for and set up their home care services.

But looking ahead, we envision a HUGE traffic jam as the NYS Department of Health undertakes this particular road repair. Should there be fewer than the 600-700 FIs in the state that currently operate? Yes. Have managed care insurance companies, lack of NYS Department of Health oversight, and some poorly managed FIs created the problems the Governor, the Assembly Speaker, and the Office of Management and Budget cite to justify this policy to move all CDPA users to one FI? Yes. Will this policy dismantle the program created by people with disabilities *for* people with disabilities? Yes. Have they used the tools at their disposal to fix the problems they created? No. The state quoted a timeline for moving these 250,000 people into one FI to be accomplished by next spring. Is that realistically possible? No.

To return to our metaphor, consider how difficult it is to merge four lanes of traffic into one due to a construction project or a very bad accident. It can bring everything to a standstill, sometimes for hours. Well, merging from hundreds of lanes of extant FIs to a single FI lane would be orders of magnitude harder. And we don't even know what the conditions will be in the new lane. Is it paved well? Or paved at all? Is it too narrow? Are there any obstructions? One lane with no exits leaves us without recourse to any random misfortune that will predictably occur.

Merges in traffic are inherently dangerous, especially at high speeds. The "merge" that the state plans involves 250,000 people somehow changing lanes all at once. Imagine a traffic jam of 250,000 cars relying on the highway to carry them safely to their exit to independence. Now imagine the quarter million car pile-up unavoidably to come. We'll be so busy trying to clear the lanes and tend to the wounded that no one will be able to get anywhere; they will be stuck in their cars, no exit in sight, enduring impossible, inevitable, disastrous gridlock amidst a furious deluge delivering tragic, needless suffering.

The Shocking Tale of the Judge Rotenberg Center

There's one place in the Western Hemisphere where torture has legal sanction as a "behavioral modification." Would you believe that just southwest of Boston, in the lovely town of Canton, Massachusetts, a boarding school named the Judge Rotenberg Center (JRC) administers powerful electric shocks to innocent children?

It's true. We have been reporting on the JRC regularly in *AccessAbility* over the years, as STIC has been part of the vanguard trying to stop this atrocity for decades, and we won't stop until the school closes, the buildings are torn down, and the earth beneath the rubble is sown with salt. So, for longtime readers, this may be repetitive, but here is a brief history of the JRC, along with the latest developments.

A student of prominent mid-20th century psychologist B.F. Skinner named Matthew Israel adopted a radical (mis)understanding and (mis)interpretation of Skinner's theories and methods and, armed with a staggering lack of conscience or decency, founded the JRC, renamed in the 1980s for the state probate judge who consistently ran interference for the Center when authorities tried to curb its excesses. Dr. Israel thought that an ideal society could be created through a series of rewards and punishments, until everyone's behavior was "perfect." In the 1960s, he tried to test his theories in communes he founded, but those tended to fall apart quickly, in no small part because he expected other men's wives, as part of his "ideal society," to willingly share a bed with him, but also because fellow adults would not tolerate his abusive measures to

"condition" behavior until "perfect." So Dr. Israel turned his attention to populations with less physical, mental, or legal capacity to resist the torments he sought to inflict; strictly for their own good, of course: He founded a boarding school, specializing in the treatment of emotional, behavioral, or developmental difficulties – among the most vulnerable children one can find.

So, since the founding of the school in 1971, the JRC has been the place where Dr. Israel and like-minded zealots would test his theories of operant conditioning through the infliction of pain, or as others might call it, thinly veiled sadism targeting those among us with least recourse. After experimenting with a variety of aversive physical punishments such as pinching, squeezing, slapping, squirting unpleasant liquids, and others, the JRC settled on a standardized method of delivering electric shocks through a series of devices Dr. Israel designed himself, used nowhere else in the world, called a Graduated Electric Decelerator (GED). (It seems the multi-talented doctor is a Renaissance man of inhumanity). The shock delivery devices, operated by remote control, would lose effectiveness over time as its victims adapted to the shock treatment, so the amperage had to be steadily increased to have a consistent effect on behavior. The highest amperage was roughly ten times the strength of a standard issue police taser, and misbehaving students didn't receive such hyper-shocks just once, but sometimes dozens of times consecutively. A taser is designed to be non-lethal, but does, rarely, result in cardiac arrest and death. Ten times that charge, several times in a row...take a minute to wrap your head around that recklessness. To call it irresponsible would be grossly inadequate. Lab rats get treated more humanely. Much more.

It should surprise precisely no one that the opportunity to torture people who have no means to resist or protest would attract a disproportionate population of problematic sorts with poor judgment to the JRC. There have been several documented, high-profile incidents where residents of the JRC were maltreated by those responsible for their well-being; since 1981 there have been six deaths of young people in JRC custody in which JRC and/or its personnel were at fault to some degree. In 2007 a prank call was made to JRC ordering restraint and shock be applied to two young men in their care; a video recording was made of this atrocity, during which over one hundred shocks were dispensed. Upon learning of this, Dr. Israel ordered all videos be destroyed, which, upon discovery, resulted in a plea bargain for obstruction of justice and Dr. Israel left JRC entirely, forever. He was about eighty years old by then anyway, and all the JRC staff had been trained by him, so little changed. Meanwhile, the defrocked doctor relocated to California where his wife was a school principal; he started substitute teaching and, with compliant or complicit supervision, started experimentation with aversive treatments again; the man is clearly devoted to his misbegotten theory, or perhaps just to inflicting pain.

The sole measure staying the JRC's itchy trigger fingers on those remote controls was a requirement that the use of shocks via the GED be authorized by a court order. It is difficult to determine whether the JRC scrupulously abided by that requirement, but for now let's assume they did. Roughly one out of three residents of the JRC had been authorized by a judge to be subject to aversive GED skin shocking. Our state, New York, sends students there, but will not sanction the GED use for those from New York. That is better than permitting it; however, the tuitions and fees paid to JRC by those residents shielded from the shock treatment, money typically paid by their school district and/or by their state Medicaid, do subsidize the shock treatments on residents from states that fail to shield their young citizens and help pay lawyers and lobbyists.

The mistreatment at JRC isn't limited to shocks – all students are subject, as they have been from the JRC's founding, to withholding of food, sensory deprivation and/or overstimulation, application of harsh smells and fluids such as ammonia, being held in seclusion and/or in restraints for long periods of time, and more. I should mention here that decades of psychological research has decisively concluded that "aversive therapies" such as, let's say torture, isn't only a moral atrocity, but *it doesn't even work*! While temporary compliance can be elicited for obvious reasons – the victims want the pain to stop – any behavioral change is fleeting, as time passes from the brutal treatments. I suppose if they just torture continuously and relentlessly, they might get results, but there are some practical problems with that.

The U.S. Food and Drug Administration (FDA) finally intervened in early 2020, formally banning any devices that can be used for aversive GED skin shocking in a new rule; this ban, delayed by a fusillade of litigation delaying implementation, will finally become effective later in 2024. The new rule is supported by extensive public comment – there's no popular opposition, thankfully. But the torture enthusiasts didn't give up!

In the pending Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Appropriations Act, initiated in the subcommittee of the same name, a small rider was inserted in the bill initially drafted under the supervision of the subcommittee chairman, U.S. Representative Andy Harris from Maryland's 1st district (mostly the Eastern Shore of Chesapeake Bay). This rider removed the authority granted by Congress to the FDA to issue the ban on devices that deliver aversive electric skin shocks, *i.e.* the GED. Merely a few lines on page 93 on a bill of well over 100 pages, that is to be passed as part of a package of thirteen major bills, split into smaller parts by subcommittee subject area – it is easy for subcommittee chairs to unobtrusively advance pet projects of theirs into legislation such as this. Why it was a priority of Rep. Harris – who in his previous career was a physician, an anesthesiologist at Johns Hopkins – to enable the continued torture of children unable to defend themselves is a curious question, and we would love to know the answer.

This was the last ditch effort by friends of the JRC – misguided, sadistic, or both – to repeal the authority of the Food and Drug Administration to ban deceptive or dangerous medical devices such as the GED. It is not only ineffective, but cruel and unusual, and if the FDA's power to forbid its use is withdrawn and the GED's use is sanctioned by a court order, the status quo, *i.e.* the pointless, brutal torture of special needs children, helpless and vulnerable in their vicious care, would be maintained.

The attempt to slip this rider into the final bill was unsuccessful – multiple advocacy groups and Members of Congress discovered the rider and rose up in the full committee markup session to demand its removal as the first order of business. No one, including the subcommittee chairman who let it in, came to its defense – certainly not in front of C-SPAN's cameras. That said, we remain vigilant that no such language be inserted back into the bill on the House or Senate floor – especially the Senate since there's much greater opportunity to add amendments to bills under consideration there.

On the NYS Medicaid/ Child Health Plus Quality Control Initiative

The New York State Department of Health (DOH), in accordance with federal regulations, must develop and publish a Quality Strategy to assess the quality of care and analyze efforts to improve it. DOH issued a draft plan for public comment, and we at STIC have thoughts.

The document is lengthy, 73 pages in all, but it might feel like 773 when you read it. It's clearly written for a small audience fully steeped in the acronyms and folkways of the various versions of managed care DOH supervises, and I suppose that's fine as far as it goes; it's not as if this is supposed to be light beach reading. But it shouldn't be so jargon-logged as to be impenetrable, because citizen laypeople have a right to look at these public documents and make heads or tails as to how their government works. It may be too hard to construct this kind of a report for an entirely general audience, but if it's inscrutable to interested parties at agencies like STIC, something is amiss.

That said, we were able to extract some pieces of information and our comments and questions follow.

A number of unacceptable practices are listed as grounds for sanction; first among them, appropriately, is "Failing to provide medically necessary services that the health plan is required to provide under its contract with NYS." Assuming the contract isn't exceedingly exhaustive in defining what is medically necessary in every conceivable situation, who decides what is "medically necessary" and what isn't? That seems important. There's also a note that DOH collects data on the primary language spoken by recipients of care. Given our mission, we wanted to know if that includes American Sign Language (ASL); some listing should be made available.

There is some welcome attention paid to the Medicaid Transportation. Several disturbing stories of very bad experiences regarding Medicaid Transportation have come to STIC's attention, particularly in more remote rural areas where the need for extra transportation is most dire; people have missed appointments because drivers never arrived, been stranded at hospitals or medical centers, inappropriate things have been said and done by drivers that, to use the currently popular parlance, made consumers feel unsafe. This program needs more resources and better supervision and metrics, and we hope in the future that transportation is given even greater attention in their QC program reviews.

Extensive discussion is dedicated, quite appropriately, to Home and Community-Based Services, the promotion of which is part of STIC's organizational mission, and which we fear is in great peril from the reorganizations and cutbacks enacted in the recent state budget this spring. Creating another layer of overhead with the single statewide Fiscal Intermediary (FI) will reduce what can be spent on health care, which seems like a suboptimal allocation of resources. Further, the disruption caused by this will negatively impact both consumers and home-and-community care workers. For the workers, transitioning to a single FI will cut into their hourly wage, the number of hours they may work, and potentially benefits and work conditions. With other FIs to work for, competition for labor creates an environment where unhappy workers can find someone else to work for. With the single FI, even with the subcontracting agencies like the Centers for Independent Living (of which STIC will be one), it is anticipated that compensation will be standardized statewide, excepting some cost-of-living adjustments.

We, as a Community-Based Organization, and as a Center for Independent Living, also support transitioning all who are able to leave institutions out of institutions and back into the community, and sponsor an Open Doors program, helping people reentering community life arrange the services they need to flourish. With the increased thresholds for eligibility for home services – from needing assistance with one or more Instrumental Activities for Daily Living (IADLs) to needing assistance with three Activities for Daily Living (ADLs), or two plus a dementia diagnosis, never mind IADLs – many fewer people will be able to take advantage of these programs and will have to stay in institutions, or, if they are not in one yet, enter one. This not only diminishes their quality of life and (this is well-documented) its duration, but it is far more of a drain on the public fisc to keep a resident fed, clothed, and sheltered, than it is having someone stop by to do laundry, sweep the floors, and drop off some groceries twice a week, simple IADLs that a moderately frail or disabled person might struggle with but who can otherwise lead a full and rich life.

Our belief is that the single FI and the increased ADL threshold for care, both enacted to save money, will instead backfire spectacularly, driving up the overall spending for long-term care. The CDPA line item might look better, but in reality the government will just shift costs elsewhere, to nursing homes and hospitals. This projection dismays us, but what is truly heartbreaking is the human cost in quality and quantity of life, on which one cannot put a price, that will inevitably come from these ill-advised reforms. Home supports and modifications are an integral part of long term care, and are critical to keeping people in their community and out of institutions, which extends lives, enhances quality of life, and saves public money.

We do support the effort to improve the health and safety of people's environments; extensive comment on this is beyond our remit, but to the extent we can be of assistance in these efforts, we shall. We also support anything that will improve the competitiveness for workers in the labor market; it's so commonly stated

as to be a cliché to say that teachers and nurses are underpaid relative to the value they add preparing our children to be productive members of society and caring for our elderly and sick, but being a cliché doesn't make it any less true.

The extra focus on mental and behavioral health care strikes us as one of the best ways to advance the Health Equity goal; underrepresented populations are even more underrepresented in seeking and finding these particular services. Similarly, improving dental health is a noble goal, and preventive care early in life is a promising avenue for long-term success; it will both address any early problems and prevent them from setting in, and perhaps even more importantly it will establish a habit on caring for one's teeth that will persist into adulthood. The extra attention – and funds – offered to the vulnerable DD and TBI populations is much appreciated. In many cases sleep dentistry is the only option for people who can't comprehend what the dentist needs to do and hence won't sit still for it. For new mothers, the increase in Medicaid eligibility from sixty days to one year is a welcome change.

We agree that creating a sustainable provider workforce is a must, and we suggest the laws of supply and demand are in play here, for labor just as for goods and services -- if you want to get more supply, you need to pay higher prices. Doctors and dentists need to receive competitive compensation, as do the home health care providers and aides. Creative compensation with loan forgiveness and enhanced benefits will be helpful, but in the end that's just money too; no free lunch to be had here. You get what you pay for.

Primary Care Providers are good at practicing medicine, less so overseeing a person's general health plan. Further, consumer compliance and cooperation with the managed care plan is necessary, and that does not happen frequently enough. We believe in giving people choice; surrendering that choice to a managed care provider, while in theory cheaper and more efficient, in practice has proven not to be, which thus fails to justify the consumer's delegation of autonomy.

"Improving access to and quality of Home and Community Based Services (HCBS)" is effectively STIC's mission statement with regard to health care. Our objectives are very much in concert, which is why the assault on the CDPA program from the governor's office is so vexing. Just recently, July 18, 2024, Governor Hochul described CDPA as "a racket" in an interview with Bloomberg News, describing the program as "wildly expensive." Well, if she thinks it's expensive now, wait until she sees what health care costs *after* she eviscerates CDPA and thousands of people are forced into nursing homes, hospitals, and other long-term care facilities. She ain't seen nothin' yet! Hochul has begun to retreat on her draconian plans for CDPA, at least rhetorically; in an August 12 interview, she declined to rule out changes and/or delays in the CDPA plan designed and forced through in June, but until it's something more than rhetorical hedging, we shall keep the political heat on her as best we can.

The goal of "(e)nsuring members are able to receive care in the least restrictive setting possible" basically reiterates the goal of improving access to HCBS. The actual standard from the Olmstead decision should be the "most integrated setting," which is a little different; the least restrictive environment may not be the most integrated. We're still waiting for an Olmstead Plan, incidentally; New York was supposed to have something formally adopted on the order of two decades ago. However, the Olmstead rule is at least intermittently observed, and the adoption and growth of Home and Community Based Services, provided by Consumer Directed Personal Assistants, is critical to doing that, which returns us to the previous point that if these programs are so important then why are they so imperiled?

Lastly, we concur wholeheartedly that program evaluation must be data-driven and that DOH and OPWDD need to be held accountable for their performance. But the data must be overseen correctly and dynamically. Simply focusing on CDPA as a line item in the budget with a rather large number attached fails to consider what the consequences will be if that number is capriciously and savagely reduced. The people receiving services through CDPA will still need services, so they'll get them elsewhere. Emergency rooms will be overflowing (and another objective seeks to prevent that), hospitals and nursing homes will be deluged with consumers cut loose by the state, quite likely more than we have capacity to handle. So some will be turned away, and others will not try in the first place, but find some workarounds through family or charitable organizations; some of these folks may find satisfactory outcomes, but we fear far too many will not. Government exists to serve the people's interests, and these bad outcomes decidedly aren't it.

courts watch

U.S. Food and Drug Administration, et al. v. Alliance for Hippocratic Medicine, et al.: **Not standing for lack of standing**

As the Court foreshadowed during oral arguments, they just were not buying what the original plaintiffs, *Alliance for Hippocratic Medicine, et al.*, were selling. In a unanimous opinion authored by Justice Kavanaugh, the Court ruled that the associations of anti-abortion doctors that brought the suit lacked standing to file the suit, so all lower court rulings were vacated and the suit dismissed.

The elements to establish standing are threefold. First, a plaintiff must establish she has suffered harm, or is likely to suffer harm. Second, that the defendant is or would be the cause of the harm. Third, that a court ruling could prevent or mitigate the harm. The Court agreed with the FDA's argument that the claim that the plaintiffs could suffer injury because *others* prescribed mifepristone, i.e., "the abortion pill," was too implausible and tenuous to establish standing to sue, and if there's no injury, the defendant can't have caused one and a court ruling can't fix one.

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(Indeed, regarding the third leg of the standing requirement, one of the aspects of the abortion pill debate that doesn't receive enough discussion is that, were opponents to be successful in legally banning mifepristone and other medications used to trigger terminations of pregnancy, a black market would spring up practically instantaneously for pills illicitly imported into the U.S.; it's one thing to restrict complex surgical procedures requiring the presence of medical professionals in a secure, antiseptic setting, but quite another to restrict a couple of small tablets that might be hidden under a staple in a document in a standard-size envelope or smuggled between gears inside a wristwatch. Also, "medical tourism," where people seeking abortions would travel to countries where it is legal to obtain the necessary medications and/or surgical treatment, would become frequent, especially for people of means; it has been reported that something similar has already arisen between states where abortion rights are restricted and those where they aren't. Technological advances – in this case, pharmaceutical abortions conducted in the home absent the presence of medical professionals – can have massive legal and cultural effects downstream, such as making abortion in the first trimester virtually impossible to regulate.)

The plaintiffs failed to establish standing on the first or second element, which left the third moot. Justice Thomas filed a concurring opinion joining the unanimous finding in full but suggesting the Court ought to have gone further and addressed associational standing doctrine. The associational standing doctrine allows units like guild or trade associations to sue on behalf of its members if the members of said association would have standing to sue in their own right, the interests at stake are germane to the organization's purpose, and there's no necessity requiring individual members to participate. Thomas notes that this is just a variety of third-party standing, and while it was not necessary to examine associational standing in this case, because standing failed on other grounds, the Court ought to address the question in a future case. Thomas implies that he believes third-party standing doctrine should be narrowed or even eliminated altogether, but regardless, the clarity and precision of the doctrine ought to be improved.

Murthy v. Missouri: **Standing athwart the First Amendment**

Yet another case decided on standing, this one authored by Justice Barrett, joined by Roberts, Sotomayor, Kagan, Kavanaugh, and Jackson; Justice Alito authored a dissent, joined by Thomas and Gorsuch. It has come to light, however, that this was an eleventh hour switch; Alito's dissent was originally to be the majority opinion for a 5-4 court, but after reviewing Alito's draft ruling, Justices Barrett and Jackson felt it went too far in restricting the government's free hand in pursuit of a clear state interest in public health, and they switched their votes, with Barrett supplanting Justice Kagan as the lead author on the opinion.

This was a substantial *de facto* win for the Biden Administration; this suit by the attorneys general of Missouri and Louisiana sought to enjoin the federal government, specifically the executive branch, from privately lobbying social media providers like Facebook and Twitter/X to curate their algorithms in such a way as to minimize or censor information that they considered detrimental to public health. Specifically, the Biden Administration was concerned about what they felt to be anti-vaccine propaganda and misinformation that, if accepted uncritically by a sufficient share of the public, could hinder the termination of the COVID-19 pandemic. The states of Missouri and Louisiana sued, charging that the federal government's *ad hoc* "jawboning" of the social media companies to suppress anti-vaccine posts was an unconstitutional intrusion on free speech.

Justice Alito was to affirm the lower courts' rulings that representatives of the White House "just talking" to private companies in an attempt to persuade them to act as they desired put an impermissible amount of implicit pressure on those companies, given the executive branch's power to inflict costs on commercial entities. He concurs with the states' argument that a "right to listen" for the public enjoins the government from suppressing speech of any kind, and posited that on questions of unsettled science, the public ought to hear all opinions, not just those favored by the government, according to the First Amendment.

Justice Barrett's majority opinion, critically, does *not* reject the states' (and Alito's) claim on the merits. Rather, once again, we see the standing doctrine used to punt on a critical constitutional issue. Barrett notes that the entities seeking redress were not the social media companies, not the authors of the information the government sought to suppress, and not even some consortium of users of the social media that objected to the suppression, but state governments acting on behalf of a presumed subset of their citizens that agree with them. That was seen as just too attenuated a claim to justify bringing a suit for damages. We can infer that Justices Barrett and Jackson harbor some sympathy for Justice Alito's expansive view of the First Amendment but were unwilling to go as far as he wanted to go. Remanding on standing grounds sets no precedent, and the justices can look for another case, presumably with a more propitious set of facts, to enjoin the government from leaning on the speech or expression of private actors to the extent they feel proper.

***Loper Bright v. Raimondo (and Relentless v. U.S. Dept. of Commerce)*: *Chevron* Reversed!**

As anticipated in the article about airline regulations regarding wheelchairs in the last issue, these cases, addressed in a joint opinion, came before the Supreme Court with the same, very narrow question: Is the principle of *Chevron* deference, a precedent in place for forty years, to remain in place?

Chevron deference was established in 1984, when the question before the Court in *Chevron U.S.A., Inc. v. Natural Resources Defense Council, Inc.* was whether the Environmental Protection Agency (EPA) could interpret and effectuate a vaguely written law by Congress according to its best judgment as an agency staffed by disinterested experts as to what the law means, or were they to be restricted strictly to the black letter law passed by Congress, signed by the President, and reviewed by federal courts. That Court ruled in favor of the agency, and defined the *Chevron* deference precedent

such that whenever Congress passed a law to be enforced by an executive agency, how that law would be interpreted and enforced would be left to any reasonable reading of the law and Congress's intent by the agency.

The principle behind this was that the agencies were the experts in the specific realm in which they worked, so they were in a better position to understand what the law required than judges trying to ascribe meaning to rather complex and technical questions – the specific question in the Chevron case had to do with the measurement of air quality according to the mandates of the Clean Air Act. Judges don't know much about measuring specific particulates in the air in terms of parts per million, etc., and most members of Congress are merely authorities on hot air. So Congress would pass laws providing executive agencies wide latitude to execute them as they saw fit, so long as they fulfilled the intent behind the law, and in the *Chevron* decision the judicial branch chose to not impose their judgments on the agency experts absent the most indefensible interpretations of a law. Pretty much anything reasonable would pass muster.

This all sounds perfectly sensible, and it worked well for a while. Many liked *Chevron* because rules promulgated by agencies tended to be predictable, and indeed when "agency capture" (a term of art describing a lobbying success in steering an agency to the will of clients) was in effect, the big players in an industry would largely write the regulations governing them themselves. The nonpolitical parts of the agency, the civil service employees, stayed stable from one administration to another; only a handful of matters would rise through the ranks to reach a political appointee's inbox, so for the most part the permanent bureaucracy could manage their own affairs.

But eventually problems arose, all over government. First, Congress, given an opportunity to shirk responsibility for, well, anything, predictably took advantage of *Chevron* to basically delegate almost everything to the agencies; for example, the phrase "the secretary (of HHS) shall…" or a variant of it appears nearly 3,000 times in the text of the 2,700 page *Affordable Care Act* (commonly known as Obamacare). The elected representatives of the people were not making many decisions about matters that affected the people – the officers and employees in the executive branch, who faced no democratic accountability (other than the president and vice president), had authority to do almost anything that suited them.

Predictably, some agencies started feeling their oats and got a little expansive about how they interpreted certain laws, knowing they had the latitude from the courts to do so. But perhaps even more problematically, the political part of the executive branch – the icing on the executive cupcake – also discovered that *Chevron* allowed them to interpret regulations expansively on agencies' behalf and try to push through desired policies that Congress won't pass. President Obama's amnesty for the "dreamers," President Trump's diverting money from the Defense Department to build a border wall, and President Biden's student loan forgiveness decrees all were justified in whole or in part by a claimed anticipation of *Chevron* deference, and although courts ultimately rejected these facially bad-faith claims in each case, so much time had passed that the policies were at least partially *faits accomplis*. Further, with the wild shifts in policy on prominent issues that occur when administrations change, in particular cross-party successions, the stability promised by deferring to apolitical agency experts was not to be on prominent, politically-charged questions. *Chevron* deference was supposed to be about recognizing subject-area expertise, but all too often it has been used to shield fairly simple ideological objectives in the executive that any layman can comprehend.

However, Chief Justice Roberts, joined by his fellow Republican-appointed Justices Thomas, Alito, Gorsuch, Kavanaugh, and Barrett, rather than critique the other branches, placed the most emphasis in his opinion on what he suggests was an abdication of judicial branch sovereignty in interpreting the Constitution and the federal laws and regulations that emanate from the Constitution. He said that interpreting the letter and meaning of laws were what courts were for, statutory law directs that

the reviewing court be the final determinative authority on all questions of law, and by deferring to federal agencies according to *Chevron* they were granting that judicial power to the executive branch, which he found to be impermissible as a general practice. Additionally, when apolitical judges interpret laws according to the text on the page, it will afford more consistency than opinions from agencies that, while not explicitly partisan, do have ideological predispositions and of course are supervised by partisans.

The facts of the cases hardly matter here, but the specific question was about whether an observer had to be placed on fishing boats in the North Atlantic to comply with the Magnuson-Stevens Fishery Conservation and Management Act (MSA). The lower courts had determined that the opinion of the National Marine Fisheries Service held (NMFS, and fifty points for Gryffindor if you've heard of it) based on the *Chevron* precedent. The majority opinion overturns that precedent explicitly and remands the question back to the lower courts, where judges will have to decide the question of whether the MSA mandates an observer or not for themselves.

This is not to say that agency-expert opinion cannot be taken into account; the *Chevron* reversal just means that agency

interpretations of laws will not be presumptively considered to be correct, except in the most egregious cases. Rather, the agencies will have to present their case to the court, and it will be weighed against the opponent's case. Agency interpretations will probably prevail the majority of the time still, but they won't have the finger on the scale they had for forty years under *Chevron*.

It is peculiar that the opinion here split down party lines, because the impact of reversing *Chevron* is not especially conservative- or progressive-coded; Democratic and Republican-run executive agencies alike will lose the interpretative authority they held for two generations, and Democrat- and Republican-appointed judges alike will be unbound by *Chevron* deference. Nevertheless, Justice Kagan, joined by Justices Sotomayor and Jackson, wrote a spirited, wide-ranging, but ultimately unconvincing dissent that argued that Congress intends agency deference when they write those vague laws, that when Congress's intent is clear *Chevron* never applied, that courts cannot possibly have expertise in all the various and esoteric specialties government agencies are engaged in (citing some cases involving tongue-twisting technical questions about alpha amino acid polymers and the varying genetics of squirrels in the western United States to make the point).

But Kagan's argument focused on the unsuitability for judges, juries, and courts for making the technical distinctions that these agencies were created to make. I believe Chief Justice Roberts, though he discreetly avoided making the point bluntly, had more in mind that the entity that created the agencies, Congress, a political branch directly responsible to the people, ought to be ultimately directing the agencies more assertively and specifically in enacting and continuing laws governing what that agency should and shouldn't do. Congress, like courts, doesn't include experts in all esoteric fields, but committee members and staffs can develop some expertise, and the agencies can and should participate in committee deliberations through formal testimony and submissions, as well as in informal ways. The idea is that Congress shouldn't be writing laws in such a way that the responsibility for interpreting them falls to either agencies or courts, neither of which have any direct democratic accountability. Writing vague laws is not too different from writing no laws at all.

As for how this may affect the disability community – time will tell. If Justice Kagan's worst-case scenarios come to pass, activist judges will geld agency discretion to advance culture war goals. (And since the courts lean conservative these days, perhaps that explains the partisan divide; of course, that shall not forever be the case.) There are lots of judges, so no doubt some will, but I am hopeful not more than a handful, and if some do, Congress can pass laws reversing any judgments of which they disapprove. The political branches can always have the last word if they so desire, if not instantly then in time. Congress can have the first and only word too, if they just write better laws and exercise more vigorous oversight of the executive agencies they create and fund. Congress was always intended to be, in the clockwork of the federal government, the preeminent branch; that changed drastically in the 20th century, for mostly honorable and well-intentioned reasons, as well as exigent circumstances – world wars, great depressions, twilight struggles, etc. We might not think of the 20th century as "the American century" if we had not empowered the executive branch, and curbed it more through the judicial branch than through Congress. But perhaps it is time the pendulum swung back a bit.

***Petteway et al. v. Galveston County:* Majority-minorities districts?**

This is yet another case from the 5th Circuit Court of Appeals, seated in New Orleans and covering Louisiana, Mississippi, and Texas, and becoming notorious as a fount of MAGA-coded rulings that have been mostly reversed by the Supreme Court. This ruling is likely to be adjudicated as well, since it creates a circuit-split (different controlling precedents in different parts of the nation) that the Supremes are obligated to resolve at some point.

The issue at hand here has to do with redistricting. Galveston County elects four county commissioners by district, and one district contains almost all the African Americans in the county. The Hispanic population, conversely, is spread rather evenly throughout all four districts. Following the 2020 census, Galveston redistricted and attempted to create a district to represent the African American community, but they could not reach majority status. When adding in the Latino population of the district, they could get to 50%.

The assertion was that this was permissible based on historical underrepresentation of both groups. Judge Edith Jones, a highly respected and long-tenured Reagan appointee who narrowly missed a Supreme Court appointment (her best opportunity probably being the seat that went to David Souter) authored a prickly opinion on whether the Voting Rights Act's Section 2, and the *Thornburg v. Gingles (1986)* precedent interpreting it, permitted the aggregation of multiple distinct minority groups to create a majority-minority (or minorities, as noted) district. Jones rejected the notion, noting several conflicting precedents and interpretations of Section 2, but concluding that the groups were too different to comport with the statutory language. There were a number of concurrences, dissents, and partial concurrences and partial dissents.

Rather than get into the weeds of this, I'll just stipulate that the weeds are tall and dense. The *Gingles* precedent is clear as mud, itself a tangle of concurrences and dissents, and it seems to conflict with other case law such as *Shaw v. Reno (1993)* which forbids race to be the sole consideration in drawing districts. The problem that keeps cropping up is that it is permissible to redistrict based on partisanship, and in several states, particularly those with a history in the Confederacy, race and party are highly correlated, and untangling that is well-nigh impossible. But legislatures and judges keep trying. This particular case appears highly likely to draw *certiorari* and be judged by the Supreme Court, that shall try again to untangle the Gordian Knot of the language of the Voting Rights Act and its subsequent amendments, as well as all the relevant precedents, some likely irreconcilable. It is actually likelier that a court with a strong majority bloc may be able to resolve the irregularities and contradictions, because there may not be as much compromise necessary to reach five votes.

Why do we discuss this here? Because it represents another example of basic civil rights reliant on the continued beneficence of the courts, precedents that can be reversed on a judicial whim. Disability rights are in the balance, not so much because of redistricting *per se*, but because people with disabilities constitute a minority group with specific interests that rely on judicial interpretations of constitutional or statutory language, which can be altered by passing laws in the Congress and also by a new interpretation by a court, usually but not always the Supreme Court. This is why codifying judicial precedents into statutes, which would require majorities in both the House and the Senate plus the President's signature to alter, is so critical.

Family Compensation and Self-Direction

By Lisa Gavazzi

The Southern Tier Independence Center (STIC) is an OPWDD Fiscal Intermediary (FI). We provide services that allow an individual to choose their own services and live the kind of life they want—in their community—versus what others want for them. This allows more flexibility to choose the right supports, hire staff the individual chooses for themselves, and make a schedule that works best for the individual.

We are currently accepting referrals for people who are interested in directing their own lives and deciding which services to utilize. STIC is also open to building new relationships with Brokers. Interested Brokers should contact our FI Specialist, Lisa Gavazzi, at sds@stic-cil.org.

FI Services offered: Community Habilitation, Respite, Paid Neighbor, Housing Subsidy, Phone/Utilities coverage, and more.

Highlighted Service for this Quarter

Family Reimbursed Respite:

Family Reimbursed Respite (FRR) is a reimbursement service to the family for the expense they incur in being relieved of their primary caregiver responsibilities. This service is designed to be used as needed, up to the $3,000 budget limit.

The STIC Fiscal Intermediary is currently providing this service to qualifying individuals. STIC is open to new consumers, without a waiting list.

For any interest or questions contact:

Lisa Gavazzi, FI Specialist at sds@stic-cil.org

City Hall, Accessible to All!

By Sue Hoyt

The Accessibility Committee at STIC would like to acknowledge the City of Binghamton, especially Ronald Lake, P.E., City Engineer, for replacing the dangerous curb cut on Hawley St. in front of City Hall with a permanent ramp. This ramp will allow people of all abilities to safely access the sidewalk, City Hall, and the Broome County offices located in this area. Thank You!

Join Us for the "Access Your World Community Services Fair"!

By Lucretia Hesco

Southern Tier Independence Center (STIC) will be hosting the **Access Your World Community Services Fair** on **October 24, 2024, from 5:00pm-7:00pm**. This event will take place at our office, located at 135 E. Frederick St., Binghamton, NY 13904.

The Access Your World Community Services Fair is designed to bring together various agencies, community organizations, and service providers to offer valuable resources and information to parents, providers, consumers, and community members. This event is a fantastic opportunity to explore a wide array of services, programs, and resources available in our community.

Event Details:

Date: Thursday, October 24, 2024

Time: 5:00 pm -7:00 pm

Location: STIC, 135 E. Frederick St. Binghamton, NY 13904

For more information about the event, please email communityevents@stic-cil.org.

If your organization is interested in participating as a vendor at the event, please scan the QR code below.

We look forward to seeing you!

Please Register to Vote, and Vote on Election Day

By Sue Ruff

For several years the STIC newsletter has strongly encouraged people to **VOTE!**

Two years ago, our yet to be retired Executive Director, Maria Dibble, wrote an editorial, "Vote Like It Matters, Because It Does."

Here are the first couple paragraphs.

"I was raised to believe that the United States was the greatest country on earth and I still believe that. Have we made mistakes? Of course we have. Are we perfect? Not by a long shot. Is everyone treated equally and fairly? Certainly not yet. But if we want to improve things in our nation, there is only one sure way to do it: **VOTE!**

We take this right to vote for granted in America. I don't think most people appreciate the value of one vote. Races across even our own region have been very close in recent years, and every single vote had an impact. Isn't that amazing? Your single vote could make the difference between a candidate winning (or) losing. It's a lot of power to have, and it should be exercised judiciously, but it should be used."

You can read the rest here and I encourage you to do that: https://stic-cil.org/newsletter/AccessAbility_Fall2022_WEB.html#Vote

In addition to President and Vice President this year, your NYS Senator, Assembly Member, County Legislator, and other town or village representatives are running for office. All these people will be making decisions that will affect your life. Some elections are decided by one vote, as Maria said. If you are not happy with the job legislators have done, your vote can defeat them. Or if you like their work, your vote can re-elect them. Local and state elections affect health, education, economic development, long term care, community based services and supports, taxes, and much more.

Election Day is Tuesday, November 5, 2024. Are you already registered?

To qualify for voter registration in New York State, you must:

- be a United States Citizen
- be 18 years old (you may pre-register at 16 or 17 but cannot vote until you are 18)
- be a resident of this state and the county, city or village for at least 30 days before the election
- not be in prison for a felony conviction
- not be adjudged mentally incompetent by a court
- not claim the right to vote elsewhere

You can check to see if you are on the voting polls at this link: https://voterlookup.elections.ny.gov/ Fill in your name, date of birth, zip code, and submit. Your voting status, legislative districts and current polling site will come up. The County also sends out post cards to registered voters with information on polling locations and times.

Or you can call your county Board of Elections (BOE) to check on your status if you don't have internet access. Broome County's BOE number is 607-778-2172. Their office is on the second floor of the Broome County Office Building at 44 Hawley Street in Binghamton.

Need to register? One can go in person to the Board of Elections, or go to the county link, print a form, or register online. https://www.broomevotes.com/register

Registering on line requires one to have a NY ID. Some people register through the Department of Motor Vehicles, Department of Social Services, or other state or county offices.

The League of Women Voters of Broome and Tioga Counties works with several community organizations to assist people with registering and requesting absentee ballots. For example, the League and the YWCA will be working together on September 17, 2024, at both YWCA locations, 80 Hawley Street and 71 Conklin Ave. League members always take registration materials to the Board of Elections the same or next day, which saves people the cost of stamps. The League will also be at STIC's Community Fair October 24, 2024, from 5 pm to 7 pm. Voters can request an Absentee Ballot with a qualifying excuse – absence from the area, caretaker duties, temporary or permanent illness or disability, incarceration or special ballot reason - for a single election, calendar year or permanent basis: https://www.broomevotes.com/absenteeballot

There are additional rules for people completing absentee ballots, which can be found on the NYS Board of Elections website: https://elections.ny.gov/request-ballot

All registrations and ballot requests must be received at the BOE by October 26, 2024.

If you are voting with an absentee ballot, put it in the mail ensuring it receives a postmark no later than November 5th as it must be received by the County Board of Elections no later than November 12th. While most people complete and mail their absentee ballot before Election Day, some will take the ballot to the BOE office or an early polling site or the polling site they would use on November 5. Due to a recent change in law, New York State voters are no longer permitted to cast a ballot on a voting machine if they have already been issued an early mail, accessible, or absentee ballot for that election. Voters who have already been issued a ballot can still vote in person using an affidavit ballot, but the affidavit ballot will be kept separate until the election is completed. Election officials will verify whether the voter's early mail, accessible, or absentee ballot has been received. If the voter's ballot has been received, the affidavit ballot will not be counted. If the voter's ballot has not been received, the affidavit ballot will be counted.

People can also request an early mail-in ballot. This is different than absentee ballots, which a person can designate to receive for every election in the future.

The early mail-in ballot does not require a reason to request one and is good for only one year. Someone may know they will be away or unavailable to go to the polls on early voting days or November 5, so they decide to vote with an early mail-in ballot. Same rules about affidavit ballots and absentee ballots apply to the early mail-in ballot if you actually show up at the polls. If you ask for an early mail-in ballot, please return it as soon as you can or at the latest, postmark by November 5. The rules for using these ballots are complicated, see https://elections.ny.gov/request-ballot.

Some people want to vote early in-person, to avoid standing in line at a polling place or because they have family or work needs on Election Day. Where and when can you vote early? https://www.broomevotes.com/earlyvoting.

2024 November General Election Early Voting Sites and Times:

Broome County Public Library - 185 Court St., City of Binghamton

George F Johnson Memorial Library - 1001 Park St., Village of Endicott

Vestal Public Library - 320 Vestal Pkwy E., Town of Vestal

Taste NY Building (Cornell Coop Ext) - 840 Upper Front St., Town of Dickinson

Saturday, October 26th, 9 am – 5 pm
Sunday, October 27th, 9 am – 5 pm
Monday, October 28th, Noon – 8 pm
Tuesday, October 29th, Noon – 8 pm
Wednesday, October 30th, 9 am – 5 pm
Thursday, October 31st, 9 am – 5 pm
Friday, November 1st, 9 am – 5 pm.
Saturday, November 2nd, 9 am – 5 pm
Sunday, November 3rd, 9 am – 5 pm

Broome County recruits poll workers: https://www.broomevotes.com/pollworkers

Live in Chenango County? Here is your information site: https://www.chenangocountyny.gov/235/Elections

And Chenango County will hold Local Registration Days on:

- Saturday September 28th from 2 pm to 9 pm at Chenango County Board of Elections
- Thursday October 10th from 9 am to 12:30 pm at Chenango County Board of Elections

The Chenango County BOE is located at 5 Court Street, Norwich, NY, 13815; 607-337-1760. Their hours are 8:30 am – 4:30 pm. Questions? Want to work at the polls as an election inspector? Email Carly Hendricks or Mary Lou Monahan. chendricks@chenangocountyny.gov or mlmonahan@chenangocountyny.gov

Tioga County's BOE site is at https://www.tiogacountyny.com/departments/board-of-elections/

James Wahls and Kelly Johnson are the Commissioners. 607-687-8219 or use email links at the county website.

All the counties in NYS are looking for poll workers. From Tioga County, "Signing up to work the polls on Election Day is an amazing way to strengthen democracy, give back to your community, and ensure safe, secure, and accessible elections this November.

As a poll worker, you will prepare the polling place for voting, set up voting equipment, sign-in and process voters, demonstrate voting procedures, assist voters, close the polling place, and canvass and report election results.

Poll Workers get paid for training and each Election Day they work.

To be eligible, you must be a New York State registered voter. If you are 17 years old, you may be eligible if your school district participates in a program under Education Law Section 3207-a.

https://www.tiogacountyny.com/media/qsfhnb0s/2024-recruiting-brochure.pdf

STIC keeps voter registration and absentee ballot forms handy. If you have an appointment here to work with STIC staff and need a registration form, ask to see me.

And please **VOTE!**

STIC's 3rd Annual Craft Fair: A Fun-Filled Fundraiser for a Great Cause!

By Lucretia Hesco

We are excited to announce STIC's 3rd Annual Craft Fair, happening on Saturday, November 2nd, 2024, from 10:00 AM – 3:00 PM. This year promises to be our best yet, with an exciting array of crafts, art, jewelry, baked goods, holiday gifts, handmade items, and more!

Join us at this festive event where you can find unique gifts for the upcoming holiday season and enjoy a delightful day with family and friends. Whether you're looking for that special handmade item or simply want to indulge in some delicious baked goods, there's something for everyone.

Highlights of the Craft Fair:

Crafts and Art: Explore a diverse selection of handcrafted items and beautiful artworks created by talented local artisans.

Jewelry: Discover stunning jewelry pieces that are perfect for treating yourself or gifting to loved ones.

Baked Goods: Satisfy your sweet tooth with a variety of homemade baked treats.

Holiday Gifts: Get a head start on your holiday shopping with unique and thoughtful gifts.

Handmade Items: Find one-of-a-kind creations that showcase the skill and creativity of our vendors.

Exciting Raffles:

50/50 Cash Raffle: Take a chance and you might go home with some extra cash!

Basket Raffles: Enter to win beautifully curated baskets filled with amazing items.

This craft fair is not only a fantastic opportunity to support local artists and crafters but also a significant fundraiser to benefit STIC. Your participation helps us continue our mission to provide essential services and support to individuals with disabilities.

We look forward to seeing you there!

Event Details:

Date: Saturday, November 2, 2024

Time: 11:00 AM – 3:00 PM

Location: STIC- 135 E. Frederick St. Binghamton, NY 13904

For more information or to become a vendor, please contact us at sticevents@stic-cil.org.

Thank you for your continued support, and we can't wait to celebrate with you at our 3rd Annual Craft Fair!

The Legacy of Rachel Michelle Bartlow-McHugh

By Laura Hulbert and Matthew Requa

On June 28, 2023, the community suffered the untimely loss of advocate, coworker, family member and friend Rachel Bartlow-McHugh after a courageous battle with esophageal cancer. Esophageal cancer has risen over 733% in the past four decades and is considered the fastest growing cancer in the United States and western world. Despite being one of the deadliest cancers in the world, there are no routine or standard screenings to detect it, and research for treatment is extremely underfunded.

On June 21st, 2024, a fundraiser to benefit the Salgi Esophageal Cancer Research Foundation in memory of Rachel was held at House of Reardon in Binghamton. The wonderfully well-attended fundraiser, which included a cash raffle and basket raffles, raised a staggering $9,730.00! This money was donated in honor of Rachel on

the first anniversary of her death. The donation will be used by the Foundation to fund current research in the development of a breathalyzer screening test for early detection of esophageal cancers.

On June 28th, 2024, a dessert sampling was held at STIC to further commemorate the legacy of this beloved and unforgettable woman. Rachel had many passions in life, including baking. As a self-taught pastry chef, she excelled in creating beautiful and delicious desserts. Staff were invited to come and sample her most legendary dessert recipes made by her family including cheesecake, pumpkin bars, cream puffs, coconut de leche cake, apple pear pie, and strawberry shortcake. Staff were also invited to participate by baking their most famous desserts to be shared and sampled in celebration of Rachel. Afterwards, in the memorial garden that was dedicated to Rachel on October 26th, 2023, Executive Director Jennifer Watson shared her memories of Rachel and invited the staff to do the same, followed by a moment a silence. In this garden, among many flowering plants and a bush in vivid shades of red, Rachel's favorite color, you will find a custom-built bench with a plaque. 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.

Thanks to the devotion and efforts of Rachel's family and all those who loved her, her contagious smile, compassionate heart, and admirable spirit will continue to inspire and help others.

"Carve your name on hearts, not tombstones. A legacy is etched into the minds of others and the stories they share about you."
~Shannon Alder

For information on how you can donate to the Salgi Esophageal Cancer Research Foundation, visit their website at www.salgi.org, or call them at 1-401-398-7785.

DSP Appreciation Week

Every day we recognize Direct Support Professionals. However, this September 8th through14th we officially celebrate you, our Direct Support Professionals. As a Direct Support Professional, you devote yourself to mentoring and assisting with the daily activities of those in your care with kindness and respect.

We see you all around our community with your clients, incorporating them into everyday life, and we are grateful. You make a difference in people's lives and make the community richer, probably more than is easy to see firsthand.

The care you provide is more than just physical. You empower people to build more fulfilling lives. Your work teaches valuable life skills and provides respite and support to overtaxed family members, which has ripple effects that can change the world for the better.

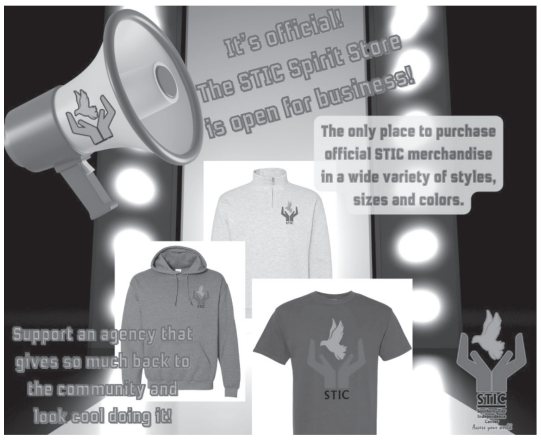
Please know that you are respected. You are valued. You are seen! And we are unendingly grateful for all that you do.

Happy DSP Appreciation Week!

The Community Habilitation Coordinators of The Southern Tier Independence Center:

Katie, Cathy, Daniel, Kendra, Whitney

Our very own Chad Eldred, Director of Operations and Programs, threw out the first pitch at the Binghamton Rumble Ponies vs. the Portland Sea Dogs game on Tuesday evening, August 13th. Eldred, a baseball enthusiast and season ticket holder, really brought the heat as the crowd and his family watched proudly from the stands.



Scan the Code to Purchase

THANK YOU!!

With Xscapes bucks you can purchase as much or as little as you need for your gifts. Share the gift of entertainment and knowledge with your family and friends. It's the gift that keeps on giving, while supporting STIC's mission in our community and the individuals we serve.

Xscapes is a great team building option for your business associates. We also see school functions or camping trips use Xscapes for amazing recreational outings. We offer five (5) different games with exciting themes that will put players into immersive environments while encouraging communication skills and teamwork. Your management team can also have the option to watch your employees play our games from the control room with our game masters running your experience. Xscapes features conference rooms for team-building break-out meetings, and you can bring food with you to make your overall experience spectacular here at Xscapes.

To book your next escape room experience visit:
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