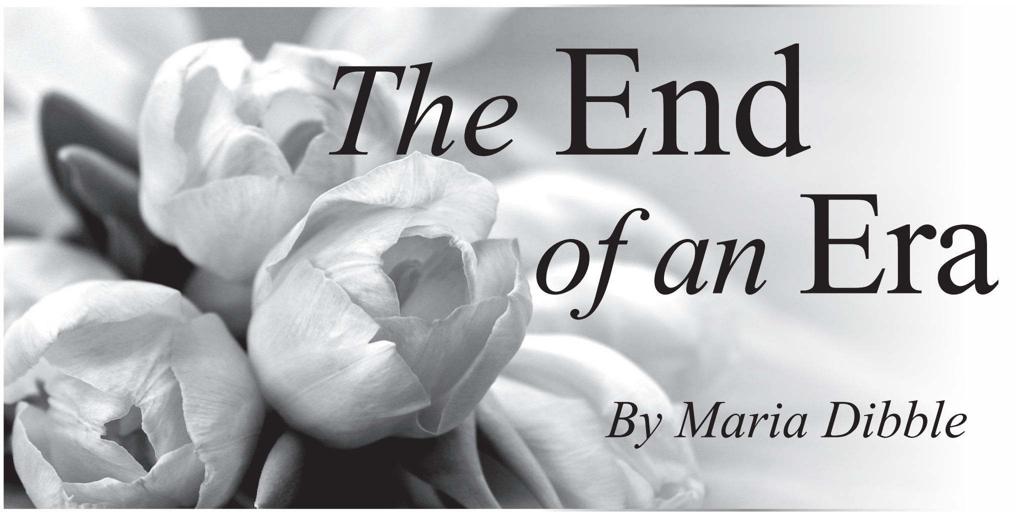
The Voice of Disability Rights in the
(Bureaucratic) Empire State since 1984

AccessAbility

Summer 2019
Number 135

INSIDE



The End *of an* Era

By Maria Dibble

Twenty years ago, despite my many reservations, a STIC board member convinced me to begin to offer Medicaid Service Coordination through STIC. I was reluctant because I thought it would be a "medical model" of service delivery that didn't put the person first and didn't consider their input or wishes. She suggested that we could use our Independent Living Philosophy of consumer control, self-direction, and individual choice to govern how we provided MSC. It was more successful than I could have ever imagined. The program grew from one employee to 22 at its largest, and we were always in the highest demand because of our IL approach.

Early on I decided that the MSCs wouldn't carry the maximum "caseload", or number of participants, allowed by regulation, but would instead make the number much smaller so that the MSCs would have time to advocate on each person's behalf. Additionally, we also made a decision to dedicate our efforts to serving people who desired to live independently in the community. This was not a judgment against those who preferred group homes, but there were many agencies that provided that kind of support, whereas STIC was the only agency that had our focus on integration. We would advocate in schools for students with disabilities, for sign language interpreters, for moving to a more integrated setting, and any other necessary advocacy that would promote the goals of the individual.

Then a few years ago, the federal government demanded that New York State stop dragging its feet on compliance with the new "conflict of interest" rules for Medicaid waivers. We at STIC absolutely believed that those conflicts needed to be addressed, because they were keeping lots of people from hearing about all of their options for integrated community living. But the state chose the "health home" model because it will get a much higher federal Medicaid match (for at least two years, anyway). So new organizations called "Care Coordination Organizations" (CCOs) that would offer the health home benefit were formed. MSC was moved to those CCOs and the service is now called "Care Management" and the Coordinators, "Care Managers" or CMs.

In July 2018 the CMs began offering the health home benefit and working under CCO auspices. The CCO that STIC "joined" is Prime Care Coordination, and we opted to keep "our" CMs as employees of STIC for a transition year. The final step of the CCO transition will take place on July 1, 2019, when our CMs will leave our employ and our physical facility, and move to a new Binghamton location for Prime Care. STIC will still be a part-owner of Prime Care, but we will have no involvement with the day-to-day activities of the CMs.

It is the end of an era for STIC, and it is an extremely emotional time for everyone involved. Thus, it is with a sense of deep sadness and loss, that I want to bid farewell to an entire department, and the individual Care Managers who comprise it. They've been an integral part of STIC for two decades, and their loss is like losing a part of ourselves.

It is very difficult to say goodbye to one employee who may be moving on to new pastures, but if you multiply that by 20+ individuals, it is hard to put into words the profound impact it will have on them, as well as on those remaining here.

Our CM Department prides itself on providing high quality comprehensive integrated services, as they should, and that will certainly continue when they become Prime Care em-

AccessAbility

June 2019

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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

Our address is:

AccessAbility
Southern Tier Independence Center
135 E. Frederick Street
Binghamton, NY 13904

Subscriptions

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

Advertisements

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

Reprints

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

Authorship

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

www.stic-cil.org

ployees, but we will all miss their knowledge, expertise and experience right here on site. Even more though, we will miss them as individuals, the people and personalities they are, the friendships they've formed and their constant and much welcome presence in our lives.

It is impossible to express or measure the loss we will all feel as we watch our friends, coworkers and all-around wonderful people prepare to move onto a new chapter of their lives and careers. But with change comes opportunities, with new friendships to form and additional people to meet, while remembering that the relationships we've established will still remain and perhaps even strengthen.

As Executive Director, I want to thank each and every Care Manager for her/his outstanding compassionate caring service to people, and for the dedication and commitment they have shown to our philosophy, mission and values. The contributions each CM has made to STIC are innumerable, and will be sorely missed. They have helped to make STIC stronger, have enhanced our reputation as advocates for community integration, and have been a part of our culture for 20 years. I hope they will take away at least as much as they've given, and bring our philosophy wherever they go.

With all of this said, I won't say "goodbye" but rather "farewell", because I'm sure we'll see you here at conferences and workshops, as well as in our joint efforts to advocate for and meet the needs of individuals with developmental disabilities and their families.

Thank you all for being a part of our lives, and for your help in shaping STIC to become the organization it is today. You will be missed!

DOH to CDPA: *"Let's Talk"*

We reported last time that Cuomo's budget proposals included a plan to completely revamp the Consumer Directed Personal Assistance program (CDPA). Some of the proposed details were dropped at the 30-day amendment point, but the most threatening change—introduction of a flat per-person-per-month administrative rate—remained.

We explained how CDPA works in our last issue (see *AccessAbility* Spring 2019); please refer to that article if you need a refresher.

CDPA started out in New York with one semi-"experimental" New York City-based agency many years ago. Advocates worked hard to get legislation and regulations issued to make it available statewide. When that happened, Centers for Independent Living (CILs, like STIC) were the preferred operators for new programs, which were supposed to make the service available in every county. The operators are called "Fiscal Intermediaries" (FIs).

Later, the state Department of Health (DOH) was induced to allow other organizations to become FIs, and so a few non-CIL CDPA programs were established. Then Medicaid managed care came along. All of the managed care plans were required to offer CDPA as well as "traditional" homecare services. As we reported, the plans quickly realized that CDPA was cheaper than traditional services so they began pushing all of their "members" who needed homecare into CDPA.

That caused a huge growth spurt; suddenly hordes of traditional homecare agencies started offering what they claimed were CDPA programs. In a lot of cases, this has been bogus. The programs do not let participants freely choose their attendants, schedule them as they wish, or train them to provide services their way. But DOH did not carry out its responsibilities to monitor these mushrooming programs and weed out the fraudulent ones. What they did was notice the rapid growth in the program. They identified it as a cost center that needed to be trimmed back.

Last year, as we've reported (see *AccessAbility* Summer 2018), Cuomo got a law passed to require all forms of CDPA "marketing" (which was very broadly defined) to be approved by DOH before it could be published. Past history with other programs indicates that FIs would likely be able to stage snowball fights in Satan's living room before DOH got around to issuing any approvals; this was clearly an intended silencing of CDPA programs, designed to slow their growth by keeping new people from hearing about them. But conversations with DOH indicated that they did seem to be aware that some of these new FIs were making bogus claims. Some of those programs advertise extensively. You may have seen TV commercials for them. But applying a pre-approval rule to CDPA programs that DOH does not apply to other Medicaid-funded long-term care services, including traditional homecare agencies and nursing facilities, was clearly discriminatory—in legal terms, "arbitrary and capricious." DOH should be conducting site reviews and program audits to determine what each specific FI is doing, and demand changes only from those that are actually doing wrong. But that costs more than simply applying a gag order to all of them. Some FIs sued but the case was argued on a questionable "freedom of speech" basis; the judge issued an incomprehensible initial ruling, and it was still in the courts this spring.

So this year Cuomo decided simply to cut the spending. He did it by proposing a one-size-fits all separate monthly administration fee for each CDPA participant, which was supposed to cover all of the FIs' costs. As we reported last time, the FI cost to run the program varies considerably with the number of attendants and hours of service each participant needs. Cuomo's flat rate fee, which we understood unofficially was to be $100 per participant per month, was a 65% reduction from the average administrative rate and would not come close to paying for everything the FIs have to do. It took a while to pry out of DOH how they arrived at that figure: Turns out they just set an arbitrary target to cut $150 million from the program's administrative expenditures; if you divide what remains after that cut by the number of "member months" for people in CDPA, you get $100.

We hope you understand that this isn't just about us, STIC, getting our money, it's about keeping the program working well for you. If the money we get to run the CDPA program is cut by 65%, we would have to lay off some already very busy staff. The program would run much more slowly and become much less responsive to your needs.

When the FIs objected to this, they were rudely dismissed (and I mean literally very rudely, in an interpersonal sense) with the claim, "Whaddya mean? All you guys do is process payroll. That can't cost that much." FIs mobilized CDPA participants and disability rights advocates and mounted a full-court press on the legislature. They got considerable early support to oppose all of Cuomo's legislative CDPA proposals—but, Cuomo already had the power to change the rate formula, and the legislature was not willing to go so far as to revoke it.

When the budget passed there were a few victories. Cuomo's DOH dropped the demand for pre-approval of marketing materials, they said some reassuring words about "grandfathering" all of the existing CIL FIs into the new program approval process, and they grudgingly agreed to meet with FIs to collect information and potentially work out a fairer way to apply a per-person-per-month (PMPM) rate. DOH initially suggested they might accept a set of rate "tiers" based on service hours, and they proposed three tiers: a very low rate for participants who get fewer than 5 hours of service each week; a middle rate for those who get between 5 and 95 hours; and a high rate for people who get more than 95 hours.

There are at least two FI groups involved in the negotiations with DOH. One is the CDPA Association of New York State—CDPAANYS, a trade group that represents most of the FIs, including STIC. The other is a group that exclusively represents CILs that are also FIs.

At their first face-to-face meeting, the CIL negotiators learned that, according to DOH, 70% of CDPA participants in New York State get fewer than five hours of service per week, while only 28% get between 5 and 95 hours weekly, and a tiny 2% get more than 95 hours.

This was shocking news to the independent living group, who reported that almost none of the people they serve receive under five hours a week. DOH seemed genuinely surprised but insisted that their data is accurate. The CIL negotiators went home and, working together, devised a formula for a tiered system that would work for the CILs and should save almost as much money (within a few thousand dollars) as DOH wanted. They sent it to DOH and awaited their response.

A few days later DOH officials met with the CDPAANYS group and told them a completely different story. They claimed that they had been basing their calculations on hours per ***day***, not hours per week. When asked how they could get 95 hours of service per day for a rate tier, they said they had "never" offered a tiered rate system to anybody. However, that offer came through the office of NYS Assembly Health Committee Chairperson Richard N. Gottfried, who was unlikely to have made it up on his own. DOH also made some unclear references to basing administration costs on actual hours used, not on hours authorized, which would be completely unworkable. The variable administrative costs result from required activities that must be conducted in order to make all of the authorized hours of service available for use each week—by hiring, orienting, collecting information from, and paying wages to a variable number of workers. The number of workers for whom this must be done increases with the number of hours authorized. In fact, variation in use of authorized hours primarily results from staff shortages and the need to bring in replacements, a situation that occurs more frequently for people who have higher numbers of authorized hours.

All of this was further evidence that the DOH employees charged to work on this project simply do not understand the fundamentals of what CDPA is, what the program operators do, and how CDPA FIs are different from other types of FIs used in other situations in New York State. To put it simply, somebody messed up and was now trying to cover up.

Advocates thought they had fairly clear information on what DOH officials were thinking, and they thought the department was going to negotiate in good faith. Those expectations evaporated, and the agency was no longer responding to questions. With negotiations in disarray and no clear path forward to a successful compromise, advocates once again geared up, and at press time were considering options including asking Gottfried and Assembly Speaker Carl E. Heastie to investigate what is going on at DOH, filing ADA civil rights complaints on behalf of people who would lose CDPA services, and other possible measures.

A lot can happen before our next issue comes out, and the people who use this service may hear from us long before then with information on what they can do to protect their rights.

"Broome County is Killing Me"

by William Martin
(reprinted by permission)

It has become far too common: another person denied medical care at the Broome County Jail, and this time with gruesome and deadly consequences. Today's epitaph is written for Rob Card, a local carpenter, artist, and family man who was sent to the jail for violating probation on a minor drug charge. At the time of his arrest on January 8th, he was being treated for a brain tumor and seizures, a fact known to the local police and court authorities.

Rather than getting the treatment he needed, his only relief at the jail was Tylenol. His condition quickly worsened, and as he had difficulty walking and clothing himself, he fell multiple times. In desperation Rob called his family and said "Broome County jail is killing me." In this history repeats itself: in 2015 Salladin Barton told his family "The guards are going to kill me. You got to get me out of here." Sal, as friends and family remember him, died shortly thereafter.

Is this why such mystery surrounds Rob Card's death? After Rob suffered a stroke and was near death in the jail, unknown local authorities—presumably a judge, a court appointed lawyer, and the district attorney, all without notifying his family—arranged for him to be released from custody. He was reportedly carried out of the jail in a comatose state on January 20th, only to be kept on life support so he could donate his organs. He was declared dead on January 22nd, a death neatly hidden from public view.

His family and friends are outraged. In less than 24 hours in March, over 400 persons signed a petition asking for answers:

Why did Rob need to be incarcerated?

Why did he receive no treatment for his brain tumor and seizures?

What lawyers and court officers directed his release in a comatose state?

Robert Card's death was the ninth at our county jail since 2011 that we know of, a rate far above state and national norms. In 2014 our jail's private medical provider was indicted and fined by the State Office of the Attorney General. Hundreds of medical and abuse grievances go unanswered in a system indicted by our own State Comptroller. Community groups, especially Justice and Unity for the Southern Tier and Truth Pharm, have for many years now presented evidence of abuse and medical malfeasance to county officials.

And in the face of all this, and a long-term falling crime rate, the county has bluntly accelerated the use of the jail as a depository for the poor who can't afford bail, far too many black residents, and those with substance use disorders and health problems of all kinds. Every year the county legislature has expanded the local jail force and the district attorney's budget, while cutting local health resources. Over 75% of those in the jail have health issues, particularly substance use disorders, for which there is almost no long-term local treatment. And too much of our short-term treatment is tied to the police and the courts, where criminal rather than medical procedures ensure lapses in recovery and a constant cycling of persons in and out of jail.

We must do better. Why do we criminalize and incarcerate and harm so many, at so high a moral (and financial) cost? County officials, the Sheriff, and the courts owe Robert Card's family, and all of us, an answer.

William Martin is a founding member of Justice and Unity for the Southern Tier and teaches at SUNY-Binghamton University.

Follow the Money

As is usual due to New York's legal fiction of a "part-time legislature" and less-than-small-d-democratic "three men (well, now it's two men and a woman) in a room" method of passing laws, there's both budget and non-budget stuff in the budget that was passed in March for the 2019-2020 fiscal year.

Most of the results were good, largely because the legislature refused to accept Cuomo's sudden late attempt to introduce a further $1 billion cut to Medicaid (reported initially as $500 million, but that was just the state share; every dollar cut from state Medicaid spending forfeits a federal dollar).

There is no "across the board" 0.8% Medicaid cut. (For the policy wonks, think *Animal Farm*: "All animals are equal, but some animals are more equal than others." These so-called "across the board" cuts rarely touch everyone equally; there are always some sacred cows among Medicaid programs that don't get cut at all, while others are cut more deeply; "across the board" actually means "average.")

There actually will be some cost-of-living increases for some direct-service people in Medicaid-funded programs, though we don't have clarity on whether those extend outside OPWDD services, or whether, within those services, they include DSPs who are not state employees.

Also very big was an appropriation of funds to implement early voting (see page 15). It's one thing to say that some polling places will open early and people will be able to vote on several days prior to the formal Election Day in November. It's another thing to pay what it costs to make that happen. $10 million was appropriated to reimburse county election boards for the extra work. There's also $25 million for computerized voting stuff—software for "electronic poll books" and "on-demand ballot printers," as well as "cybersecurity protection."

We haven't had a chance to review what all of that actually means, but we want to inject a few words of caution about electronic voting: It is **IMPOSSIBLE** to make an all-electronic voting system secure against hacking, whether by corrupt politicians at home or by Russians, Iranians, Chinese, or others abroad. (Your author is also a cybersecurity specialist and programmer; this is on the level.) New York's system, which requires paper ballots that can be stored indefinitely, is actually quite good. Voting data on any computerized device is much easier to modify without leaving a trace than paper ballots are. Still, if you are given an opportunity to print out and keep a paper copy of your ballot, you should always do so. The "electronic poll books" are more suspect. Poll books are those big books that have copies of your signature pasted into them; you have to sign across from them so the poll workers can validate your signature before you can vote. But more importantly, those books contain the names of every person who will be permitted to vote at each precinct (at least, those who won't have to file for preliminary approval). Again, they are paper, and difficult to tamper with. But if the voting lists are electronic, and especially if they are "online" (that is, available to the internet), they can easily be altered. The Russians were definitively, no-doubt-about-it, caught snooping around in the online voter registration data of several states in 2016 and earlier. They could have easily removed random names from the voter rolls, or inserted fake names, or simply scrambled them into the wrong precincts. They don't have to change the actual vote counts to create a huge problem; they just have to screw up the works enough so that people will stop trusting elections. If that happens, we will start looking more like some of those countries where every election is disputed in court, in the streets, and sometimes with guns.

The NY Connects program, which pairs Centers for Independent Living (CILs, including STIC) with county Offices for Aging to provide information clearinghouses for people seeking long-term-care services, got a $1 million increase over two years.

The CILs themselves got a whopping $500,000 increase in their general operating appropriation. That's not per center; it's for all of the roughly 40 centers in the state. It amounts to $12,500 per center, which doesn't even justify the time it took to write this paragraph, but hey, it's the first increase in something like 13 years, and we try to be accurate here.

As predicted, once again Cuomo's attempts to put an end to spousal/parental refusal in Medicaid, to remove "prescriber prevails" from the Medicaid preferred drug program, and to allow school districts to apply for waivers to avoid fully complying with the Individuals with Disabilities Education Act (IDEA), were defeated.

Also, the Long Term Care Ombudsman Program and the division of the Access to Home program that serves non-veterans who are not eligible for Medicaid were level-funded.

Some of the things that disability advocates ask for every year, and are denied every year, were denied again, including tax credits for making residential construction "visitable" by people with disabilities, and for hiring people with disabilities other than the developmental kind. Also rejected was the effort to revive the State Office of Advocate for People with Disabilities.

Both the Assembly and Senate attempted to duplicate a previously-passed law to require the state to seek federal approval for a "community-based high needs rate cell" (a higher per-capita rate for people with more significant disabilities) in Medicaid managed care. There is actually no need for such legislation to be passed again. It was done once, and as we understand it, DOH asked the feds for it, and the feds refused. Either DOH needs to substantially revise its request (and we don't know if they are working on that) or they need to wait for a different federal administration. But it doesn't much matter in the near term, since it won't actually be needed until the Traumatic Brain Injury and Nursing Home Transition and Diversion Medicaid waivers are moved over to managed care, which won't happen until at least 2024, if ever.

The biggest non-money item was passage of a statewide prohibition on discrimination by landlords on the basis of source of income. New York City has had this for years, but despite years of advocacy from the disability community, the Republican Senate had always refused to extend it statewide. Now that Democrats control both houses of the legislature, that impediment is gone. (That is ***not*** intended as a partisan statement, and many disability activists may rue the day it happened the next time an assisted suicide bill comes up.) Landlords can no longer refuse to rent to someone purely because they have a Section 8 or other form of housing subsidy, or because they rely on SSI for income. This is a substantial victory for disability rights advocates.

courts watch

Tri-City, Endor, et. al. v NYC Taxi and Limousine Commission: An Endor Beginning?

We last reported on this case in December 2018 (see *AccessAbility* Winter 2018-19). Various for-hire-vehicle "base" companies in New York City, some of which are the local operating arms of companies like Uber and Lyft (others are various livery or "black car" companies whose vehicles are dispatched in response to a phone request and can't be hailed on the street) sued the city's Taxi and Limousine Commission to stop its plan to require them to ensure that at least 25% of the vehicles used are accessible to motorized wheelchairs.

That suit was filed in April 2018. Unbeknownst to us, the parties agreed to a settlement almost immediately. The settlement addresses one key complaint of the plaintiffs—that a pilot program that gave operators the option of meeting minimum wait times for arrival of an accessible vehicle instead of vehicle percentage requirements was temporary. The settlement makes the wait-time provisions permanent.

From the riders' point of view, the settlement has a couple of improvements compared to the original pilot: It mandates that each base company that accepts ride requests must either be an "approved accessible vehicle dispatcher" or contract with one. In order to be approved, an accessible dispatcher must demonstrate it has relationships with at least ten other base companies that it can call on for accessible vehicles, and must provide projections for how many accessible vehicles it will have available from those companies. The original pilot only required dispatchers to network with two other base companies. Also, although the wait-time requirements start out loose and get tighter over time as in the original pilot, the new final requirements are more stringent: by June 2021 at least 80% of requests for accessible vehicles must be met within ten minutes, and 90% within fifteen minutes. Failure to meet those wait times will result in the company being required to conform to the original 25% accessible vehicle requirement.

On the other hand, enforcement seems lax. A company that faces the vehicle percentage requirement would be fined $50 per each 100 trips that did not meet the standards each calendar year. Compare this to the fines, starting out at $500,000 and ramping up to $1.5 million, that were actually proposed ***by the companies*** for failure to meet the wait time requirements, on average. The new rules count actual non-compliant trips rather than averaging all wait times. But under the new rules, a company would have to have 1 million non-compliant trips in a calendar year to be fined $500,000.

ILRC, Smith, et. al. v Lyft: Kinder, Gentler Obnoxiousness

Meanwhile, in San Francisco in March of this year, a Center for Independent Living (a CIL, like STIC) sued Lyft in federal district court for failure to provide accessible rides.

The suit is similar to other federal lawsuits against both Uber and Lyft (for another Lyft example, see *Lowell and WDOMI v Lyft*, a suit filed by a CIL in Westchester County in December 2017). Although Lyft has an "access mode" to allow people to request accessible vehicles, in many locations all "access mode" does is provide contact information similar to that found in a telephone directory for services that offer accessible transportation. Lyft in San Francisco and Westchester County does not even make an effort to dispatch any accessible vehicles its drivers might have.

The suit is interesting because the San Francisco CIL, Independent Living Resource Center, points out that Lyft has made an effort to portray itself as a kinder, friendlier, more socially responsible service than Uber, which has become widely known for corporate malfeasance and mistreating workers, as well as for its militant libertarian approach to government regulation. But legally, Lyft has taken the same approach that Uber has; it claims that customers can't sue the company because they agreed to arbitrate all disputes, and it claims that it is not a transportation company. Lyft, while asserting that it does not have to comply with the Americans with Disabilities Act accessibility requirements, claims that it has a more expansive view of access to transportation, arguing that the mere availability of such companies makes lower-cost transportation available to more people, and thus benefits people with disabilities.

This may be true for people with disabilities who don't use power wheelchairs, can afford smart phones, and live in larger cities. But for them, the only potential benefit may be lower cost, since they already had good taxi service available—at least, before companies like Uber and Lyft drove cab companies out of business. But it doesn’t help the people for whom lack of accessible transportation poses the greatest barrier: people who use power chairs and live in smaller cities or rural areas.

***Andreyeva*, *Moreno* and *Tokhtamen*: Who Won, Really?**

This case is tricky to understand. A NYS court combined several similar cases and reversed lower-court rulings that had the effect of invalidating a long-standing New York State Department of Labor (DOL) interpretation of its own regulations governing minimum wage in jobs involving 24-hour shifts. Although this sent some pretty-clearly abused homecare workers back to the drawing board, some disability advocates are claiming victory.

The judge who wrote this decision was Jenny Rivera, who sits on the New York State Court of Appeals. She’s the top of the pyramid for NY State courts. The lower court, whose rulings she overturned, is the Appellate Division of the New York State Supreme Court. (There are two kinds of Supreme Courts in NY; statewide and local, and it gets weirder than that. If you want to try to understand our state’s byzantine court structure, you can go here: https://www.nycourts.gov/courts/structure.shtml) The names listed above belong to homecare workers who sued their employers—homecare agencies—for violating the state minimum wage law.

DOL has recognized that 24-hour shift work is a special case since 1960, and the federal Fair Labor Standards Act has done so since 1939. Both NY and federal law and regulation contain the idea that merely being required to be in a service recipient’s home for 24 hours doesn’t justify paying for 24 hours of work. The state and the feds both recognize that such a worker who is sleeping, or eating, or is scheduled to do either and not actually made to perform work during that time, isn’t entitled to be paid for that time.

It’s certainly possible to argue that if you demand that somebody stay in some location in order to be able to perform work on very short notice, you should pay him for that restriction on his freedom of movement. That’s what the homecare workers argued.

It might be a valid moral argument, but it also might be valid to argue that the worker should pay rent for use of the living quarters. In any case, the practice predates the widespread use of homecare, but it certainly isn’t novel in other 24/7 shift contexts.

DOL has always said that when an attendant is required to be in a person’s home for 24 hours, that attendant must be paid at least minimum wage for at least 13 hours of work, **<u>IF</u>** the following things are true:

1. The worker is “afforded” eight hours of continuous sleep time per 24-hour shift.

2. The worker actually “gets” at least five hours of uninterrupted sleep per shift.

3. The worker is “afforded” three one-hour meal breaks per shift.

Eight hours for sleep plus three hours for meals totals eleven hours. 24 minus 11 equals the 13 hours for which the worker must always be paid.

This is a “subject to call” work situation. The worker has to be able to be reached and respond immediately if ***occasionally*** needed to provide a service. But the worker must be given a schedule that presumes that her breaks will not ordinarily be interrupted. This pretty much mirrors the much older federal rules.

Note that there’s a difference between what the worker is “afforded” and what s/he actually gets. DOL’s position has always been that if the worker has to get up during his/her five-hour sleep period to do any amount of work, s/he must be paid for the full ***eight*** hours of lost sleep, and that if any of her one-hour meal breaks is interrupted for work, s/he must be paid for that hour. (Also, there is no requirement that the worker actually ***be*** asleep for five continuous hours, only that s/he not be interrupted during that time.)

These class-action cases all turn on whether a class can be “certified.” There are several requirements to certify a class, but one of them is that all class members must be experiencing the same kinds of harm, so that a decision made about the class can remedy the harm for all of its members.

The homecare agencies argued that no class could be certified, because the harm to each worker may be substantially different; some workers may have constantly been interrupted during the sleep period to, for example, help a person go to the bathroom, while others may have been able to sleep peacefully most nights but not others. That is not a valid argument, according to Judge Rivera; NY law concerning class action suits is very accepting of these kinds of differences.

What got Rivera riled was that the lower courts threw out DOL’s interpretation and invalidated almost sixty years of precedent. Those courts said that the “plain language” of the minimum wage law required payment for 24 hours of work, and that a class could be certified for any homecare worker who wasn’t paid for all of that time.

Many homecare agencies ignore the word “occasionally” as used above. They schedule people for 24-hour shifts, knowing full well that they will get few, if any, uninterrupted breaks due to the needs of the people they serve, and then they refuse to pay for more than thirteen hours of their work. The judge recognized this fact in a few eloquent sentences:

“While we ultimately conclude that the Appellate Division failed to afford adequate deference to DOL’s interpretation of the Wage Order, we do not ignore plaintiffs’ and amici’s claims that a vulnerable population of workers is being mistreated. Plaintiffs’ allegations are disturbing and paint a picture of rampant and unchecked years-long exploitation. Plaintiffs allege, among other things, that they rarely received required sleep and meal time during 24-hour shifts, were expected and required to attend to patients numerous times each night, and that defendants failed to track actual hours worked or make a serious effort to ensure adequate sleep and meal times, as required by law.”

Rivera’s decision informed the lower courts that DOL’s interpretation of the rules is perfectly valid, and that therefore they must take the cases back and see if there aren’t other reasons to certify a class. She did not say the workers didn’t have a case.

Disability rights advocates understandably don’t like anything that tends to reduce the availability of attendants. The workers have argued that instead of assigning people to 24/7 "live-in" jobs, two workers should be assigned to work two twelve-hour shifts. It's hard enough to find one good, reliable attendant in a lot of places in New York State, let alone two.

But this decision is pretty thin gruel on which to base a disability rights celebration. All people should be paid for all of the time during which they are required to actually perform work. Clearly there are a lot of homecare agencies that have deliberately abused the system to avoid doing that. It's equally clear that when the workers come back with a class based on that abuse, they will win their case.

Disability rights advocates should not pit their welfare against that of the people who serve them, as long as those people respect them and their civil rights (we have not changed our position on the often despicable behavior of public employee unions and some of their members). They should unite with them and call for higher wages (including overtime pay) and better benefits, and for Medicaid rates that are high enough to enable agencies to afford those things.

Wit v United Behavioral Health: Bad Behavior

And now we delve into the murky world of health insurance. Although it may involve a slog through the regulatory weeds, the trip will be worth it, because this case reveals a method that insurance companies use to get around the federal mental health parity law: provide the minimum amount of treatment that will make the "presenting symptoms" go away, and then deny further coverage. Historically, this approach has been what puts people who are at extreme risk of homelessness, victimization, and erratic, dangerous behavior "back on the street." It's an approach that state and local government have also taken in NY, and for the same reasons: to save money. Now a federal judge has declared that, at least when private insurance companies do it, it's illegal.

The federal Mental Health Parity and Addiction Equity Act of 2008 requires that medical insurance plans that cover mental health treatment must not apply limits to coverage for that treatment that are not also applied to physical health treatment. This is typically taken to mean that cost caps and limits on hours of service or numbers of visits, if any, for both types of treatment must be the same. However, as reported by *Modern Healthcare* in 2018, "Many of the barriers that still exist come from what are known as insurer non-quantitative treatment limitations." That includes different, and more restrictive, utilization review procedures, which this case is all about.

United Behavioral Health (UBH, also known as "OptumHealth Behavioral Solutions") is part of United HealthCare, a huge national medical insurance company. UBH does utilization review and makes coverage determinations—approvals and disapprovals—for insurance plans that offer coverage for mental health and substance abuse treatment services. The plans are operated by UBH, by other insurance companies that contract with UBH for the service, or by "self-insurers"—large employers that use their own funds to pay for services rather than purchase insurance.

This is a class action suit. The plaintiffs are a group of people who were denied coverage for various types of mental health or substance abuse treatment services by UBH. They sued in federal court for the northern district of California, but UBH/Optum operates in New York State, serving as the "administrative" delegate for behavioral health plans and offering a HARP (Health And Recovery Plan, a form of Medicaid managed care for people with mental health disabilities) plan of its own. The suit accuses UBH of violating the federal ERISA law (Employee Retirement Income Security Act), which mandates minimum requirements for health insurance plans provided by most employers across the United States.

On February 28, 2019, the judge, Joseph Spero, issued "findings of fact and findings of law" that upheld the plaintiffs. UBH, he said, is legally liable for breach of fiduciary duty and for wrongful denial of benefit claims. The judge still needs to determine "remedies," and UBH has said it will reserve a decision on whether to appeal until after he does that.

Under ERISA, insurance plans have a "fiduciary duty" to people covered by those plans. The law says:

"a fiduciary shall discharge his duties with respect to a plan solely in the interest of the participants and beneficiaries and ...

(A) for the exclusive purpose of:

(i) providing benefits to participants and their beneficiaries; and

(ii) defraying reasonable expenses of administering the plan;

(B) with the care, skill, prudence, and diligence under the circumstances then prevailing that a prudent man acting in a like capacity and familiar with such matters would use in the conduct of an enterprise of a like character and with like aims;

. . . and

(D) in accordance with the documents and instruments governing the plan insofar as such documents and instruments are consistent with the provisions of" ERISA.

This may come as a surprise to many. Medical insurance plans provided by an employer are actually not supposed to prioritize saving money above providing appropriate services! Imagine that! Not even if they are managed care!

In UBH's case, the "documents and instruments" were the company's Level of Care and Coverage Determination Guidelines. The judge found that those guidelines had a goal of "'mitigating' the impact of the 2008 Parity Act" on expenditures. In so doing, they ignored what mental health and substance abuse practitioners consider to be "generally accepted standards of care," and that means they are not consistent with ERISA.

According to the plaintiffs' prime witness, those standards require that more than just a person's "acute" or "presenting" symptoms be treated. They mandate that all of the person's "biopsychosocial" factors be assessed and that all of the chronic, underlying, and co-occurring conditions be "effectively treated" (see here for more on the biopsychosocial model: https://en.wikipedia.org/wiki/Biopsychosocial_model). Although the plaintiffs only had two expert witnesses to describe the standards, all, or nearly all, of the UBH witnesses agreed generally with their testimony about what the standards are—if only when cross-examined to show that UBH's guidelines don't follow them.

The guidelines contain information for service providers, and for UBH employees who make coverage decisions. The "clinical best practice" portion is aimed only at service providers and is treated as advisory. The guidelines for coverage determinations (approvals and denials) generally ignore, and sometimes outright contradict, the best practice recommendations—and UBH requires them to be followed.

In testimony before the court, various United Health employees claimed that despite the strictness of the guidelines and their emphasis on "acuity," in reviewing claims they would follow the generally accepted standards of care. The judge did not find these statements "credible" (he meant they lied).

Now, other judges may look at this judge's decision and say, "Hey, this guy isn't a psychiatrist. Judges aren't qualified to evaluate the details of whether a psychiatric treatment guide meets generally accepted standards." So if this case is appealed to the relevant circuit, that could be the response. On the other hand, this is California, where liberal judges are in abundance, and that kind of response is more likely to come from a conservative.

However, the judge also described testimony from UBH employees that clearly indicated that UBH's "commercial business" intentionally focuses on "the reasons why somebody came into treatment at that point," and not on ensuring effective treatment for chronic, underlying, and co-occurring conditions. He also found that the company's financial side "infected" the coverage determination side by including money people in the work groups that devised the guidelines, people who also frequently communicated their desire to minimize benefit expenditures to the people who make the determinations. That may be a stronger point for an appeals court.

Although some mental health advocates are calling this decision a victory, disability rights activists who look at it closely might disagree. Apparently the generally accepted standards of care favor institutionalization over community integration. The judge called out UBH's failure to pay for segregated congregate treatment programs in many cases. Here are three quotes from the decision:

Quote 1: "The evidence at trial did not support the conclusion that under generally accepted standards of care, there is a balancing of effectiveness against the restrictiveness or intensity factor; in other words, the fact that a lower level of care is less restrictive or intensive does not justify selecting that level if it is also expected to be less effective. Placement in a less restrictive environment is appropriate only if it is likely to be safe and just as effective as treatment at a higher level of care in addressing a patient's overall condition, including underlying and co-occurring conditions."

Okay, we certainly don't want people in less restrictive settings that don't work for them. That's the approach that has been taken for some people in the *O'Toole* adult home case (see *AccessAbility* Spring 2019), and the results have not been good.

Quote 2: "Research has demonstrated that patients with mental health and substance use disorders who receive treatment at a lower level of care than is clinically appropriate face worse outcomes than those who are treated at the appropriate level of care. ... On the other hand, there is no research that establishes that placement at a higher level of care than is appropriate results in an increase in adverse outcomes. ..."

Well, that's substance abuse treatment, not the type of mental health treatment that most disability rights advocates get exercised about. But there is at least anecdotal evidence that isolating people with substance abuse issues beyond a certain point, after they've detoxed and gotten some initial instruction, can make it harder for them to return to an ordinary setting, where the rules and environment are much different, whereas assisting them to cope with real-life circumstances that stimulate self-destructive behaviors as they arise is more likely to be successful. On the other hand, it's also true that nearly all people who develop substance abuse problems start out by self-medicating to address those "underlying, contributing, and co-occurring" mental health disorders. So maybe if we remove the silo walls between substance abuse treatment and other forms of mental health services, we'd get better results? Beyond that, not everybody involved in this case had a substance abuse issue; people with major depression and bipolar disorder, for example, were also included.

And segregation, all by itself, is an "adverse outcome" for all human beings.

Quote 3: "In general, when the criteria designate a treatment placement that is not available, a strategy must be crafted that gives the patient the needed services in another placement or combination of placements. The paramount objective should be safety and effectiveness, which usually requires opting for a program of greater intensity than the placement criteria indicate."

Uh-oh. When in doubt, lock 'em up.

There's also a discussion of the relevance of a person's "motivation" to participate in treatment. Apparently the generally accepted standards allow for a "force treatment first and hope they get motivated later" approach. Most of us understand that when it comes to certain types of mental illness that involve hallucinations or delusions, there will be times when people who don't want to be treated must be treated anyway. It's harder to accept that principle when it comes to substance abuse treatment; indeed, a lot of folks in that field believe that only people who "hit bottom" and acknowledge they have a problem can be effectively treated (that's a principle of 12-step programs but it's not exclusive to those programs, for which there is little reliable evidence of long-term effectiveness). The decision does not mention that people have a civil right to refuse treatment, though that may only be because the context is a bunch of cases in which an insurance company refused to pay for treatment that people asked for. Still, this decision might be less disturbing if the judge had made distinctions between substance abuse and other types of mental health disabilities.

To summarize the downside: This judge does not like the fact that "UBH's Guidelines ... actively seek to move patients to the least restrictive level of care at which they can be safely treated, even if a lower level of care may be less effective for that patient." The case is about people who requested services that were denied, which implies that they chose to be segregated. On the other hand, a lot of these people were actually family members seeking services for loved ones, and in our experience many family members of people with mental health or cognitive disabilities do not really consider personal autonomy and community integration to be high priorities for their relatives.

To summarize the upside: The judge also doesn't like the guidelines because they say that the person's situation should be reviewed every three to five days and the person should be moved to a "lower" (less expensive) level of care, or dropped from treatment entirely, unless there is "... compelling evidence that continued treatment in the current level of care is required to prevent acute deterioration or exacerbation of the [person]'s current condition." There's no doubt that stopping a treatment that is making a person better, unless that will clearly and immediately make the person worse, is bad idea. More to the point of the parity law: Would any doctor in their right mind recommend stopping a 10-day round of antibiotics if the symptoms went away after day 5? How about stopping a surgical procedure to fix a bleeding problem and sewing the person up as soon as the patient's blood pressure improved, without making sure there were no more bleeds? But perhaps the judge would agree that in considering "better" vs "worse," all of the person's underlying and contributing "biopsychosocial" factors should be considered. Is a person really "better" if they stop using drugs while locked up, but also lose contact with their friends and family, and their job?

We'll follow this case and let you know what else the judge does decide.

NY ON SPECIAL ED “WATCH LIST”?

In March the Albany *Times-Union* reported that several New York State Regents were unaware, and surprised to find, that New York’s special education system had been on a federal “watch list” for a decade.

As the *Times-Union* reported, “‘I’ve been here eight years, and last month was the first time I’ve seen all the red dots,’ said Regent James Cottrell, referring to the scores that have landed New York in the ‘Needs Assistance’ category on the federal Department of Education’s list.

‘I’m just totally confused on how we’ve managed not to know this,’ added Regent Judith Johnson. ‘How could this have happened?’

‘Looking at it in the aggregate is shocking,’ said Regent Nan Eileen Mead.”

The story conveyed the impression that the Regents were relying on State Education Department (SED) officials to provide them with information, and SED had been downplaying the situation, presenting it in confusing ways, or even omitting information from their reports, at least until the one they got from SED in March. We at STIC actually kind of thought that the Regents, who have oversight responsibility for SED, would be interested and concerned enough to collect information independently from federal sources rather than relying on what the people they are overseeing tell them. Silly us.

Okay, that’s just being snotty. So instead we’ll try to answer Regent Johnson’s question. The Regents, like virtually everybody else who plays a non-political oversight role in government, would rather not know if things are going badly, because then they would, at the very least, have to work harder to do something about it, and at worst, might get blamed for knowing about it and not doing anything, and lose their jobs. So a newspaper reporter publicly popped open the lid on this particular cesspool of unpleasant facts, and the Regents did an uncomfortable little public jig, sort of like a kid who’s got to go to the bathroom really, really bad. And yes, that’s very snotty, and quite true.

We actually reported on this a few years ago, so it’s not that hard to find out what’s really going on if somebody actually tries. We did a bit of our own digging again this year.

The issue is educational outcomes for students with disabilities. The state has been on the “Needs Assistance” list for the part of the Individuals with Disabilities Education Act (IDEA) that serves children aged 3 to 21 (Part B) for ten years. We’ve been on the list for Part C (which serves infants and toddlers) for one year. “Needs Assistance” means the state has had trouble either meeting various IDEA compliance requirements (such as getting Individualized Education Plans done on time or ensuring that behavioral plans are developed for students who need them) or achieving various student performance goals (scores on Regents and other exams, graduation rates, and such).

> We thought that the Regents would be concerned enough to collect information independently from federal sources rather than relying on what the people they are overseeing tell them. Silly us.

When a state is on the list for two years or more in a row, the federal Department of Education (DOE) is required to take some enforcement action. DOE ordered NY to get “technical assistance” to improve its performance. Since the state’s been on the Part B list for ten years, that “assistance” doesn’t seem to have helped very much, but that’s the limit of what DOE is required to do.

But there’s another federal law that addresses school performance with regard to disabled students: What used to be called the “No Child Left Behind Act” and is now the “Every Student Succeeds Act” requires schools to report test scores across several categories of students. When performance drops below a certain level, individual schools or entire districts get placed on “focus lists” by the state education authorities, which, again, just means they are supposed to get technical assistance to do better.

There are no districts in STIC’s core service area on a focus list due to the performance of students with disabilities, but there are several in counties served by one or more STIC programs. They are: Cincinnatus, Cortland, Dryden, Elmira, Sidney, and Waverly. The Binghamton district is on a focus list due to its poor performance with students who are black, and/or Hispanic, and/or “economically disadvantaged.” The rate of disability among all of those groups is higher than for the general population, and quite a few of those kids could actually have disabilities but have not been formally “classified” as such.

Sadly, there is nothing really new here, neither in the lousy performance of our schools, in SED’s lack of interest in doing anything about it that might actually really help, nor in what the Regents know.

STIC NEWS

Brindisi in the Vortex

by Maria Dibble

STIC was very pleased to have Congressman Anthony Brindisi visit our agency and meet with our staff. It was the first visit of a congressional Representative to STIC in many years, since the previous representative from this area refused to come to our agency.

The Congressman was very supportive of our issues, and signed onto the Disability Integration Act as a sponsor on his first day in office (fulfilling one of his campaign promises). He answered questions about a variety of issues, clearly supports many of the concerns of people with disabilities, and ensured us that he would fight against any cuts or changes to Medicaid, Medicare and other programs critical to people with disabilities. We provided him with a packet of information about some new bills to consider, and he said he would review them. Additionally, we asked him to contact the Food and Drug Administration to urge them to release a decision regarding the use of electrical shock aversive therapy to treat behaviors, as is done at the Judge Rotenberg Center, and is considered torture by most. He agreed to work with us on this critical issue.

Congressman Brindisi and STIC Executive Maria Dibble stand before STIC's Wall of Fame.

After speaking with staff, we gave him a tour of STIC. He was quite impressed with the scope of our services, and was especially interested in our Vito Sirotkin Sensory Room, which contains equipment for children and adults who have sensory disabilities.

Lastly, he toured our Xscapes rooms, and even walked through the "Vortex", an attraction that distorts visual perceptions and can be somewhat disorienting. He seemed to enjoy the experience.

Overall, we found him to be quite congenial and a great listener. He appeared to be genuinely concerned with the issues we brought to his attention. It was a positive event for everyone.

STIC hopes to host one of his forums in the fall.

Congressman Brindisi contemplates the image of Senator Chuck Schumer on our Wall of Fame.

Let's FACE It

by Maria Dibble

I'm very sorry to report, that our Early Childhood Direction Center (ECDC) and Parent Technical Assistance Center (PTAC) will both be ending as of June 30 of this year—at least as we know them. Instead, the State Education Department is restructuring their programs to better meet the needs of students with disabilities from age three to 21, and they issued new requests for grant proposals.

STIC applied for the Early Childhood Family and Community Engagement (FACE) Center and the School-Age FACE Center, programs that will supplant ECDC and PTAC. The EC Face Center will serve families and students birth to five, and the SA FACE Center 5 to 21. I'm very pleased to announce that as of this writing (mid-May 2019), we have been tentatively awarded both grants, pending comptroller and budget approvals. We are looking forward to this partnership with the New York State Education Department Office of Special Education to improve outcomes for children with disabilities and provide training, information, technical assistance and more, to families/students with disabilities, as well as educators, school personnel, community agencies, and all stakeholders involved.

I'd like to acknowledge the great work done by both the ECDC and PTAC programs, and to thank the highly qualified and dedicated people who staffed it. Many of the same staff will be remaining to work with the new FACE projects.

Still Waiving at Ya!

by Maria Dibble

I'm very pleased to report that STIC was awarded another five-year contract to continue operating both the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Waivers Regional Resource Development Centers. Our talented and dedicated employees have worked diligently to assist people with disabilities to avoid nursing home placement, or to move out of those facilities and to live integrated lives in their communities. We've been very successful in assisting many program participants to improve their lives and gain more independence, and we are pleased to continue these efforts.

Staying Healthy

by Maria Dibble

STIC has been awarded another five year grant to continue operation of the NY State of Health Navigator Program. These dedicated staff assist people to enroll in health insurance that resulted from the Affordable Care Act. Many individuals and families that never had health care are now able to afford the insurance and cover their families, sometimes for the first time in their lives. Our navigators truly believe that everyone has the right to health insurance coverage, and they demonstrate it with every applicant they assist.

Maria Dibble Honored by Daughters of Columbus

On April 27, 2019, STIC Executive Director Maria Dibble received the 2019 Community Service Award from the Daughters of Columbus in Endicott at their 86th. Annual Dinner Dance. The Daughters are affiliated with the Sons of Italy.

Maria was nominated by STIC’s own Katina Ruffo for her decades of work and advocacy on behalf of people with all types of disabilities of all ages, both in our community and across New York State. Maria said she was shocked and humbled by the recognition. She also was happy to point out that she is of Italian descent; her maiden name was Farruggio. Assemblywoman Donna Lupardo, who was in the audience, was, in turn, shocked by that information. “I never knew you were Italian!” she told Maria.

Also honored were Justin Struble, the 2019 Citizenship Scholarship Essay winner, and Colleen Renda, Lifetime Achievement Award winner.

(from left) Kathy Spatafora, President of the Daughters of Columbus of Endicott, Sue Bock, Immediate Past President, DOC, Maria Dibble, Katina Ruffo.

STIC Executive Director Maria Dibble delivers her acceptance speech; next to her is Katina Ruffo

Several STICsters visited the Daughters of Columbus to honor Maria Dibble: Standing, back row (from left): Casey Flanagan, Jennifer Watson, Chad Eldred, Diane Button. Standing, front row: Nicole Gasbarra, Laura DiRenzo, Katina Ruffo, Cathy Sostre. Seated: Susan Link, Richard Farruggio, Maria Dibble, Ken Dibble.

Adventure in a Magical Land

by Bill Bartlow

The Southern Tier Independence Center and Xscapes are proud to announce the opening of “The Wizard & the Dragon”, our fourth escape room. This room has been in the planning for years and is perhaps our most immersive and challenging escape room. As such, it is recommended that players have previous escape room experience before taking on this challenge.

Here is the plot. To gain more magical power, the wizard has stolen five eggs from a now very angry fire breathing dragon. If the eggs are not returned to the dragon she has threatened to burn down the entire town.

Your team must retrieve the locked up eggs from the wizard’s home, journey through a magical land of elves and invisible people (the Huldafolk) to arrive at the dragon’s lair and return the eggs without being seen by the dragon. You must obtain temporary invisibility from the Huldafolk by giving them something they desire and further compensate the dragon by adding to her treasure horde. The wizard’s grimoires will guide you through this 90-minute adventure if you can interpret them and gain the insight they provide.

This game requires a good deal of mental agility and is not an experience for novice players. Consequently, teams may want to warm up by taking on our other three escape rooms: “Valley of the Kings”, “Pulse”, or “Twilight Zone, Binghamton’s Rod Serling Experience”.

For more information and to reserve a playing time please go to our website www.xscapes-stic.com or call STIC at (607) 724-2111 ext.227.

TheChildren'sAgenda
Smart Choices. Bold Voices.

Kids Can't Wait Community Stories

Parent/Guardian(s) Name	
Child's Name/Age	
Email Address	
Address/City/State/Zip	
County	

Which racial or ethnic group(s) do you most identify with? *(Check all that apply)*

☐ African American / Black
☐ Hispanic / Latin / Spanish origin
☐ Native Hawaiian or Other Pacific Islander
☐ Asian
☐ White
☐ American Indian / Alaska Native
☐ Middle Eastern / North African
☐ Not listed ____________________

My child is: ☐ receiving services ☐ waiting to receive services ☐ previously received services from ☐ Early Intervention ☐ Preschool Special Education ☐ Both

List approximate date services were applied for: ____________________

Has your child received their initial evaluation? ☐Yes ☐No

If yes, list approximate date of initial evaluation: ____________________

After initial evaluation was your child approved for services? ☐Yes ☐No

If yes, please list services approved for: ____________________

____

____

Has your child started receiving all services they were approved for? ☐Yes ☐No

If yes, list date services began: ____________________

If no, please explain: ____________________

____

____

Briefly tell how these services or lack thereof have impacted the life of your child and family:

____

____

____

____

____

____

____

____

____

____

Return completed forms to Kristen Rogers – Advocacy Coordinator – The Children's Agenda

TheChildren'sAgenda

Smart Choices. Bold Voices.

Disclaimer:

By submitting this form, I have shared with the The Children's Agenda my personal experiences related to Early Intervention and/or Preschool Special Education. I hereby grant The Children's Agenda permission to use my name, story, and/or statements in their work – and the work of their assignees – to promote and protect access to Early Intervention and Preschool Special Education Services. I have not received payment or any other consideration except that The Children's Agenda may only use my name as permitted below. The Children's Agenda use of my name, story, and/or statements includes but is not limited to any and all of The Children's Agenda advocacy before courts and policy-makers, publications, reports to funders, and promotional materials, including but not limited to print and electronic publications, newsletters, and websites. The Children's Agenda will make best efforts to share final copy of any use of my story, but in the event that they are unable, I waive the right to review or approve the finished product where my name, story, and/or statements appear. I release The Children's Agenda and its agents, officers, assignees, and employees from all claims that I have or may have related to the The Children's Agenda use of my name, story, and/or statements.

Usage of Name: *(Initial all that apply)*

_____I grant The Children's Agenda permission to use my full name in reference to my story.

_____I do not grant The Children's Agenda permission to use my full name. Instead, I grant The Children's Agenda permission to use my first name in reference to my story.

_____I do not grant The Children's Agenda permission to use my full name. Instead, I grant The Children's Agenda permission to use my story anonymously with no name attached.

_____I represent that I am 18 years of age or older and understand and agree to these terms.

Signature

Date

Return completed forms to Kristen Rogers – Advocacy Coordinator – The Children's Agenda

SELF HELP

Support Early Intervention and Preschool Services

from The Children's Agenda

Research shows the importance of providing services to children with developmental delays and disabilities as early in life as possible. Unfortunately, Early Intervention and Preschool Special Education services in New York State are in crisis. A high number of children identified as needing services are sitting on wait lists because there are not enough Early Intervention or Preschool providers to accommodate their needs. Winning Beginning NY is an organization that advocates for services for young children. As part of their long range advocacy, Winning Beginning NY, in cooperation with The Children's Agenda, are gathering stories of families' experiences in order to educate legislators and the governor over the next year.

Some of the barriers that prevent services for young children include the rates that are paid to providers and the difficulties in getting private health insurance to pay for EI and Preschool services for young children.

Local health departments care deeply about young children who are eligible for services in their regions, and their hands have been tied by statewide shortages and financial battles.

The Children's Agenda has created a survey form (pages 12 & 13). The Educational Advocacy Team is supporting this effort by asking families to please take a few moments to tell about their experiences. Stories can be shared with a name or anonymously. Each situation is unique but collectively all children have the right to receive the services necessary to allow them to reach their full potential.

Completed forms may be returned to:
Kristin Rogers/Advocacy Coordinator
c/o The Children's Agenda
1 S Washington St, #120
Rochester, NY 14614

Or find them on Facebook at:
https://www.facebook.com/54301688477/posts/10157440615348478/?sfnsn=mo

Follow the Money with ASAN

from the Autism Self-Advocacy Network

Every year, the US government makes a budget. The federal budget decides how much money to spend on important things like Medicaid, roads to drive on, good schools, clean water, services for people with disabilities, and much more. You'll start hearing more about the federal budget this summer, as Congress debates their next budget deal. It's easy to feel lost when people are talking about sequestration caps, continuing resolutions, omnibuses, appropriations and more. The federal budget process is complicated and confusing, even to people who have worked in the government for a long time.

But the federal budget impacts all our lives, and we all get a say—we just need the right tools. That's why we're pleased to announce our newest plain language toolkit, **Follow the Money: The U.S. Budget and You**. This toolkit explains:

- What the federal budget is
- What taxes are
- What the budget process is
- What happens when the budget process doesn't work
- What we can do to influence the federal budget

The Budget toolkit is available in two versions: an Easy Read Edition and a Plain-Text Version. Both versions are written in easy-to-understand language and are screenreader-friendly.

You can get them here:
https://autisticadvocacy.org/policy/toolkits/budget/

Get Email from DOH

(from the NYS Department of Health)

The NYS Department of Health, Disability and Health Program is excited to announce the creation of an electronic mailing list (NYSDHP-L). The purpose of the NYSDHP-L is to share information, services, resources, and training opportunities relevant to individuals with disabilities, organizations and individuals working with people with disabilities, and various government agencies.

Resources disseminated through the mailing list may include:

- Engagement opportunities
- Data reports
- Funding announcements
- Toolkits/Resources/Publications
- Training opportunities
- Enrollment opportunities for programs and workshops

To subscribe **please send an email to dhp@health.ny.gov** with your name and organization indicating you would like to join. You will then receive an e-mail confirmation that you have been added to the mailing list.

If you have any questions, please contact the NYS Disability and Health Program at dhp@health.ny.gov.

We look forward to hearing from you!

Disability & Health Program Team
Bureau of Community Chronic Disease Prevention
150 Broadway Suite 350
Menands, NY 12204
Tel: 518-408-5142/Fax: 518-474-3356
www.health.ny.gov

MHAST Unveils Our House Respite Program

(from the Mental Health Association of the Southern Tier)

Our House provides a nurturing, home-like environment for individuals facing a mental health challenge. Guests are able to stay for up to five days in a residential setting, where we provide a place to relax and re-group. Here at Our House, we encourage a focus on wellness where people have a safe environment to work on an individualized goal plan and learn additional coping skills to deal with stress and anxiety. Our House is a Peer run program. The staff of our house has lived experience which they share with our guests. There is no charge to stay at Our House, but we do ask if an individual is insured that they bring their insurance card with them.

The requirements to stay at Our House:

- Must be at least 18 years of age
- A resident of Broome County
- Experiencing a mental health crisis as defined by the individual
- Medically and Physically stable
- Able to maintain acceptable personal hygiene and sobriety
- Must have permanent housing
- Able to prepare their own meals and clean up after themselves
- Walk stairs
- Able to understand and sign necessary paperwork
- Willing to adhere to the Guest Agreement upon entering Our House

Our House currently has openings. If you have a client that you feel meets the above requirements, please give us a call at 607-771-8888 Ext 350.

Early Voting Comes to Broome County

The Broome County Board of Elections has announced the Early Voting Center locations and times for 2019.

There are three sites for Early Voting ahead of the November General Election.

- Broome County Public Library, 185 Court Street
- Oakdale Mall, near the former Sears wing
- George F Johnson Library, 1001 Park Street, Endicott

Early voting takes place beginning on October 26, 2019, and running through November 3. Note that the times are different depending on the dates:

Oct. 26: 12 – 5 pm
Oct. 27: 12 –5 pm
Oct. 28: 10 am – 6 pm
Oct. 29: 12 - 8 pm
Oct. 30: 12 - 8pm
Oct. 31: 7 am – 3 pm
Nov.1: 10 am – 6 pm
Nov. 2: 12 – 5 pm
Nov. 3: 12 - 5 pm

There is no early voting for the June 25 primary election.

SCAM PREVENTION TIPS

TIPS TO REMEMBER:

- YOUR BANK, THE SOCIAL SECURITY ADMINISTRATION (SSA), OR OTHER ENTITIES WILL NEVER CALL OR EMAIL YOU AND ASK FOR YOUR SOCIAL SECURITY NUMBER (SSN), PERSONAL IDENTIFICATION NUMBER (PIN), CREDIT CARD OR BANK ACCOUNT NUMBER, OR OTHER CONFIDENTIAL INFORMATION.
- NOTE THAT IF YOU CALL YOUR BANK, THE SSA, OR OTHER ENTITY, IT IS STANDARD PRACTICE FOR THEM TO ASK YOU FOR YOUR DATE OF BIRTH, ADDRESS, LAST 4 DIGITS OF YOUR SSN, OR OTHER IDENTIFYING INFORMATION FOR SECURITY PURPOSES TO CONFIRM YOUR IDENTITY.
- BE CAUTIOUS ABOUT UNSOLICITED EMAILS, PHONE CALLS, OR UNUSUAL MAIL PARTICULARLY IF THEY ARE FROM AN UNFAMILIAR COMPANY OR PERSON. ADDITIONALLY, CAUTION SHOULD BE USED WITH UNEXPECTED AND UNFAMILIAR VISITORS TO YOUR HOME.
- DON’T BELIEVE PROMISES OF EASY MONEY OR ITEMS. REMEMBER: IF SOMETHING SEEMS TOO GOOD TO BE TRUE, IT MOST LIKELY IS.

WHO YOU CAN CONTACT FOR ASSISTANCE:

- ATTORNEY GENERAL, NYS LOCAL OFFICE: 251-2764
- BETTER BUSINESS BUREAU OF UPSTATE NY: (716) 881-5222
- BROOME COUNTY DISTRICT ATTORNEY STEVEN CORNWELL: 778-2423
- BROOME COUNTY MENTAL HEALTH, MEGAN WISE: 778-2351
- CRIME VICTIMS ASSISTANCE CENTER: 722-4256
- DISABILITY RIGHTS NEW YORK: (800) 993-8982, TTY: (518) 512-3448
- SOCIAL SECURITY ADMINISTRATION: 866-964-3971

STIC
Southern Tier Independence Center
Access your world.

135 E. Frederick St.
Binghamton, NY 13904
(607) 724-2111 (voice/TTY)
Toll Free (877) 722-9150
email: stic@stic-cil.org
RETURN SERVICE REQUESTED

This newsletter is also available in large print, on cassette, and online, at:
www.stic-cil.org

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

Free Access Is Not Free

STIC is a 501(c)(3) corporation, and governing documents, conflict-of-interest policy, and financial statements are available to the public upon request.

If you would like to support STIC, please use this form. Minimum membership dues are $5.00 per person, per year. If you want to be a member, you must check one of the **first five** boxes **and** the “Make Me a Member” box. **NEWSLETTER SUBSCRIPTIONS DO NOT COUNT AS MEMBERSHIP DUES.**

☐ Individual $5
☐ Supporting $25
☐ Patron $50
☐ Contributing $100
☐ Complimentary $_______
☐ Newsletter Subscription $10/year
☐ **Make Me A Member**

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

Name ____
Address ____
City ___________________________ **State** ___ **Zip**_______
Phone ____

All donations are tax-deductible. Contributions ensure that STIC can continue to promote and support the needs, abilities, and concerns of people with disabilities. Your gift will be appropriately acknowledged. Please make checks payable to Southern Tier Independence Center, Inc.

THANK YOU!

Southern Tier Independence Center

EXECUTIVE DIRECTOR
Maria Dibble

ASSISTANT DIRECTOR
Jennifer Watson

ACCESSIBILITY SERVICES: Frank Pennisi

ADA SERVICES: Frank Pennisi

BEHAVIORAL CONSULTING:
Gerard Griffin Rachel Schwartz Yasmin Van

DEAF SERVICES: Heather Shaffer

DEVELOPMENT: Bill Bartlow

ECDC: Karen Lawrence

EDUCATION SERVICES: Stephanie Quick

HABILITATION SERVICES: Cathy Sostre
Theresa Thornton Matthew McLain
Hannah Hickox Kim Kappler Brittany Lynady
Lucretia Hesco Terry Valdes Julia Massaro
Kathleen Scanlon Katie Trainor-Leounis

HEALTH EXCHANGE NAVIGATORS:
Christy Sodan Winta Michael Joy Stalker
Pamela Rockermann Loretta Sayles
Chad Eldred Theresa Kircher Patricia Lanzo
Brittany Pritchard Brittaney Carey

HOUSING SERVICES: Grace Eggers

INTERPRETER SERVICES: Stacy Seachrist

MONEY FOLLOWS THE PERSON:
Peg Schadt Krystal Pierre Millien
Marcy Donahue

NHTD RESOURCE CENTER: Ellen Rury
Daena Scharfenstein Belynda Raminger
Laura O’Hara Pamela Lounsberry
Shelby Tennant

NY CONNECTS: Amy Friot
Eileen O’Brien

PEER COUNSELING: Jane Long
Danny Cullen Robert Deemie
Richard Farruggio Susan Link

PERSONAL ASSISTANCE SERVICES:
Susan Hoyt Tess Savage Tyasia Jewell
Katina Ruffo Alicia Riehle

PSYCHOTHERAPY:
Charlie Kramer Jane Long

PTAC: Sue Lozinak Beth Kurkoski
Shannon Smith

SUPPORTED EMPLOYMENT:
Kandi Stevens Michelle Dunda
Rachel Barton Crystal Musshafen

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER: Belinda Turck
Ellen Rury Cortney Medovich Lori Wilmot
Valerie Soderstrom Shelby Tennant

TECHNOLOGY SERVICES:
Jessica Kendricks Decker Ayers