

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

AccessAbility

Fall 2015
Number 120

The Final Prescription

by Maria Dibble

New York's news has periodically featured discussion of the minimum wage, with the most recent iteration being the Governor's naming of a panel that recommended increasing the wage for fast food workers to \$15.00/hour over six years. Somewhat less recently, the Governor went to war to protect nail salon workers working in sweatshop conditions.

Let me first state for the record: I strongly support an increase of the minimum wage to \$15.00 per hour over the course of a few years for all New Yorkers, not just one group.

That being said, here is my issue: NY will consider, and perhaps approve, a higher wage for fast food workers but balk at, and refuse, a request to raise the minimum to \$15.00 per hour for personal care attendants (PCAs) and other types of homecare workers, the people who provide essential services to individuals who need assistance to bathe, go to the toilet, get and eat food, and various other life-sustaining tasks.

Again, no offense to fast food workers, but is flipping a burger a more important job than caring for people with disabilities and senior citizens? Or, put another way, why is flipping

a burger at McDonalds worth more than flipping a burger in your disabled grandmother's kitchen? Is gluing sparklies on a young lady's fingernails before the "big date" more important than trimming the nails of a young man whose spinal cord injury keeps him from using a nail clipper?

Of course, if we increase pay to homecare workers, then the Medicaid rate must go up to compensate providers. This, naturally, would cost more money, and since a large and growing number of Medicaid homecare services are delivered through managed care, it would destroy the claim that managed care saves money. You may have heard Governor Cuomo say that NY has "bent the curve" on rising medical costs and saved some large dollar amount because of managed care, but what he fails to mention is that some of that savings came from cutting the rates that providers are paid to serve consumers.

Providing personal care is physically and emotionally draining work. It involves heavy lifting, and often, dealing with people who are in pain, confused, and sometimes pretty grouchy and demanding. It requires a strong sense of ethical responsibility, including sometimes handling other people's money and private

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papers. To make a semi-adequate living at it, most workers (outside New York City, at least) need a reliable car to travel between different consumers, putting in 2 hours here, 3 hours there, in order to add up to a full work week. These things do not come cheap. How can we expect the people who are caring for our moms and dads, sisters and brothers, sons and daughters, to survive on \$9.00 an hour?

Some say, or shout, that raising the minimum wage will "put businesses out of business" or "cost jobs". But isn't that what they always say, every time the wage is raised? And isn't it always true that after the fact, when the economists publish their studies, nothing of the kind happened?

We're the richest country in the world. If we can't pay all people a wage that will allow them to feed their families, provide shelter and put clothing on their backs, what kind of society are we? What kind of a world are we creating for our children and grandchildren, and what

AccessAbility

September 2015

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.

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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.

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kind of message are they getting from seeing us favoring one group over another for receiving a decent wage? How do we explain to a child why cooking some fries is more crucial to our social structure and economy than providing basic care to a human being?

We're the richest country in the world.

If we can't pay all people a wage that will allow them to feed their families, provide shelter and put clothing on their backs,

We've become so callous in the way we look at just about every issue that it all comes down to "the bottom line" and nothing else. Is there any hope that we can at some point add human dignity to the equation?

How do we keep people from saying, "This is horrible! Assisted suicide would be better than this! After all, it only costs \$300, once?"

what kind of society are we?

How do I explain it to my mother?

"Mom, the person who cooked the hamburger you got from Burger King will soon be making more money than the lady who helps you shower every day."

How do we keep these invaluable workers from thinking, "Why should I help someone go to the toilet and wipe their butt and have them be nasty to me into the bargain, when I could be down at Arby's, making sandwiches for better money?"

How do I keep my mother from thinking, "If my arthritis didn't put me in a wheelchair and make me dependent on Medicaid as the only insurance that pays for my aides, I wouldn't be such a burden on everybody?"

There is already a shortage of attendants, and it is steadily getting worse because wages aren't keeping up with the cost of living. Without some change, the only place for the folks who can't get services will be in a nursing home, where we can pay \$10,000 per month to maintain the body, because, most assuredly, the spirit and will to live will be gone.

save the taxpayers money. Just like fast food workers, attendants getting minimum wage typically receive significant subsidies from the taxpayers in the form of food stamps, WIC and HEAP benefits, Medicaid coverage, and more. The taxpayers always pay for all medical services for everybody. Managed care just shifts part of the cost from paycheck deductions for taxes paid to the government to paycheck deductions for health insurance paid to employers (see page 5).

So let's end the "tax relief" shell game. Employers and business lobbyists, stop subsidizing your businesses on the government's back, and stop being so mean to the people who feed your teenagers and take care of your mothers alike. Politicians, how about ensuring reliable, quality service, and being honest about what it really costs? I know, you're laughing now because I used the words "honest" and "politician" in the same sentence. Keep laughing, until it's your turn to face disability and the tough choices of neglect in your own home, abuse in a nursing home, or that final \$300 prescription.

News & Analysis

Yeas and Nays

New York State government has an odd constitutional wrinkle: Although there is a deadline by which the Governor must sign or veto bills passed by the Legislature (10 days after passage when the Legislature is in session; 30 days when it's not), the clock doesn't start ticking until the Legislature formally "sends" the bill to the Governor. In NY, bills are routinely passed but held up until some political calculus or last-minute negotiation determines that it's time to send them to the Governor, and these decisions are made by legislative leaders even when that body is officially adjourned.

So after the budget and related program bills are passed in the spring, a small deluge of bills

are sent to Governor Cuomo for his action immediately. Then, during the dog days of summer, more passed bills are slowly trickled out, and we may not find out what action Cuomo takes on them until the fall or even the Christmas holidays. When there's a "pocket veto" (that is, the Governor silently ignores a bill—"puts it in his pocket"—until the deadline is reached, at which point it is considered to have been vetoed), it's difficult or even impossible to learn what happened to it. Although both houses have "bill tracker" websites, they are not always updated for every bill.

So here's what we knew and didn't know about various bills relevant to the disability rights community at press time in late August:

M a n a g e d
care doesn't

Cuomo Vetoes

Prescriber prevails for Medicaid managed care. NY Medicaid, like most private insurance and Medicare prescription plans, has a list of “preferred” medications—usually generic versions—that it will pay for. Under current NY law governing “fee-for-service” or “State Plan” Medicaid, your doctor can appeal Medicaid’s refusal to pay for a specific drug, and if the appeal is rejected, the doctor still wins. This is a good thing, because some “generics” aren’t quite exactly the same as their brand-name equivalents, and within various classes of drugs, some that are the most effective options for specific individuals aren’t on the list at all. Every year Cuomo proposes to end this practice and give the state the final say, and every year the legislature rejects it. However, also every year, the number of people whom this helps shrinks, because it doesn’t apply to Medicaid managed care. As of now, all nondisabled Medicaid recipients and most of those with disabilities are in managed care. So the Legislature passed this bill to extend “prescriber prevails” to cover every Medicaid recipient. It’s no surprise that Cuomo vetoed it; the primary purpose of managed care is to cut costs by limiting people’s options.

Cuomo Signs

“Clarified rules” for service dogs. The federal Americans with Disabilities Act (ADA) prohibits public accommodations and employers from denying people with disabilities the use of “service animals” unless the animal is “out of control” or not housebroken. The ADA regulations also have specific provisions for use of miniature horses as service animals. Although these rules apply to all public accommodations and employers in NY, someone apparently thought it would be useful to enact some additional rules into state law. These rules appear to limit protection to dogs only, and specifically to “guide dogs, hearing dogs, and service dogs” that have been “professionally” trained by a recognized training program for the purpose. Thus miniature horses, or service monkeys, or “companion” cats or ferrets or whatever, would seem valid targets for discrimination in NY. This is, of course, bogus, because the federal rules take precedence over state law, and they impose no such limitations. New York can enact civil rights laws that provide greater benefits than federal laws do, but it cannot restrict people’s rights more tightly than federal law does. In a way, it’s too bad, because some people with disabilities have tried to con kindly storekeepers into believing

that their ordinary pets are “service animals”, and those people ought to be miniature-horse-whipped. But this law, which actually includes language explaining that it must be interpreted to be consistent with ADA regulations, and therefore changes exactly nothing, will bring more confusion than clarity to the situation.

“Title II.” This bill modifies the New York State Human Rights Law to apply provisions similar to the ADA’s Title II to state and local governments in NY. Disability rights advocates in New York, principally led by STIC’s own Frank Pennisi, have been working to get this done since the mid-1990s. Advocates got a “Title III” bill passed and signed in 1997. That bill pretty closely mimics the ADA language which requires “public accommodations” such as stores, restaurants, theaters, motels, medical service providers, and more to be accessible to and usable by people with disabilities; physical modifications are required if “readily achievable” (which means not too difficult or expensive considering the total resources available to the owner, and the feasibility of phasing in modifications over several years); program modifications such as alternate locations or means of access, and use of sign language interpreters, are required unless they would be an “undue burden” or require a “fundamental alteration” of the place. The new law modifies the state’s definition of “public accommodations” to include similar places owned, operated, or funded by state or local governments. Title II is also the basis of the US Supreme Court’s *Olmstead* decision, which says that Title II applies to government-funded disability-specific programs and services and that unnecessary segregation of people with disabilities by them is illegal discrimination. NYS Human Rights Law is less clear on this point; it specifically includes “hospitals” and “clinics,” and “wholesale and retail stores and establishments dealing with goods or services of any kind.” A sheltered workshop funded by the Commission for the Blind (CFB), for example, may not meet this definition: although it provides a service (pre-vocational or job readiness training), it is not a “store,” and though it might be an “establishment,” it is neither “wholesale” nor “retail” under any reasonable definition of those terms. The NYS law also defines “discriminatory practices” in a way that tends to avoid the *Olmstead* reading of the term. Group homes and institutions directly operated by the state may be excluded because they are associated with the NYS Dormitory Authority, a “public authority.” It will be interesting to see if a court

case arises under the NYS Human Rights Law that can impose stronger anti-segregation requirements on state agencies such as OPWDD or CFB than the ADA does. At the very least, the bill makes the complaint investigation and enforcement capabilities of the state’s Human Rights Division, which are more responsive than those of the feds, available to people facing disability discrimination by state and local government programs. The bill was held up so Cuomo could sign it in late July, near the 25th anniversary of the signing of the ADA. As a result of this achievement, STIC is very proud to announce that Frank Pennisi received the David Veatch Advocacy Award from the New York Association on Independent Living.

Passed, Not Yet Signed

Visitability tax credit. “Visitability” means that a person with significant disabilities can “visit” you in your home. Generally it means there should be one level or ramped entrance with a door wide enough to accommodate a wheelchair, as well as an unobstructed path through your living room to an accessible lavatory. This bill was passed by both houses and, if sent to the Governor and signed, will provide a tax credit for building or remodeling a home to make this possible.

“Continuity of Care.” This bill would require OPWDD to allow people living in developmental centers and state-operated ICFs to live in them indefinitely if “they” (most likely, their parents) want them to get services exclusively from state employees and there are no openings in state-operated community residences. This would violate federal Medicaid law regarding medical necessity, “active treatment,” and discharge planning for those facilities, as well as a direct order from the federal government that NY must close nearly all of those places by a specific deadline (see *AccessAbility* Summer 2015). The bill passed both houses but at press time it did not appear to have been sent to the Governor. He has no legal choice but to veto it, but that doesn’t mean he won’t make an illegal choice and dare somebody to sue him for it.

Not Passed

On the good side:

Lever voting machine exceptions: The old-style mechanical lever voting machines have been illegal under federal law for several years because many people with disabilities can’t use them without assistance. However, NY State has repeatedly violated federal law by

passing state laws granting exceptions to certain precincts to continue using them for certain elections on the grounds that accessible machines are too hard for those precincts to use. The good news is that these exceptions were not extended, and therefore will “sunset” out of existence at the end of the year. The bad news is that the allegedly accessible machines that NY chose to buy aren’t really very accessible at all in practice, especially for people who can’t read print, including voters who are blind, have low vision, or significant cognitive disabilities. Although the volunteers at polling places have allegedly been trained, they typically have no idea how to handle even basic problems with the accessible features of the machines. People with these disabilities are thus forced to spend an hour or more waiting for a county Board of Elections expert to arrive and “fix” the machine, and then cope with the machine’s extremely slow controls, or have a nondisabled person operate it for them, just like they did with the lever machines.

“Employment First Act.” This bill would direct OPWDD to attempt to renegotiate its agreement with the federal government to close sheltered workshops, and get permission to use Medicaid funds to continue to pay for them so people with developmental disabilities can “stay in the workshop with their friends.” This, like the “continuity of care” bill, runs afoul of federal Medicaid law, which requires medical necessity to justify use of funds, and it repudiates a direct order from the feds, who will never “renegotiate” it. At press time, both the Assembly and Senate websites indicated that this bill never got out of committee.

Assisted suicide. Three such bills were introduced in the legislature this year; we reported on one of them in *AccessAbility* Spring 2015. None of them reached a floor vote in either house.

On the bad side:

Nurse Practice Act amendments: As we’ve reported previously, in order to implement

the federal Community First Choice option for homecare services in a way that makes it usable by people who need it, NY has to modify its Nurse Practice Act to create a new type of licensed homecare worker, an “Advanced Home Health Aide” (AHHA). AHHAs would be virtually indistinguishable from Licensed Practical Nurses (LPNs) in terms of training, experience, and supervision. Thus it makes no sense that opponents keep saying this would endanger vulnerable people with disabilities. Rather, it would enable thousands of people who have no living or interested relatives to leave nursing facilities and live in their own homes, and this would displease nursing facility operators who help finance the campaigns of the politicians who oppose the bill. One of the latter, Senator LaValle, blocked the bill this year. Last year, it was Assemblymember Glick. The year before that, it was Cuomo’s health operatives. Next year it will probably be somebody else, so that disability advocates can’t effectively target anyone.



Are You on the Bus or off the Bus?

Part of the Cuomo Administration’s rush to managed care has involved disrupting vital transportation services paid for with Medicaid dollars.

Transportation to and from doctors’ offices, hospitals, clinics, and therapy providers has long been considered a “medically necessary” expense payable by Medicaid. This doesn’t just include “ambulette” service—those special vans that accommodate wheelchairs. Up until recently, quite a bit of Medicaid transportation was provided by mass transit systems, especially municipal bus systems. Because deep poverty is a basic requirement for Medicaid eligibility, most people using the service can’t afford to own a car, and they also can’t afford a cab.

Some people, notably minor children with developmental disabilities on the OPWDD Medicaid waiver, can qualify for Medicaid even with middle-class incomes. However, some of these children need highly specialized services not available locally, or in some communities, the local specialists are subpar, ranging from ineffective to dangerous. The travel costs for these children, at times requiring airfare, hotel, and meal expenses, can be too high even for some lower middle-class families. Medicaid has historically paid for this when medically justified.

Before managed care, payment for Medicaid transportation was approved and managed at the county level by Departments of Social Services or by Community Alternative Sys-

tems Agencies (CASAs). Over the years, the county systems acquired a deep understanding of the local transportation networks’ capabilities and deficiencies. They knew which bus routes were overcrowded at which times, and which taxi operators were less than honest. They also acquired a lot of information about the more frequent users of Medicaid transportation. All of this helped “grease the wheels,” you might say, to enable the county systems to operate efficiently, effectively, and reliably while meeting most people’s needs most of the time.

But Cuomo’s Medicaid Redesign Team didn’t involve a lot of people who understood how this all works. Their simple and highly deficient logic was: It should be cheaper to centralize the administration and scheduling of Medicaid transportation than to pay 62 county systems to do it.

And perhaps it is. But as with any government service, getting the job done is critical; if you don’t get it done, you’re wasting even the reduced amount of money you’re spending to do it.

As we mentioned, public mass transit was often used in pre-managed care days for Medicaid transportation. Most people on Medicaid are on it because they are poor, not because they have any sort of disability, and a lot of people *with* disabilities can use an ordinary

bus. In fact, Medicaid for public transit was so common that county systems bought unlimited monthly bus passes for their clientele, and sometimes paid direct subsidies to the bus operators. In many smaller communities, public bus systems were highly dependent on this Medicaid money to maintain their operations. Managed care ended the direct subsidies immediately. The smaller systems felt the bite but soldiered on, assured by the Cuomo Administration that the private contractor they hired to manage the new system would still buy bus passes for most people.

Except they didn't. At first, they established a cumbersome system for providing passes, because conventional wisdom suggested that it was inappropriate to buy unlimited monthly passes; why should Medicaid pay for your trip to the movies? Or for getting you to work? So you had to schedule all of your medical appointments as far in advance as possible, then request the appropriate number of single round-trip passes, and any necessary transfers, from the contractor. After some delay, the contractor would mail them to you. However, the contractor soon realized that the amount of office labor, paperwork, and postage this required was extensive. They ran the numbers and found that, "bottom line", it would be cheaper if they had people request cab service for their appointments, even though it cost much more than the bus fare. They may have negotiated special rates with some cab companies, but they also stopped buying bus passes.

And smaller public transit systems went into the red. Some of them, such as Tioga County's Ride Tioga, shut down completely. Others, like Cortland Transit, which lost 40% of its revenue, are in danger of doing so. Larger ones, like Broome County's BC Transit, have cut services deeply.

You might think that at least the poor people are getting nice cushy cab rides. You'd be wrong. The increase in demand has, in some communities, overwhelmed the capacity of the cab operators—or the subset of cab operators that are not shady, fly-by-night concerns. So people are jammed into cabs 4 to 6 people at a time, and are late for their appointments, or sometimes simply can't get a cab for a particular time at all and must go back and forth between the medical office and the transportation contractor to get something arranged.

Poor people who need Medicaid generally can't afford cars. They depend on public transportation for *everything*, including, significantly, to get to and from whatever (usu-

ally part-time, low-wage) jobs they are able to find. What's a great way to get nondisabled people off Medicaid? Help them find good-paying jobs that provide health insurance. What's an essential requirement for a good-paying job? Reliable transportation. You can probably see where we're going with this, but Cuomo's managed care "experts" didn't. So now they have a problem.

The most obvious solution to the problem is to order the contractor to buy bulk monthly bus passes for people. Unfortunately, there's a little matter of a "contract" that prevents the state from telling the contractor how to run the business. We don't know when the contract expires, but apparently not soon enough to prevent the collapse of small-town public transit across the state. The second most obvious solution is to increase state subsidies for public transportation. That's not even on anybody's radar in the government; they just laugh at us when we suggest it. So we are witnessing the spectacle of state officials floundering around proposing "pilot" studies to "coordinate" non-existent transportation "resources," and asking people for public comment on how the state's disability service agencies can improve transportation for people with disabilities without spending any more money.

We'll tell them again, in case they're listening:

PUT THE MONEY BACK.

Along with this debacle, the state has also been making it harder for people to get transportation and related costs to distant locations for special services. These requests are often routinely denied, and advocates have to go to work with multiple letters, phone calls, and meetings to get them restored. In the meantime, the health of the people who need these unusual, specialized services deteriorates, increasing the extent of their overall medical needs, and thereby increasing the total amount of Medicaid funds that must be expended for them.

There may be some light at the end of this tunnel. Of course, it could be an oncoming

train, but that may not be a problem because the train will probably run out of fuel before it hits us due to budget cuts. At any rate, two upstate Republican senators, James Seward and Tom O'Mara, held a public hearing on this issue in Cooperstown in July. They were positively bombarded with complaints by transit administrators and other people from almost every upstate county. The hearing made it crystal clear that this is a widespread, pervasive, and serious problem, and not just a few whiny complaints from the usual suspects, as some bureaucrats like to characterize us. As the senators said, "The future of public transportation is being put at risk by Albany's attempt at a statewide, one-size-fits-all approach to these local systems. It's a developing crisis for many rural residents. [Those in Albany] are looking at this issue with tunnel vision, not realizing the impact of their actions on others." Another term for this is "Whack-A-Mole Budgeting."

Following this well-publicized hearing, the state Department of Health (DOH) held a meeting between "stakeholders" and the transportation contractor in Binghamton in August. This meeting was also well-attended by knowledgeable people who presented hard facts. One suggestion from the authorities was that STIC take on the role (and the administrative expense, possibly without reimbursement) of handing out bus passes. We'll look into it but aren't promising anything. Beyond that, there were no immediate results. However, the fact that DOH called the meeting after Cuomo was blasted in the media suggests that something might come of this. Stay tuned.

Waiving Managed Care?

The Cuomo Administration has consistently said that all of the state's Medicaid programs must, and eventually will, be converted to managed care. The state's timetable for these conversions, though not very rigid, had been moving steadily toward that objective for two of its specialized-disability Medicaid waivers until this summer. Advocates had made



If the weather is bad, call 724-2111 (voice/TTY) to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

steady progress on convincing both houses of the state legislature to pass a bill to delay those conversions, when the state Department of Health (DOH) announced it was calling a temporary halt.

The state's Traumatic Brain Injury (TBI) waiver serves people who have significant disabilities as a result of head trauma sustained after the age of 22. The Nursing Home Transition and Diversion (NHTD) waiver serves people aged 18 – 64 who are in a nursing facility and want to get out, or are at risk of being placed in one. Both waivers provide an array of services to enable people to live in their own homes and participate in community life. Among them are Home and Community Support Services, a form of personal assistance service that provides an aide to supervise people who are not safe alone. Other services common to both waivers include Independent Living Skills Training, Community Integration Counseling, and Positive Behavioral Supports. The NHTD waiver also includes Peer Mentoring. Full disclosure: STIC operates Regional Resource Development Centers (RRDCs) for both waivers—and darn good ones, too.

These waivers were created because the services they provide are essential to enabling people with these disabilities to be safe and successful in their own homes and community settings. Advocates are concerned that these services will become unavailable under managed care. DOH has issued vague assurances that people's needs will be met, but it has refused to provide details on how it will ensure that managed care organizations (MCO) cover these services, which are outside the typical range of acute medical and basic home care services they are familiar with. OPWDD, in trying to get federal approval to convert its system to managed care, has involved people with disabilities, their families, and advocates in all aspects of detailed planning, and repeatedly solicited and responded to public comment, and the feds still haven't okayed it. DOH has followed no such process.

STIC has heard from back channels that the federal Centers for Medicare and Medicaid Services (CMS), which must approve the state's plans, is not happy with DOH's failure to involve the public in its planning, and is not enthused about these proposed conversions.

So the transition to managed care, which was supposed to begin in January 2016, has been delayed until January 1, 2017. DOH has formed a "stakeholder workgroup" to discuss the issues. They also said they will continue

to reimburse service providers under these waivers at the same rates for two years after the transition is completed.

Here's what's important to understand about this:

Waiver services are already "managed."

With unmanaged fee-for-service medical treatment, you can walk into an independent doctor's office, and if the doctor decides you need something, he sends a bill to Medicaid and they pay it. If you need something else, another bill is sent and paid. For most services, there is no limit on how often this can happen. In managed care, the amount of money the MCO gets to spend on you is capped. The MCO is supposed to meet your needs no matter what, but if you have a lot of needs, the MCO will have to pay for it out of the total pool of funds it gets to cover all of its patients, including those with fewer needs. This is almost exactly how Medicaid waivers work.

You can't just walk into a provider's office, get waiver services, and have the provider bill Medicaid. You have to be approved to be on the waiver. Then you have to have a service plan, which must be approved by the RRDC. The RRDC must monitor a capped pool of funds allocated to all waiver participants, and ensure that the total amount spent doesn't exceed the cap. The RRDC will not give you everything you ask for in your plan if it costs too much.

Substituting MCOs for RRDCs in this process would thus appear to accomplish nothing in terms of saving money. However, Cuomo's people say they are sure it will. Why is that?

MCOs, unlike RRDCs, are required to hold millions of dollars of their own money in reserve to cover cost overruns and other "risks." MCOs offer a range of insurance plans to employers, which is where they get most of this money. So NY bets it can get away with not paying the full cost of serving people on these waivers and MCOs will have to kick in the rest. Historically, that's been a bad bet. MCOs will eventually demand rate increases, and if they don't get them, they will drop out of the program. This has happened many times in many states, including NY. Eventually the states are forced to raise rates. But short-sighted politicians only care if rates stay low until the next election. They can claim they've saved the taxpayers money. But they haven't. In reality, private employers will subsidize the provision of Medicaid services. The politicians have simply shifted the costs to the people who employ the taxpayers, and those employers will raise the amount that the

taxpayers have to contribute for their health coverage as a result.

But MCOs don't want to drop out of government-funded health insurance programs. They are a much more predictable and reliable revenue stream than employer health plans. So they will try as long as they can to operate on the state's rates, and they do this by tightly restricting the services people can get. They'll try anything to do this, from denying children coverage to using the more recent "safety" dodge. In this case, some MCOs refuse to provide community services to people who want to leave nursing facilities because of "safety" concerns. People already in those places are "grandfathered in" to managed care at higher rates; if they return to their own homes, the MCO can only get the standard rate to serve them. So they claim they'll be unsafe if they do that. The main purpose of the Medicaid waivers is to keep people out of nursing facilities, and the RRDCs have been very good at it. MCOs? Not so much. As we reported last time, that may be precisely why Cuomo wants this transition (see *AccessAbility* Summer 2015, "Feeding the Elephant").

Generic services aren't enough. Ordinary home care is well understood by MCOs, at least at the national level. "Visiting nurses," medically-oriented home health aides, and less skilled personal care assistants have long been features of Medicaid state plans, and as states have expanded managed care, those features have been incorporated into MCOs. However, the things these workers can do are strictly limited, and thus they only really work for a relatively small number of people. Ordinary home care is oriented toward doing self-care tasks for people with physical disabilities; people with cognitive disabilities such as TBI or Alzheimer's may not have many physical needs. They may need to be watched so they won't forget to turn off the stove, or wander somewhere and get lost; or they may need behavioral supports to help them control potentially harmful impulses. They may not need to have anything done for them, but simply need reminders to do things. And they need this help not only at home but in public places like stores, restaurants, or workplaces. Ordinary home care can't do this; it's not allowed. It's not so much that MCOs can't learn to deliver these types of services, it's that they don't know how to do it now, and DOH has refused to explain how it will ensure that they *will* learn it. Traditional concepts of "medical necessity," service "intensity/duration," and "therapeutic benefit" get kind of fuzzy when you're talking about assigning a worker to make sure somebody doesn't wander off—a

feature that is not specifically paid for in, but just comes along with, locked nursing facilities. (We're having trouble getting OPWDD to understand this issue too.) Without very clear instructions from the state authorities, it's easy to see how MCOs will try to deny these services to people who need them: "What, you want me to pay a **medical aide** to remind a guy to feed his cat and lock his door when he leaves the house? How is that 'therapeutic'??!!"

Well, the cat provides emotional support that prevents the guy from becoming clinically depressed, and not getting his house robbed has many painfully obvious advantages, but this is not how insurance and medical administrators in MCOs and DOH think. It's a very dangerous thing they're contemplating, putting the well-being of thousands of people who have been successfully supported in the community by these waivers into the hands of these bean-counters.

A year's delay, and a mandate to force DOH to work with people who understand these issues better than they do, are the absolute least that can be done to prevent a disaster. STIC has been invited to participate on the workgroup, and we'll keep you informed.

Strike up the HARPs, but No DISCO Dancing

There isn't much to report on OPWDD's efforts to get its Medicaid waiver reauthorized, or its mandatory regulatory reforms, and optional DISCO managed care initiative, approved by the feds. The agency is still working with stakeholder committees (STIC is on a few of them) to develop plans to address new federal requirements for more integrated and individualized non-residential services, and what to do about certain types of programs that appear illegal under the new regulations. OPWDD responded to comments on its request for input on proposed new regulations governing operations and payment for prevocational and supported employment services by essentially throwing up its hands. They acknowledge that there are several important unanswered questions, and say the actual meaning of the rather skeletal regulations, which took effect on July 1, will be hashed out later.

The agency's timetable for waiver implementation has clearly slipped again. There has been no announcement of federal final approval of its revised waiver, which was supposed to have happened in July. So the feds are still balking at OPWDD's plans, and that's a good thing.

The agency no longer issues forecasts about its DISCO managed care timeline, since the feds aren't even going to look at that until the current waiver and regulatory reforms get approved. However, OPWDD has convened a panel of "experts" to think about how to ensure that managed care works without hurting people. This "Transformation Panel" has announced seven public forums to be held around the state in September. They only last two hours, and we suspect there will be a lot of worried people attending, so we don't know how much opportunity you will have to speak. When OPWDD holds these kinds of events, the conversation is typically dominated by organized employee union members and pro-segregation parents. We know that pro-segregation parents are in the minority, but because they are mostly older and either retired or "traditional" couples in which the wife doesn't work outside the home, it's easier for them to attend a daytime public meeting. If you don't like segregation, and you don't think that OPWDD employees should control the agenda, then you really need to make an effort to be there and make sure your voice is heard. By the time you read this, the downstate forums will already have taken place; here's the rest of the schedule. More information on this is at:

http://www.opwdd.ny.gov/opwdd_about/commissioners_page/transformation-panel

September 24

Syracuse
12 noon – 2 pm

Rochester
5 pm – 7 pm

September 25

Buffalo
11 am – 1 pm

September 29

Albany
5 pm – 7 pm

September 30

Plattsburgh
12 noon – 2 pm

Over the summer, the federal Centers for Medicare and Medicaid Services (CMS) approved the portion of New York's 1115 Medicaid experimental "Partnership" waiver that adds Home and Community Based Services (HCBS) to the Office of Mental Health's (OMH) HARPs program.

Policy wonks understood that sentence. For the rest of us:

HCBS is a set of services designed to enable people with significant disabilities to lead meaningful lives in their own homes, get real well-paid jobs, and take part in community activities. Things like "habilitation" (learning to do community stuff like taking care of your home, buying groceries, eating in restaurants, doing things cooperatively with friends, or volunteering); prevocational services (help to develop job readiness skills); supported employment; and various forms of counseling or assistance to control undesirable behavior. The services you get are determined by a person-centered plan; that means you get to control the planning process as much as you are able, and your abilities, needs, and interests are front-and-center. You may also have the ability to self-direct some of your services, meaning you decide who gets hired to serve you, and you can train and schedule them to suit your needs. Up until now, these services have been available to people with a wide range of disabilities in New York, but not those with mental illness. HARPs (Health and Recovery Plans) are the main way that OMH will now introduce these services. (There are other ways; see below.)

If this is done well, it will fill in a huge service gap in NY. These types of services have really helped improve the lives of many people with developmental disabilities, brain injuries, and other physical disabilities. We strongly encourage people with mental health disabilities to learn about this and do as much as they can to ensure they are included when these services roll out.

That's the short version. Naturally, there are some limitations on how this works and some rules which have to be followed, so here's the fine print:

Eligibility

You must be eligible and approved for Medicaid. However, you cannot also be receiving

Medicare ("dual enrolled") or getting services from OPWDD. OPWDD has its own HCBS waiver, and the state isn't ready to provide HCBS to people who also have Medicare (see page 8).

You must be an adult. Children with mental health disabilities who are not in managed care can already get HCBS services through a Medicaid waiver, and those services are supposed to be moved into managed care for children in 2017.



Your diagnoses must fall into the categories of “serious mental illness” and/or “substance use disorder.” You must also have “serious behavioral health issues.” We don’t have the specifics on these limitations, but we can say that the new services are not for people who are doing well with just medication management and some counseling.

You must be in certain forms of Medicaid managed care. HARPs will be available for those in “mainstream” managed care (it appears, for now, that long-term managed care participants are excluded from this program). If you are in a HIV “Special Needs” Plan (SNP), you can get the new services through that plan. If you’re in a “Health Home”: Health Homes are already supposed to provide services similar to HCBS, but since they haven’t been paid enough to do that, they’ve relied on “agreements” with service providers who volunteer to provide the services without pay. These are scarce. The current state budget provides an increase to Health Home rates, but we don’t know how that’s working so far. In any case, there is supposed to be an arrangement whereby HARPs and SNPs will contract with Health Homes to do the service coordination for people who then, allegedly, will receive HCBS from the HARPs or SNPs.

Enrollment

The new services will be phased in gradually, first in New York City and later, upstate. It’s going to be a year or so before they reach us up here, but it’s important to start learning about this and begin taking steps to ensure your eligibility. OMH says it already knows who, among the people already receiving its services, will be eligible, and when it’s time it will send you a letter about this. Watch for this letter. If, by the time your region begins to phase in this program, your managed care organization (MCO), SNP, or Health Home is already offering the new services, you will automatically be enrolled in them. However, you will be given a choice to opt out, or to choose a different provider if more than one is available.

As best we can tell.

Timetable

Right now, OMH says it is evaluating applications from MCOs that want to offer HCBS/HARPs plans. Also, there are supposed to be start-up grants available for organizations wanting to provide the new HCB services, with priority given to those with “little or no Medicaid managed care experience.”

Enrollment notice letters are supposed to be rolling out now for New York City. Actual enrollment begins to phase in there in October.

Upstate, the letters should begin to go out in April 2016, and actual enrollment for mainstream managed care will begin in July 2016.

What to Do

HARPs will offer “peer support.” Only one other Medicaid waiver (NHTD) does this. If you provide this service, you should immediately contact OMH about getting approved as a provider. If you need start-up money to do it, then also ask about the grants.

If you are a person with mental health or substance abuse disabilities and you believe that peer counseling or support would help you, be sure to ask specifically for it when your service planning process begins.

When your time rolls around, be on the lookout for your enrollment letter. Remember, if OMH thinks you are eligible, you will be **automatically** enrolled. But you can choose a different plan or provider, or opt out completely, so you need to pay attention to the letter when it comes. There’s a deadline for changing your plan. If you think you should be eligible for these new services and you don’t get a letter, don’t wait too long. Contact OMH and ask what’s going on.

More information on all of this is at:

http://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/index.htm

Fed Up with FIDA

Due to billing, eligibility, and other differences, people who receive Medicare are not typically eligible to participate in Medicaid managed care programs even if they also receive Medicaid. Some years back the federal government offered states a way to address this by developing “pilot” projects for “Fully Integrated Dual Advantage” (FIDA) programs. “Advantage” comes from Medicare “Advantage” plans, which are managed care plans for Medicare recipients. “Dual” refers to the “dual eligible,” the people who have both Medicaid and Medicare, usually elderly people living in poverty. “Fully Integrated” is supposed to mean that people can get all of their Medicare coverage for basic medical needs and prescriptions, plus any of the wide variety of long-term care services that Medicaid can provide, from one program.

One of the reasons the program may not have much value is that, so far, it hasn’t had much success. Several states are running these pilots, and most have experienced very low enrollment and low consumer satisfaction. This is true in New York.

New York’s project would extend many “Home and Community Based” (HCB) services similar to those available from the state’s Medicaid waivers to people who receive both Medicare and Medicaid. The reason NY would like to do this is because Medicare, which doesn’t require any contribution of state dollars, would pick up part of the cost. The reasons why people would want to enroll in such a program are less obvious. Most “dual eligibles” who need these kinds of long-term care services are at least theoretically eligible to receive them from the state’s Medicaid waivers already. One glaring exception is people with mental health disabilities, who won’t be allowed to get the new HARPs services (see page 7) if they are enrolled in both Medicaid and Medicare. This exclusion is a New York State decision; it could have designed its “Partnership” Medicaid waiver to include them but did not.

There are 21 approved FIDA plans in New York, and over 50,000 people eligible to participate. By July of this year, only a little over 4000 had enrolled, and over 47,000 had opted out. One reason seems to be that doctors are telling eligible patients that if they do enroll, they won’t see them anymore, according to *Crain’s Health Pulse*. Doctors have cited vastly increased requirements for care coordination and paperwork from the FIDAs, without adequate payment.

Most of these plans don’t serve people with developmental disabilities; dual-eligibles in that category have a separate, smaller pilot project available. But almost everyone who would be eligible for it would also be eligible for the OPWDD Medicaid waiver, which covers nearly all of the same long-term care services without imposing managed care annoyances. The only significant exception seems to be people with developmental disabilities living in nursing facilities. Federal law requires they be offered the option of leaving and being served in the community, but they can opt to remain in the facilities while receiving specialized services for their disabilities, at state expense. However, the OPWDD waiver can’t pay for services in those facilities, so New York would dearly like to find another source of payment for them.

Noll v IBM: The Limits of Desire

Alfred Noll is a Deaf software engineer (computer programmer) who works for IBM in Poughkeepsie, NY. He sued his employer in federal district court alleging violation of the Americans with Disabilities Act (ADA) Title I requirement that employers must provide “reasonable accommodations” when possible to enable otherwise qualified employees to perform the essential functions of a job, unless to do so would be an “undue burden.”

The federal district judge ruled against him, so he went to the Second Circuit Court of Appeals. That court also ruled against him.

Noll alleged that the law requires IBM to caption all of the videos on the company’s internal computer network.

A few of the company’s videos are captioned, but IBM has over 40,000 videos on its network. Noll is able to request written transcripts of any video and receive them within 5 days. He can also request a sign-language interpreter fluent in his native language, American Sign Language (ASL), to translate any video in real time, either in person or remotely, and receive that assistance immediately. IBM contended that this is a reasonable-enough accommodation.

Noll said it was “tiring and confusing” to divide his attention between an interpreter and a video, a problem he did not complain about when using an interpreter at a live meeting, even when the speaker was using a PowerPoint presentation. The court said that this is likely to be an issue any time a deaf person uses an interpreter, which seems reasonable to us.

And as the court pointed out, “reasonable” and “effective” are the two tests to be applied here. Noll, by all accounts, is effectively doing his job and gets good evaluations from his supervisor.

He might have been able to argue the “effectiveness” point if the videos were highly technical and the ASL interpreter unable to fully convey their content. But he didn’t do that.

The “take away” being promoted by analysts of this case is that the ADA does not require an employer to provide the specific accommodation requested, as long as it provides accommodation for the person to do their job effectively. The fine print of the Circuit Court’s decision qualifies this a bit. “Effectiveness” is a requirement of the law, and there are circumstances in which a generic accommodation,

such as an interpreter, may not be effective, and it may be “reasonable” to provide a much more individually tailored accommodation. Noll produced expert testimony that some Deaf people comprehend captioned videos better than those that are interpreted. However, Noll did not show that his ability to do his job effectively was compromised. If he had, the decision might have been different.

We agree with the decision the Court made. As Mick Jagger said, “You can’t always get what you want, but if you try sometime, you just might find, you get what you need.”

Homecare Association v Weil: The Limits of Exploitation

This is the case we mentioned last time (see *AccessAbility* Summer 2015) in which the federal Department of Labor (DOL) and David Weil, the Administrator of its Wage & Hour Division, were sued to prevent them from extending overtime payment protections to homecare workers.

Congress passed a law in 1974 extending overtime protections to “domestic workers” and gave DOL broad authority to write regulations defining what that means. In revising its regulations in 2013, DOL pointed out that in 1974, there were very few professional homecare workers; most people who needed those kinds of services received them in institutions, which were required to pay overtime as needed. So the regulations DOL issued back then exempted those who hired people to do what used to be called “elder sitting” from the overtime requirement, reasoning that in most cases they were friends or neighbors hired to help out on a part-time basis, people who weren’t making their living by doing this, or weren’t “primary breadwinners” for their families.

Since the mid-70s, this picture has entirely changed. Millions of people with disabilities now receive homecare from professional workers, and the need for this service is growing. DOL’s obligation is to protect workers, and there is now a clear need to protect this very large class of workers from exploitation.

So there are a couple of changes in the new federal regulations: First, third-party employers can no longer get an exemption from the requirement to pay overtime wages for workers hired to provide “companionship” or “live-in domestic services” to people with disabilities. Second, the meaning of “companionship” has been narrowed to include only services

where things like “meal preparation, driving, light housework, managing finances, assistance with the physical taking of medications, and arranging medical care” take up less than 20% of the worker’s time, and other things, like bathing, toileting, dressing, or feeding, aren’t allowed at all.

The exemption still applies to situations where you hire and pay for your own companions or live-in providers, but “companion” now has to meet the new definition even in that case.

The homecare providers sued to stop the new regulations and won in federal district court, which issued an injunction barring DOL from implementing the regulations. So DOL appealed to the District of Columbia federal Circuit Court, and as we predicted, in August of this year, a small panel of that court overturned the lower court.

It’s not a complicated decision. The 1974 law clearly gives DOL discretion to determine “domestic service.” DOL’s explanation of why these changes are necessary makes perfect sense. Although the homecare providers claimed that the changes would force people into institutions by making homecare workers more scarce, the court cited evidence indicating there is no significant variation in how many people get 24/7 service between states that require overtime and those that don’t. DOL also contends that the rule will actually benefit people with disabilities because it will make this kind of work more attractive, thereby easing recruitment and retention problems for homecare. There doesn’t seem to be any evidence supporting this claim either, but the lack of evidence for the opposite claim is decisive.

On August 21, the Circuit Court gave the providers seven days to request a re-hearing by the full court. If they don’t request it, then the injunction will be lifted and the new regulations will take effect. This newsletter went to press before that deadline expired.

Although the providers might appeal to the Supremes, the Circuit Court’s decision is based on a specifically related finding of the Supreme Court, so the providers are likely to lose there too. That would be the right decision. People with disabilities have been oppressed, experiencing neglect, abuse, and deep poverty as a result of segregation, but oppressing and exploiting another class of poor people to benefit them goes beyond the pale of acceptable solutions.

Unweaving Tangled Webs

The issue of whether federal law requires websites to be accessible to people with disabilities has long been regarded as “squishy.” For example, one could argue that the Amazon website is just as much a “place of public accommodation” (ADA Title III) as your local Wal-Mart. But some courts have said that public accommodations must be physical locations, and others have found that because a website doesn’t really “exist” in a single location, but rather delivers content that comes from various servers and is ultimately formatted by individual computers’ browsers, there is no “nexus” to establish which laws or courts have jurisdiction over it. Also, the ADA allows “alternate” methods of communication to provide access to goods, programs, or services when making a public accommodation accessible isn’t “readily achievable.” So the fact that you can call Amazon and order things over the phone has been considered adequate if you can’t use the website.

In 2010, the federal Department of Justice (DOJ) issued proposed regulations on this topic that supported that view. However, those regulations were never finalized.

Meanwhile, the National Association of the Deaf (NAD) filed two lawsuits against private universities, Harvard and MIT, for failing to caption thousands of videos on their websites.

DOJ filed “statements of interest” in both suits in June 2015. Contrary to its 2010 proposed rules, DOJ now says that the ADA has always com-

pelled public accommodations to make websites directly accessible without requiring “alternate” methods. Further, if the website is public, then it must be accessible to the “public at large,” and not just those directly associated with, or purchasing anything, from the website’s owner. In the case of universities, that means if they have a website, and anybody can visit that website, and they post videos of their professors’ lectures on it, then those videos have to be accessible even to non-students. DOJ did not say specifically that the videos must be pre-captioned or captioned upon request, but it doesn’t seem likely that there would be any other way to make them accessible to deaf people.

In the *Noll* case above, the court ruled that ADA Title I, the employment title, does not require IBM to caption all of its 40,000+ videos as a reasonable accommodation for an employee with a disability. DOJ’s statement doesn’t relate to that case at all, as similar as the issue might seem.

However, there might be some relevance to the problem of OPWDD’s uncaptioned Person Centered Planning training videos on its website. (STIC has told the agency that those videos should be captioned, but this was ignored.) We say “might” because the cases on which DOJ is commenting are Title III “public accommodations” cases, not Title II state/local government cases. NY recently enacted provisions similar to Title II into state law, by redefining the state’s list of public accommodations to include anything that was already in that list that is owned, operated, or paid for by state or local government. (The list specifically excludes public schools

and universities, but OPWDD is covered.) DOJ doesn’t have jurisdiction over state law, but its statement could be used as an “expert” reference if some deaf people want to sue OPWDD over its videos.

DOJ’s statement doesn’t only apply to video captioning. It requires any public website of any public accommodation to be accessible to and usable by people with disabilities (presumably with the usual “unless it’s an undue burden or fundamental alteration” limitations), period.

That includes people with visual disabilities who use screen-reading software. A primary problem with websites for blind people, though, is excessive clutter. People who can see can (usually) fairly easily find what they’re interested in on a busy website covered with pictures, ad banners, videos, and text by quickly looking it over. Blind people have to laboriously click around and wait for their screen readers to completely read almost everything to them before they can get to what they want. It takes them much longer to “skim” a web page than it does for sighted people. Ideally we’d like to say that cluttered websites are not accessible to blind people, period, but claiming that they should be spared advertising or attempts to direct their attention to new content probably wouldn’t fly. However, DOJ’s willingness to get involved when somebody sues might be an opportunity to get some improvements. Web access standards already suggest that every webpage should have a link at the top that lets you jump over graphics and menus and go directly to the main page content. Perhaps this standard will now be legally enforceable.



STIC’s Honor Roll

There are many good people doing good work in the disability field in our region. Each year, though, a few of them rise above the crowd and demonstrate, with their creativity, energy, and dedication, truly exemplary service to individuals with disabilities, to the cause of disability rights, or to STIC. These few become recipients of STIC’s annual recognition awards. This year’s awards luncheon took place on June 18. Here are our

2015 honorees. We thank them here; please thank them again when you see them.

THANK YOU!

Outstanding Accessibility Achievement

*Bill Barber, Commissioner of Parks and Recreation
City of Binghamton*

Bill has always been supportive of access for people with disabilities to parks and recreational facilities. This year his comprehensive plan to make all Binghamton City parks accessible will be completed.

Outstanding Agency Support

*Kathy Creagh, Self Direction Coordinator
Broome DDRO Region 2*

Kathy is a dedicated local OPWDD employee who has been helpful to STIC staff, has

interceded with the Albany bureaucrats when necessary to get things done, and has been supportive to people with disabilities and their families as they work through the complex and sometimes confusing “Front Door” intake process.

Outstanding Business Support

Bryans & Gramuglia CPAs, LLC

The company has been a significant sponsor of our Haunted Halls of Horror fundraising event for several years.

Delta Engineers, Architects, & Land Surveyors PC

The company has been a significant sponsor of the Haunted Halls for several years.

Security Mutual Life Insurance Co. of Central NY

This company is one of STIC’s oldest supporters, contributing substantial sponsorships

to various fundraisers including our golf tournament, the Hometown Holiday Light Festival, and the Haunted Halls.

Tioga State Bank

The bank has been an important sponsor of the Haunted Halls and, before that, the Light Festival.

Visions Federal Credit Union

Visions has been a consistent and significant sponsor of the Haunted Halls and the Light Festival.

Outstanding Consumer Support

Reva Reid

AMBUCS Binghamton Chapter

AMBUCS (American Business Clubs) is a national not-for-profit service organization that focuses on independence and mobility for people with disabilities. AMBUCS' AmTrykes division designs and builds accessible tricycles. For several years, Reva has led the Binghamton chapter's efforts to raise funds to provide these trykes to local children for no charge.

Deborah Reynolds

Deb has helped set up for and clean up after fundraising events, attended various rallies, and provided useful information to those investigating injustices. She has helped several people become more independent over the years, and most particularly, she has given outstanding support for 8 years to an individual served by STIC.

Patti Scott, Community Fiscal Services

Broome DDRO Region 2

Patti is a dedicated OPWDD employee who is highly creative in working with us to devise Individual Support Services (ISS) plans, and very responsive to calls for help. She fully supports the goal of people with developmental disabilities living in the community, and does her part to make it happen.

Outstanding Foundation Support

M&T Charitable Foundation

This foundation has provided significant support as sponsors for the Haunted Halls for several years, and before that sponsored the Light Festival.

The Victor and Esther Rozen Foundation

Hersh S. Rozen, Executive Director

The Rozen Foundation has been a strong supporter of the Haunted Halls for several years.

Outstanding Volunteer Support

Jean Van Buskirk

This longtime member of STIC's Board of Directors is very involved in promoting inclusion and community integration for people with disabilities, and also volunteers with the Haunted Halls.

Rob Van Buskirk

Rob is a dedicated Haunted Halls volunteer.

Christina Hust

Christina has served STIC faithfully as a former Board president, and also as a Haunted Halls volunteer.

International Brotherhood of Electrical Workers Local 325

The members of IBEW Local 325 have provided extremely generous in-kind support to STIC for many years, working hard to keep the Hometown Holiday Lights lit, and more recently to help design, build, and maintain the complex electrical systems that power the Haunted Halls of Horror, as well as supporting other projects.

Ken Shampang

Ken is an almost fanatical Haunted Halls volunteer, working on construction and other aspects of the event almost daily at times.

Jonathan Stringer

Jonathan is a dedicated Haunted Halls volunteer.

Karl Wokan

Karl has been a highly dedicated STIC Board member for several years, serving as Treasurer and taking an active role in STIC activities, as well as volunteering with the Haunted Halls.

Sara Wokan

Sara is a dedicated Haunted Halls volunteer.

Outstanding Fundraising Support

John Hart Studios

Bobby Hart & Patti Pomeroy

Cartoonist Johnny Hart was one of STIC's earliest supporters, and we still use the origi-

nal artwork he produced for our publicity efforts nearly 30 years ago. More recently Johnny's family has strongly supported the Light Festival and the Haunted Halls.

These Thy Gifts

STIC would like to thank those who contributed to our 2015 Annual Campaign and who agreed to have their names publicized. This annual mailing is a very important source of support for STIC. If you received the letter and haven't responded, there's still time. Please use the form that came with the letter so we can properly credit your gift to this effort.

THANK YOU!

Louis Augostini

Beverley Breuche

Gerald L. Day

Jack and Barbara Devore

Sharon DiGennaro

Stephanie Crawford

Harlan and Laurie Forrest

In the Name of Vince Augostini

Betty Gannon

Thomas Gannon

Roberta Griffis

In Memory of Charlotte Kinsley

Barry Kinney

Helen Kostun

In Memory of William J. Kostun

Donald S. Law, Jr.

Sam Liberto, Jr.

In Memory of Saverio and Filomena Liberto

Joseph P. Lomonaco

Rosemary Martin

In the Name of Danielle Stento

Joyce McLarney-Bradley

In Memory of Charles Bradley

Janet Ottman

Michael and Debbie Rigo

In Memory of All and in the Name of Michael

Deborah Root

In Memory of John Root

Patricia J. Rotundo

Heather H. Ruff

In Memory of Ann Kaltenbach

Sue Ruff

In Memory of Ann Kaltenbach

Ronald E. Russ

John, Jr. and Rita Sejan

Steven Van Austin

Dawn Weber

In Memory of Mary Daggett

Karl P. Wokan

Come on Home

by Joanne Carlyle

“There’s No Place Like Home” is just one of many new exciting things happening in the Housing Program at STIC!

On April 27, 2015, STIC welcomed me to their amazing team as the new Housing/Benefits Specialist. With over ten years of experience working with consumers to ensure that their housing needs are met and developing relationships with landlords and consumers, I am so excited to join a team where I am able to advocate and be heard regarding the crisis that is going on in our community around the need for more accessible, affordable and safe housing.

Accessible housing is in great demand and as the Housing Specialist, I work with individuals and families to locate housing that accommodates them by providing referrals to places that fit their needs. I have also brought back STIC’s Housing Coalition, “There’s No Place Like Home”. Our first meeting in August was a full room with local stakeholders talking about what services they offer, what they think is needed in our community and how we can meet this need. I will continue to work extremely hard with other local agencies, developers and funders to end the need for accessible housing in our community.

Obtaining benefits such as SSI, SSD, SNAP and other needed assistance can be very difficult if there is not a clear understanding of the “rules”. Denials happen often and as the Benefits Specialist I assist individuals in filling out the proper papers and help advocate for those who have been denied. Nine times out of ten, individuals are denied benefits, but it is so important to follow

through and request a hearing to ensure you receive the benefits you are entitled to.

I am looking forward to a very long haul at STIC and advocating to be heard in order to make many changes in our community with housing and benefits that are greatly needed.

Contact me at (607) 724-2111 Ext. 231.

“I alone cannot change the world, but I can cast a stone across the waters to create many ripples.” — Mother Teresa

Veterans Directed Home Care Program

by Joe Toman

With Veterans Directed Home Care, veterans with a disability can choose who they hire for their personal care, including friends and eligible family members! The project is funded by the Veterans Health Administration. Services are provided through STIC’s Consumer Directed Personal Assistance program (CDPA), in cooperation with the Broome County Office for Aging (OFA).

For more information, call Joe Toman, STIC Veterans Peer Advocate, at 724-2111 (voice/TTY). To apply for the program, call Mark Frank at OFA at (607) 778-2411.

A New Vision

by Richard Farruggio

I am a relatively new addition to the Peer Counseling staff here at STIC. I specialize in working with people who are visually impaired or totally blind.

Peer counseling is just one of the many services I can help you and your family members with. I am also familiar with equipment which can make life easier for individuals with low vision or who are totally blind.

A few examples of these items include magnifiers in many sizes, equipment to enlarge a full page, with devices with speech to allow people who are totally blind to scan and read mail, bills and much more. I also have familiarity with

screen enlargement and screen reading software for computers, and I can direct you to a variety of helpful catalogs that address all aspects of living with a visual disability.

If you or your family need some help in learning about these areas, please contact me via phone at (607) 724-2111.

I am only part-time and my office hours are on Thursday from 9 am till 5 pm. Please feel free to leave me a message any time and I will return your call on the next Thursday.

I look forward to hearing from you or a family member or friend who may have questions.

ASAC Thanks You

by Sue Hoyt and Betsy Giannicchi

The ASAC committee is an advocacy group at STIC that works with local business and municipalities to help make our community more accessible for people of all abilities.

ASAC would like to recognize and thank Buttermilk Falls State Park, Ithaca, NY.

Their lower park entrance (main entrance) and picnic area are **FULLY** accessible.

Buttermilk Falls State Park
112 E. Buttermilk Falls Road
Ithaca, NY 14850
(607) 273-5761

We would also like to acknowledge the Red Apple/Kwik Fill gas station in Port Crane for re-stripping their parking lot and adding a proper handicapped space with an access aisle.

Red Apple/Kwik Fill
27 Albany St, Port Crane, NY 13833, NY

We applaud your efforts and would like to point you out as an example to other business in the area. Thank you on behalf of people of all abilities.





Darkness Returns

by Bill Bartlow

"I believe that men are generally still a little afraid of the dark, though the witches are all hung, and Christianity and candles have been introduced." — Henry David Thoreau (1817 - 1862)

I think that when they get to the **BLACKOUT** section of the Haunted Halls of Horror, our visitors will be more than "a little afraid of the dark" and of what they may encounter in it. In fact I've already advised our security team leader to expect sheer panic. It's going to be that scary.

"Phantasmagoria". Now there's a word for you. As Mr. Webster informs us: "noun, fan-taz-mə-gor-ē-ə: a confusing or strange scene that is like a dream because it is always changing in an odd way; an exhibition of optical effects and illusions; a constantly shifting complex succession of things seen or imagined; a scene that constantly changes; a bizarre or fantastic combination, collection, or assemblage."

That pretty well describes the **6th annual Haunted Halls of Horror**. We've expanded to almost 16,000 square feet of haunt and reconfigured over 75 percent of the attraction to provide our fans with an ever-transforming and fresh Halloween experience, complete with phantasms in the **NECROPOLIS** and gore in **BLOOD CREEK MASSACRE**.

As I have been telling folks who have visited our tent at venues around town, this is going to be a "bring a spare pair of underwear kind of scare". And that it will take 30 to 45 minutes to go through this year's attraction, provided that they aren't tripping over the people curled up on the floor in front of them.

That really seems to spark their interest and results in a lot of smiling faces on young and old eager to attend. I wonder what Henry David Thoreau would have to say about people seeking the adrenaline rush of a good creepy scare; probably something about human nature seeking altered states. Well, we're here to provide you with one.

I'm sure this will be a record-breaking year for our fundraiser, with all the increased publicity. Look for our illuminated billboards and the banner we'll have over Court Street in Binghamton. We'll have a radio campaign on WILD 104 FM. We were at the Spiedie Fest, the All-Siders Reunion in Recreation Park, Binghamton University's August Festival, the B-Mets Zombie Night, and Blues on the Bridge.

It has been a blurring whirlwind of exposure, but it in no way compares to the new

VORTEX of TERROR 3-D attraction which will be the most amazing, startling, and disorientating thrill ever featured at the Haunted Halls.

An additional special treat is in store for all as we highlight the phenomenal work of local artist David "Cabal" Francisco in our 3D area.

By the time one reaches the **OUTBREAK**, breaking out will be the overwhelming impulse, but that won't be so easy in the maze and fog of barrels, pallets and creatures who don't want you to escape their realm.

So, the word is out there. Here it comes again, bigger and better than ever before. Come to the 6th Annual Haunted Halls of Horror...

If you dare, and don't forget that spare pair.



6th Annual Haunted Halls of Horror

October 9, 10, 16, 17, 24, 25, 30, 31:
7 pm – 10 pm

NEW Late-Night Nightmare Performance!

October 24: 7 pm – 1 am

Admission: \$13.00

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Binghamton

For Information:
(607) 724-2111
www.hhh-stic.com

SELF HELP

Keep Your Children

*(from the National Council
on Independent Living)*

In August the federal Department of Health and Human Services and Department of Justice released a new technical assistance (TA) document entitled *Protecting the Rights of Parents and Prospective Parents with Disabilities*. The document is intended to advise state and local child welfare agencies and courts on their obligations to protect the rights of parents and prospective parents with disabilities.

The TA stemmed from a rising number of discrimination complaints by people with disabilities involved with the child welfare system, as well as enforcement activities finding uneven protections among child welfare agencies and courts. It provides a clear overview of the need for this guidance, citing several recent cases of discrimination as well as the 2012 National Council on Disability report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*. The TA also provides an overview of child welfare agencies' legal requirements under Title II of the Americans with Disabilities Act and Section 504 of the federal Rehabilitation Act, stating that, "the goals of child welfare and disability non-discrimination are mutually attainable and complementary."

Too many of us know from experience the discrimination parents with disabilities face. Too many of us have been faced with the possibility of our children being taken away simply because we have disabilities. This guidance makes clear that child welfare decisions must not be based on harmful stereotypes, and that parents and prospective parents with disabilities must be protected from this type of discrimination.

You can read it at:

http://www.ada.gov/doj_hhs_ta/child_welfare_ta.html

Protect Your Children

Disability Rights New York (DRNY), the official New York State Protection & Advocacy (P&A) agency for people with disabilities, is investigating inappropriate use of restraints or "time-out rooms" in schools across the state. They are seeking information on recent cases: those that occurred during the previous school year or early this fall.

If you report a case to DRNY, they will help you decide "next steps which may include accessing the school and student records or filing a complaint with NYSED, or a range of other options." They will protect your identity if that's what you want.

Julie Keegan, Supervising Attorney for the developmental disabilities P&A program at DRNY, said, "Assessing what's happening or not happening in actual cases provides an important context for the survey information we collected last fall (we had over 300 responses!). I would really appreciate your help in this effort. It will make a big difference in this very problematic area of behavior intervention."

Contact Julie at:

(518) 432-7861 (Voice)

(518) 512-3448 (TTY)

(800) 993-8982 (Toll Free)

(518) 427-6561 (Fax)

Julie.keegan@disabilityrightsny.org

COMMUNITY PROGRAMS

Special Education Task Force Training

Bullying and Its Effects on Students with Disabilities, Part I

This first part of a two-part series will focus on the roles and responsibilities of school personnel when children are the victims of bullying. How does bullying affect a free and appropriate public education? How are incidents documented? How can students be supported by school staff and administrators? How can instances of mistreatment at school be resolved?



Lauri Thomas-McCoy, Director of Special Education & Related Services, Deposit Central Schools

Experience: special education teacher K-12 special class, resource room and direct consultant teacher services, sub-CSE chairperson, special education school improvement specialist concentrating on supporting districts in serving their students with disabilities and assistant principal and Dignity for All Students Act (DASA) Coordinator for her building.

Julie Michaels-Keegan, Supervising Attorney, Disability Rights NY

Experience: For ten years prior to joining DRNY, Julie practiced independently through the Law Office of Julie Michaels Keegan, a firm devoted exclusively to special education law and future care planning throughout upstate NY. Through private practice and her position as a Special Education Resource Specialist at the Parent Network of the Capital Region, Julie has provided hundreds of trainings on a wide variety of special education issues to attorneys, parents, school personnel, advocates, and service providers.

Shain Neumeier, Staff Attorney, Disability Rights NY

Shain is a person with disabilities who has experienced bullying in school settings and will share perspectives as a former student.

Part II (coming in Spring, 2016) will focus on the roles of parents, in-school mentors, other students and advocates in helping children to develop self-advocacy and coping skills around difficult social issues and experiences.

September 24, 2015

6:30 PM – 8:30 PM

Maine-Endwell High School

Questions or Needs: (607) 437-0077

Please Register:

Email your name and contact phone number to register@familyrn.org; put "Bullying" in the subject line.

Register by phone at (607) 437-0077.



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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.**

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

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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

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