

# AccessAbility

Autumn 2014  
Number 116



I am 57 years old, not disabled (yet), and very worried.

I have type-II diabetes and osteoarthritis. These conditions, even when treated, tend to lead to loss of mobility in later life. For certain forms of advanced arthritis, especially, there are no very effective or completely safe treatments.

I live in Broome County in upstate NY, a region that is slowly losing doctors. This is a smaller community; it has never attracted the best medical professionals, and now, as managed care kicks in for people with disabilities, and price competition begins to seriously pressure health insurance companies to cut costs, it is getting harder to get adequate medical care here.

Just three years ago, I used to be able to call my doctor and he—himself, not a nurse or a clerk—would call me back within 24 hours to talk to me. He would answer questions about treatment and prescribe medications over the phone, or if I had a serious problem he would see me within 24 hours.

Today my doctor's medical group keeps putting up barriers between him and me. I can't call in prescription renewal orders anymore because the clerk who takes them always screws them

up. If I need to ask a question about my treatment, I have to leave voicemail, in return for which I get voicemail that doesn't answer my question, so I have to call and leave another message, and get another voicemail response. It can take several days to get a single question answered. As for getting seen quickly for a serious issue—forget it. It takes two or three days of message passing to correctly convey my wish to be seen and get an appointment scheduled. If the matter is really urgent I have to go to a walk-in clinic and see a doctor who doesn't know me and is likely to misdiagnose me, after which I still have to ask, and wait for, an appointment with my doctor so he can fix the mistakes the walk-in doc made.

I'm not a hypochondriac or a guy who likes to go to the doctor. I rarely need to ask for medical help—but I'm 57, and that's gonna change.

The medical profession often talks about how it needs to manage pain better. But pain management is like the weather; everybody talks about it but nobody does anything about it. Well, that's not exactly true; the one concrete step that's been taken in recent years is politicians' mad rush to pass laws to make it harder for doctors to prescribe pain medications. When it comes to pain, doctors are more risk-averse than ever. For example, I can take powerful NSAID medications to actually reduce arthritis inflammation as well as pain, and risk kidney damage, so I can walk and garden and do other things. Or I can take opiates (if I can get them), or no medication at all, and lose my ability to do much of anything. This should be *my* choice to make, but somehow in doctors' minds it never is. Instead, when doctors compare the risk that I might acquire a specific serious disease to the risk that I might stop being able to do something important in my life, they always say I should prefer losing my abilities to shortening the amount of time I spend living without those abilities.

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This is about quality of life. I have some movement limitations and pain now; it's no big deal, I can manage. But I'm 57, and that's also gonna change.

Then there's long-term care. We at STIC are always talking about that: how nursing homes provide a miserable quality of life and home-care, especially consumer-directed homecare, is the way to go. But is it?

Most people who need ongoing supports due to disability are eventually going to have to deal with Medicaid. You can spend your own money on services until you run out, but if you don't die first, you'll then need Medicaid.

Sometimes people try to be proactive about this. For example, my dad bought private long-term care insurance. Beginning a few years before he died, he developed severe circulatory issues. He couldn't walk more than a few feet before he

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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.

had to sit down, couldn't lift much weight, got tired very quickly. So he tried to use his long-term care insurance to get some help around the house, but they wouldn't pay for it. Why? He couldn't pass their needs evaluation. By the time he was able to pass it, he was in a nursing home because he needed round-the-clock support, and the insurance wasn't going to pay for that in his home.

So private long-term care insurance, which is extremely expensive, isn't something I can depend on if I want to stay in my own home and have a decent quality of life. But what if I decide to pay for some help with my own money?

Well, if I want to do it myself, and have it work, I have to do *all* of it myself. Due to various laws and regulations, I have to do everything a small business would do to hire employees, including maintain all the records and paperwork, pay the payroll taxes, issue paychecks, plus recruit, train and supervise my workers. Then I can set my own wages and benefits at a level that ensures I can get enough reliable people to work enough hours to meet my needs. What's wrong with that?

It's more money than I have, realistically. It's more than all but the richest people have, in fact, if they're going to need services for more than a few months. It's also a huge amount of work, and it's very complicated, and I could easily mess up and be faced with fines or penalties for noncompliance.

But I have another option. I can use the Consumer Directed Personal Assistance (CDPA) program. They'll handle all of the paperwork and reporting, and I can just hire, schedule, and supervise my own attendants so they can give me exactly the help I need, just the way I need it, when I need it, right?

Not if I want to pay for it myself. The CDPA program is not allowed to accept private payment.

Okay fine. Suppose I have survived increasingly debilitating arthritis without help until I've spent all the retirement money I've saved up, and now I qualify for Medicaid. Problem solved, right? I can use CDPA then.

Probably not. See, I'm a quirky kinda guy. I'm eccentric, not very social, not family-oriented. Prickly, even. Okay, annoying. The bottom line is, I can't identify any family members or friends who I could hire as my attendants. CDPA will not take care of finding attendants for me, so that's three strikes right there. But suppose I

sweeten up over the next few years, out of my abject fear of ending up helpless, so I can find some people to hire. The next question is, are they available at the times I want, to put in all of the hours I need? Probably not. Under CDPA I also have to arrange my own backup, also out of my tiny pool of known associates, to make sure I don't end up spending the night sitting in my wheelchair when my regularly-scheduled attendant doesn't show up to put me to bed.

Okay, so maybe CDPA is not for me. I should use a "traditional homecare agency" to hire attendants for me and make sure I have backup. In fact, I don't even need Medicaid for that; I can do that with my own money. So how well does that work? Funny you should ask.

Now remember, since I'm not running my own small attendant business, I've given up the ability to set wage and benefit levels high enough to get and keep all the help I need. I have to depend on whatever the homecare agency does in that regard. This is not a big town. It doesn't work that well here, at least in part because there is not a huge pool of available people to do the physically and emotionally demanding work of being a homecare attendant at or near minimum wage, with no benefits, which is what the agencies offer, at all hours of the day, seven days a week.

It happened to my mother-in-law just last weekend. Her attendant called in sick; the agency had a pool of just three possible backup workers to call, all of whom weren't available. Agency policy is "the family is the backup." So my wife and I had to go over and help her get out of bed, go to the bathroom, take medications, and get breakfast—and we both have arthritis and difficulty lifting. We did it, that day, but I'm 57; I won't always be able to do that.

But wait, isn't there a Medicaid waiver somewhere that will let me set my own wages and benefits, hire, train, and supervise my own attendants, and yet still have an agency handle all of the nasty legal paperwork and billing stuff? Yes there is! But it's only for people with developmental disabilities, and among them, only those who qualify for institutional care. I am 57, but I don't have a developmental disability, and that's never gonna change. In fact, all of the Medicaid waivers have that institutional care requirement; they aren't for people who just need some help getting around or getting things done.

But! But! Suppose I live in a big city where there are plenty of attendants to go around, and even to provide backup, and I meet all the other

wonderful requirements for living a great life as a person with a disability: I'm poor, I'm in serious pain and need a lot of help, and I have Medicaid long-term care services through a traditional agency. Yeah, a big city, say... New York City!

See page 7. There we describe a lawsuit that was just brought against the state of New York for arbitrarily cutting homecare services for people just like me—er, just like I would be. The case is *Taylor v Zucker*, in which Janie Taylor, whose principal disability (she also has diabetes and high blood pressure) is an unsteady gait requiring assistance to do anything that involves standing or walking, sued because her managed care organization (MCO) cut her personal assistance services from ten hours to five hours per day, without following proper procedures.

Medicaid law requires that homecare programs, whether through MCOs or not, provide all of the homecare services that are “medically necessary” for the individual, and further requires state government to see that they are provided and not cut without proper cause, adequate notice, or the right to appeal.

I knew I was on the right track by moving to New York City. Ten hours of service per day to help a person walk and do chores on her feet is enough to provide a pretty nice lifestyle. She can go to the bathroom as soon as she needs to, have a meal or a snack whenever she wants, and get outside for shopping or fun quite often. This is good; this is what most people think it means to be “living in the community.” But how much of that is really “medically necessary”?

For purposes of comparison: if Ms. Taylor was in a nursing home, she would still be fed, would still have her toileting needs addressed, and would have some opportunities for recreation. However, she would spend nearly all her time in bed or a wheelchair. She would most likely be diapered or told to use a bedpan rather than be helped to the bathroom; if she used diapers they'd be changed perhaps three times a day. She could get a shower maybe once a week. Meals would be institutional in nature and quality. Recreation would consist of watching TV or going to the “day room” for some group activity.

But, you see, there really isn't anything in the Medicaid homecare “medical necessity” rules that requires people's *quality of life* to be any better than it would be in a nursing home. Ms. Taylor has a good legal argument that the MCO

didn't follow proper notification or appeals procedures, and the state didn't make sure it did. She'll probably win. But she won't have an argument if the MCO does follow those procedures and explains why the previous level of service wasn't medically necessary. Ms. Taylor could wear diapers in her own home and get them changed infrequently. She could eat simple, pre-cooked microwave meals on a rigid schedule. Her trips outside the home could be strictly limited to necessary shopping. This could be done with 5 hours of service per day, or even less. In fact, this is what most NY upstate counties do; people like Ms. Taylor and my eventual self would never have gotten ten hours of service per day here in Broome County, or anywhere else outside of New York City, to start with.

The ADA is no help here, folks. Ms. Taylor's lawyers cited the ADA Title II prohibition against unnecessary institutionalization; they said people losing homecare services could force them into institutions. That is certainly true for some folks, but for Ms. Taylor, going from 10 hours a day to 5 hours wouldn't have that effect. ***It would have the effect of turning her home into an institution.*** The ADA doesn't prohibit that.

But what if we had a “performance based” medical service system that focused on functional, rather than clinical, measures of health and wellbeing? Couldn't it create incentives for community-based services that promote quality of life? That's the vision of some of the people who designed NY's new Delivery System Reform Incentive Payment (DSRIP) program.

But that program is focused on reducing hospital admissions, a required outcome; functional benefits are desirable side-effects but not required. Reduced hospital admissions ultimately can be achieved merely by not admitting people to hospitals (perhaps by tinkering with the definitions of “hospital” and “admission,” and maybe even “reduced”; don't laugh, it's been done before), no matter what their state of health, and without providing adequate preventive services at all. New York State government has a long history of entangling, and ultimately strangling, great human service visions in webs of nitpicking regulation, administrative incompetence, political gamesmanship, and cynical deceit. There's no reason to expect anything different from DSRIP down the line.

And please don't tell me that my specific problem can be fixed if New York just applies for one more Medicaid waiver, or tweaks this or that Medicaid regulation. I've been in this business for a long time. I know they're never gonna get it right by going that route.

Many years ago I stood up at a statewide Independent Living conference general session and said, “I don't have a disability—yet. I'm in this business because I know I'll eventually get one, and I want to have reliable, high-quality community supports available by the time I do, so I

can have a decent quality of life and won't end up in a nursing home.”

A disability support system based on medical necessity and risk management is a flawed and

fragile system, easily disrupted on grounds of cost and scarcity of expertise. No matter how much people advocate to “reform” that system, it's never going to work well enough to give me the reliable support and quality of life that I want, because it is too complicated, too expensive, and too focused on keeping people (just barely) breathing instead of happy and productive. We need a completely different system.

The philosophy of Independent Living was founded in the 1960s by people with disabilities who railed against the patronizing, stifling conditions forced on them by the “medical model.” Since then, that passion has faded, and today most disability rights advocates implicitly accept the medicalization of our support services, and they laugh at me when I say it has to end. Well, I need them to get out of the trenches in the managed care wars, at least part of the time, and focus their eyes back on the prize: getting the “medical” out of our services. All the way out.

Most of the supports that people with disabilities need are not “medical” at all. They do not need to be subjected to a “medical necessity” model or be financed by a medical insurance system. Yes, all sorts of things can be shoehorned into “medical” using twisted logic, but those rationales all come down to substituting “medical” for “survival” or “productivity,” massively inflating costs and reducing the overall workability of the system as a result.

We often do need sophisticated medical treatment plans, expensive medical practitioners, and rigorous oversight to prevent malpractice in order to address our medical needs. But we just

*The ADA is no help here, folks.*



need some help eating or going to the bathroom or walking in order to be happy and productive for as much time as we have left. That kind of help is a lot cheaper and could be a lot easier to get if we made one important change: provide a source of money for people with disabilities to use to for the supports *they* deem necessary for their quality of life.

I've said it before and I'll say it again: retired people get handed thousands of dollars of government money every month, and nobody asks them to account for it, and nobody restricts how they can spend it. If they spend it foolishly, nobody rescues them either, or thinks they should. It's called Social Security. What if we handed people with disabilities thousands of dollars of unrestricted government money every month and told them they can spend it however they want to get whatever support services they need?

Retired people can use some of their Social Security money to buy seeds and plant gardens, or they can skip that step and buy fresh fruits and vegetables at the store and then cook them, or they can skip both steps and buy frozen microwave dinners or go to Burger King. Nobody tells them they can't make those choices with that money, *even if they also have disabilities*.

Why can't people with disabilities use a monthly check to, in effect, run a small business to hire, train, and pay attendants, and do the employment paperwork and accounting? Or they can skip the paperwork and accounting steps and buy services from the CDPA program. Or they can skip all those steps and buy services from a traditional homecare agency. And those programs could offer a "cost plus" option, where I could set, and pay for, my own wage and benefit levels, plus a standard administrative rate.

And why do we use the archaic "institutional level of care" standard to decide when people can start getting certain kinds of help? What in tarnation do institutions have to do with any of this? It's like telling people they can only have a cell phone to call their next-door neighbor if they used to need a telegraph to send messages to the next county. Wouldn't it make more sense to provide a small amount of money as soon as a person begins to need some help, and then increase the amount, if necessary, as their needs increase?

If we got our supports and services out from under Medicaid regulations, their unit costs would be cut dramatically, and there wouldn't be nearly as much pressure to nickel-and-dime people to death. If we don't do that, there's nothing to prevent the cost-cutters from turning our own homes into nursing homes.

And we need to do it soon, because I'm 57, and that's gonna change.

## News & Analysis

### The Great Betrayal

This is an election year (see page 14). The bad thing about election years is that politicians focus single-mindedly on a few big things they think will elicit the most campaign contributions. People with disabilities themselves don't have a lot of money to give to campaigns or pay lobbyists, so they aren't on politicians' radar right now. Big segregated programs, as well as medical organizations and public employee unions, do give a lot of money to politicians and lobbying firms, so they get catered to. Those groups are mostly just interested in protecting their own jobs, but sometimes they think they know what's best for you, so they try to protect you from yourself. This, they think, is "supporting" people with disabilities.

About the only thing that can divert most politicians from their usual self-serving and/or paternalistic courses in an election year is a perceived threat to their personal power. This spring Governor Cuomo got some push-back from left-wingers in his own party for not supporting all of their issues. The Working Families Party, which usually endorses Democrats, made noise about not supporting Cuomo for a second term. Cuomo was also facing a Democratic primary challenge from his left, and pressure from new

left-wing Democratic NYC Mayor Bill de Blasio and the people who elected him. Although his Republican opponent's chances were not taken seriously by anyone, Cuomo seemed rattled. With just a couple weeks left in the legislative session, he called for dismantling the "Independent Democratic Conference" (IDC), a group of five Democratic Senators who formed a coalition with Republicans to establish a Senate majority that grants them special perks. Cuomo's remarks were seen as high-handed by many, and the Senate leadership vowed to stop cooperating with him. Suddenly, nothing was getting passed.

That included several measures supported by the disability community that seemed to be on a fast track. The details are murky though; it's not clear in some cases whether people who didn't really want to support us used this "leadership crisis" as an excuse. What we do know is this: Advocates had hard-and-fast promises from legislative leaders—committee chairs and others with influence—with whom they'd developed what they thought were good relationships over several years, that certain bills, such as those to enact Title II of the ADA into state law, and modify the Nurse Practice Act to support the Community First Choice (CFC) Medicaid service option, would pass this year. Those prom-

ises were broken without explanation or apology. Well, there was one explanation; a Senator who should have known better opined that the CFC bill looked like "some kind of product of the Working Families Convention."

Instead, the Senate and Assembly passed several laws that threaten the civil rights of people with disabilities, and only one that supports them.

### Holland Avenue Freeze-Out

The "Freeze Unsafe Closures Act" was a bill introduced to curry favor with public employee unions that fear losing jobs as institutions operated by OPWDD are closed over the next few years. These closures are mandated by the federal government; or, rather, the feds have set a deadline after which no federal money can be used for these facilities. If the state chooses to keep them open, it will have to use its own money to do so. However, refusing to close them would also likely jeopardize federal approval of OPWDD's new Medicaid waiver proposals, and of OMH's HARP's plan. It would be a financial disaster for the state.

The bill contained blatantly false, bigoted language describing people with disabilities now in institutions as either too "fragile" or too "dangerous" to live in the community.

The bill was sponsored in the Assembly by Donna Lupardo (D-124th District) and in the Senate by Tom Libous (R-52nd District). Both politicians claimed authorship. But there's plenty of responsibility to go around. Assembly co-sponsors included four out of the seven Assemblymembers who represent our region, including Clifford Crouch (R-122nd), Christopher Friend (R-124th), Barbara Lifton (D-125th), and Philip Palmesano (R-132nd). Along with Libous, the other two Senators representing our region, James L. Seward (R-51st) and Thomas F. O'Mara (R-58th), sponsored the Senate version.

The bill did not seem to have a future until the closing days of the legislative session, when Libous allegedly made an impassioned push for it and unexpectedly got the Senate to pass it. Lupardo, who is not ordinarily regarded as influential, was somehow able to get help from Assembly leaders, including Mental Health Committee Chair Aileen Gunther, to fast-track it through several committees and bring it to the Assembly floor for an impending vote. By all accounts Cuomo was planning to veto the bill, since it would put the state on a collision course with the federal government. Instead, he suddenly granted Libous and Lupardo a meeting to discuss the issue. Insiders suggested that the highly-influential pre-indictment Libous offered to partially clear the legislative logjam that Cuomo's ill-considered remarks about the Senate leadership had created, in return for a "deal" on the closures.

And so a deal was announced: the closures will go forward as scheduled. Cuomo agreed to meet with Libous, Lupardo, and public employee union representatives to discuss how union members might find other jobs in the developmental disabilities service system going forward. No date was set for these meetings, and nothing specific about jobs was promised to the unions, at least publicly. However, Cuomo also ordered OPWDD to work with county mental health departments on a "Memorandum of Understanding" to ensure that a county mental health representative will participate in every discharge plan for every person living in

one of the facilities to be closed. Cuomo also directed OPWDD to review protocols for handling people who are remanded to its institutions by judges to make sure no such people are released without a judge's order (no such releases have occurred), and, more ominously, to review the "voluntary" vs. "involuntary" status of every person in those facilities to make sure they are "appropriate."

Now, as we said, it's an election year. After November 4, assuming Cuomo is re-elected, he may conveniently postpone any meetings with union officials indefinitely.

Also, much of this deal is illegal under the privacy requirements of the federal Health Insurance Portability and Accountability Act (HIPAA), and federal Medicaid regulations. People who live in Medicaid-funded institutions have the right to control who participates in their service planning. The state cannot force them to accept county mental health employees at their planning meetings if they do not want them there. The state can't even tell the county mental health department about those meetings with-

out permission from the individual. Further, the state cannot undertake a wholesale process to change people's admission status from "voluntary" to "involuntary" purely to slow down releases from institutions to satisfy union demands. Institutions for people with developmental disabilities, by law, are not permanent residences, and people must be discharged from them as soon as more integrated settings appropriate to their needs can be established. When people leave institutions, they will most likely get services under a Medicaid Home and Community Based Services waiver. The new regulations for such waivers require that people be able to freely choose who provides their services. There will be no legal way to force people to work with former institutional staff merely so those people can keep union jobs. (See page 14 for more on how to protect your rights.)

Both the federal Department of Justice and the Centers for Medicare and Medicaid Services (CMS) have been notified of the potential crimes that Cuomo, Lupardo and Libous seek to perpetrate. Disability advocates across the state are on high-alert watchdogging this process and will use all legal means at their dis-

posal to ensure that nobody's release from an institution gets blocked or slowed down by this bogus political pandering. In the end, Lupardo's and Libous' "deal" will amount to nothing more than another shabby episode in the history of political backstabbing for the sake of lining campaign coffers. However, voters with disabilities may remember it on November 4.

### Community No Choice

As we've reported, Community First Choice (CFC) provides another way to use Medicaid to pay for certain types of homecare services. Its advantage over Medicaid waivers that do the same thing is that needs can be established by a functional assessment without regard to a particular diagnosis or age group. This means the service would be available to people who fall through the cracks between the state's waivers for people with developmental disabilities, brain injuries, and certain types of physical disabilities. People eligible for CFC who are able to direct their own services, or who have a "designated representative" to do so—and can identify people to provide the services—will be able to use the Consumer Directed Personal Assistance (CDPA) program. However, there are a lot of people in nursing facilities who could have higher quality lives in the community (at least for now; see our Editorial) but who aren't capable of supervising their own services, and who don't have relatives or friends who can do so for them. The federal rules for CFC potentially allow it to be used for some tasks—such as child care, pet care, and snow removal—that personal care attendants, including CDPA workers, aren't allowed to do. The catch with CFC is that in order to make it as flexible as it can be—or flexible enough to be worth doing at all—the state must modify its Nurse Practice Act (NPA) to let people other than nurses perform the same kinds of "health related tasks" that the NPA lets CDPA attendants do, such as administering oral medications, cleaning trach tubes and ventilators, giving some types of injections, and inserting catheters.

Some advocates have claimed that if the state doesn't modify the NPA the feds won't approve its use of the CFC program, which will mean NY will lose a few hundred million dollars in Medicaid incentive payments. That's not entirely accurate. The CFC regulations make it clear that a CFC program can proceed with only minor NPA modifications, or even no modifications at all. The "health related tasks" are an optional feature, not mandatory. Perhaps CMS is disinclined to approve

*Both the federal Department of Justice and the Centers for Medicare and Medicaid Services (CMS) have been notified of the potential crimes that Cuomo, Lupardo and Libous seek to perpetrate.*

the program under those circumstances, but there is no regulatory basis for them to reject it. But without the NPA changes, we could have a CFC program that almost nobody can use, and therefore, very little of that incentive money could be drawn down.

As we reported last time, Cuomo had proposed a bill to amend the NPA. It created “Advanced Aides” who would be trained to perform the “health-related tasks” under the close supervision of nurses. The concept was receiving considerable support in the legislature until the influential Assemblymember Deborah Glick (D-Manhattan) suddenly blocked it. Glick was told that the bill would not allow the highly-trained, tightly-monitored Advanced Aides to do anything that CDPA attendants, who are not formally trained and are supervised only by the people they serve, aren’t already doing safely and successfully, but she kept saying the bill would endanger people with disabilities. An Independent Living activist participating in an ADAPT-organized sit-in at the Capitol in Albany on June 12 reported that an unidentified “aide for a Democratic Assemblymember” told her that the bill would create a “Willowbrook in the community.” Glick never did provide a rational explanation for her opposition, leaving advocates to speculate that personal favors or personal trauma were involved.

In any case, something loosened up Glick’s roadblock, and she agreed to a watered-down version of the bill, which passed the Assembly in the closing days of the session.

The Assembly version only specifically provides for medication administration, and limits other tasks, to be determined later, to those that a Licensed Practical Nurse can perform. Supervising Registered Nurses appear to be given permission to delegate any other tasks within that scope to Advanced Aides, but a workgroup has to issue a report by March 1, 2015, on what specific tasks could be delegated, and no tasks other than medication administration could be delegated before January 1, 2017.

The Senate, however, refused to take it up, apparently due to the flap with Cuomo. So as of now there is no NPA modification, and likely no usable CFC program.

### **Weathering the Storm**

The legislative session showed that all of our “friends” in the state legislature are of

the fair-weather variety, but Assemblyman Richard Gottfried (D-Manhattan) braved the storm better than most.

He sponsored, and tirelessly worked to pass, a bill to restore appeal rights to people in Medicaid managed long-term care. One of the strategies that the Cuomo Administration has adopted to save money is to make it harder for people to appeal cuts to their services. For Medicaid managed long-term care (MLTC), now in effect in New York City and slowly spreading to the rest of the state, participants must first exhaust an internal appeals process within the Managed Care Organization (MCO) before they can get the Medicaid Fair Hearing with an impartial judge that is guaranteed them by federal law. People are supposed to get “aid continuing”—that is, no change in services—until all appeals, including the Fair Hearing and any appeals of that decision, are exhausted. But Cuomo’s plan limited aid continuing to appeals based only on the initial conversion from fee-for-service Medicaid to MLTC. Once you were in managed care, the MCO could cut your services a few months later, and while you could appeal, the cut would take effect, which could force you into a nursing home—perhaps losing your real home forever—while waiting for your appeal to be resolved. Gottfried’s original bill not only restored aid continuing to all appeals processes, it eliminated the requirement to exhaust a predictably negative internal appeal with the MCO before going to a Fair Hearing. Unfortunately, Cuomo rejected the latter point, but agreed to restore aid continuing, a significant victory.

Gottfried also sponsored the Assembly’s CFC bill, as well as other important bills on the disability community’s agenda that would have: prohibited discrimination by landlords on the basis of source of income; required “visitability” in new housing construction; enacted ADA Title II anti-discrimination requirements for state and local governments into state law; and waived “sovereign immunity” in lawsuits against state government in disability civil rights cases. None of those bills passed, sadly.

Gottfried stood firm and did not support the Lupardo/Libous bill to prevent closures of state institutions.

He also did not support a bill to make it harder for investigators from the state’s Jus-

tice Center for People with Special Needs to interview people with disabilities who report neglect or abuse. The original bill had no safeguards against conflicts of interest; it would have let perpetrators of abuse block an interview on the grounds that it would be “traumatic” for the victim or that the victim couldn’t be trusted to tell the truth. It also required that administrators of a program from which a complaint originated be given advance notice of the interview, time they could use to intimidate the victim. The bill was modified to give the Justice Center more discretion in deciding whether the victim can be interviewed, but it still requires an unacceptable level of advance notice for program administrators. Unfortunately, this bill passed; at press time we didn’t know if Cuomo would sign it.

Gottfried also did not support another wrong-headed bill that would have let banks, on their own discretion, refuse to give so-called “vulnerable persons” their own money if they thought the person was being robbed or swindled. Fortunately, that one didn’t pass.

However, nobody’s perfect. In the wake of the much-publicized death of an autistic teenager who wandered away from his school, Gottfried jumped on the bandwagon to support the ill-conceived “personal locator” bill called “Avonte’s Law.” It would have required police agencies to establish a missing-persons locator program to detect signals from electronic “personal locator” devices (perhaps strap-on, perhaps microchips embedded under the skin) attached to “vulnerable” or “aging” persons. OPWDD would have been required to pay for the devices if they were requested by any “parent, guardian or agent” of a vulnerable person. The problem with the bill is that it provides no protection for the civil rights of self-directing people with disabilities. People requesting the devices would not have to prove that the person they want to monitor actually needs such a thing to address a serious, objectively-documented, safety issue. It would give a blank check to overprotective relatives and risk-averse facility operators to hunt down people who have a right to go where they want, when they want. Fortunately, this bill did not pass.

Gottfried also voted for a bill to let school districts and villages continue to use inaccessible lever voting machines. That bill passed and was signed into law by Cuomo.



# courts watch

## **Taylor v Zucker: Benign Neglect?**

This class-action lawsuit is similar to *Johnson v Shah* (see *AccessAbility* Summer 2011); it's about New York's failure to ensure that people's homecare services are not cut or canceled arbitrarily as a result of cost-control efforts, including managed care. *Johnson v Shah* was only about Certified Home Health Agencies (CHHAs) providing a specific form of homecare that is mandated under federal Medicaid law. *Taylor v Zucker* covers all forms of homecare, including "traditional" personal assistance services, CDPA, and private-duty nursing.

*Johnson v Shah* resulted in a settlement agreement between the CHHAs, the state, and the plaintiffs in which the CHHAs agreed to stop cutting services arbitrarily, and the state agreed to make sure they did that—but as of July of this year, when *Taylor v Zucker* was filed in federal District Court in New York City, homecare agencies were back to doing it, and the state was back to letting them.

Federal Medicaid law and regulations say clearly that state Medicaid programs must provide adequate services to address "medically necessary" needs, and if any changes to services are proposed, the recipient must get advance notice and a chance to appeal, and be allowed have those services continue until all appeals are exhausted. The "medical necessity" requirement carries the expectation that services can't be reduced if the person's medical needs haven't changed—but only if the services were based on an accurate assessment of medical necessity to begin with. Nothing prevents a state from taking away "unnecessary" services, as long as it follows proper procedures.

In July, Howard Zucker was Acting Com-

missioner of the NYS Department of Health (DOH), having replaced Nirav Shah. Janie Taylor, one of three named plaintiffs, is an 84-year-old former homecare worker who lives alone in New York City. She has diabetes and high blood pressure, but most significantly, an unsteady gait that requires her to have someone steady her when she walks so she won't fall. She can walk very slowly



without help, but can't carry anything, and may fall at any moment. Falls in elderly women can be fatal due to hip fractures and resulting complications. Until July 1 she was getting 10 daily hours of homecare, which involved an attendant to help her walk to and from the bathroom, cook meals, and do errands outside her home.

On June 23 she got a document labeled "Summary of Authorized Services" from her managed care organization (MCO), which said she was authorized for 5 hours of daily service beginning July 1. The document does not describe this change as a "reduction"; it calls it a "new authorization." The document did not explain that Ms. Taylor had a right to an internal appeal with the MCO, an impartial Medicaid fair hearing, or to aid continu-

ing during appeal. It also did not provide a reason for the change in hours. On June 30 her doctor called the MCO and asked for an internal appeal. The MCO called Ms. Taylor on July 1, told her that her internal appeal was denied, and pulled her attendant out of the house after five hours of work.

She called a lawyer the same day, and the lawyer helped her request a Medicaid fair hearing. The following day the lawyer called the head of the state agency responsible for overseeing fair hearings and got the hearing request processed; the agency head also ordered the MCO to provide aid continuing. As of July 15, the MCO had not done so, and state officials had taken no further action to make them.

Similar practices were experienced by the other two named plaintiffs: at the MCO level, there were clumsy attempts to hide the fact that services were being reduced or eliminated by avoiding those words in written notices; failure to inform people about their appeal rights; failure to comply with advance-notice requirements; and sudden service cut-off with refusal to provide aid continuing. Among state oversight officials, there were failures to respond to appeal requests and complaints within the time frames specified by the regulations, and haphazard follow-through even after being contacted by lawyers.

One of the plaintiffs was an 18-year-old man with Noonan's Syndrome, a congenital disability that comes with potentially serious heart and lung problems and can be severe enough to qualify as a developmental disability (and probably would in this case). He lives with a physically-disabled uncle and an aunt who works two jobs and can't do much for him. He goes to a "special school" during

the day, where services are available, but yet inexplicably was getting 24-hour CDPA service. There was also no explanation for why he was depending entirely on managed home-care services and not enrolled in the OPWDD HCBS waiver. The MCO announced that the service would be gradually phased out over several weeks, to zero hours. He appealed, but the state refused to order aid continuing when contacted by his lawyer.

The other named plaintiff was a 65-year-old man with physical and mental health disabilities. The complaint suggests that due to the latter he needs a lot of guidance to keep him organized and focused on getting things done, including personal hygiene, cooking, and making sure he follows a proper diabetic diet. He was getting 12 hours of personal assistance a day; his MCO wanted to cut him to 4 but after an internal appeal changed that to 8 hours a day. The state failed to order aid continuing immediately and only did so a month after the service was cut.

The complaint and some of the media coverage imply that this is a problem that was caused by managed care, but it's really not.

It's about cost-cutting and inadequate oversight. *Johnson v Shah* was about the behavior of direct-service provider agencies in the New York City region and DOH's poor oversight, not managed care companies. Another down-state case, *Strouchler v Shah* (see *AccessAbility* Winter 12-13), which revolved around people's services being cut due to cost pressure that drove bogus interpretations of the regulations, was strictly about actions taken by New York City and state agencies. Historically, the state doesn't have a better track record of monitoring and enforcing its own compliance with regulations, or that of county governments, than it does that of private MCOs. And NY has been trying to cut Medicaid costs through various questionable and sometimes outright illegal methods since STIC began publishing this newsletter back in the 1980s.

Here is the thing we need to be concerned about: it is possible for a state to apply extremely narrow definitions of "medical necessity" without violating any laws. The plaintiffs in this case have a good technical legal argument that the MCOs didn't follow proper notification or appeals procedures, and the

state didn't make sure they did. But they don't have a defense if the MCOs do follow those procedures and provide a rational justification for why the previous level of service wasn't medically necessary. In that case, we are at the mercy of judges who may, or may not, buy into complex chains of logic used to explain why failure to provide enough service hours may lead to a slow degradation of health that, in turn, will result in a need for more expensive medical services down the road. (See our Editorial in this issue.)

The case has not yet been heard by the judge; we'll let you know what happens.

### ***Sciarrillo v Christie* Dismissed**

As we predicted, a federal judge has dismissed this suit filed by parents of residents of developmental centers in New Jersey who were opposed to the facilities' closure (see *AccessAbility* Winter 13-14). Unfortunately, we can't provide details on the judge's ruling because the US Department of Justice's website was malfunctioning at press time.

We do know the families have appealed the decision. We'll continue to follow this case.

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# OPWDD Responds

As we reported last time, OPWDD solicited public input on its system reform and Medicaid waiver plans. STIC submitted comments on the issues of compliance with the new Home and Community Based Settings (HCBS) regulations issued by the federal Centers for Medicare and Medicaid Services (CMS), various aspects of the new waiver, and on OPWDD's plans for evaluating the performance of service providers. (See *AccessAbility*, Summer 2014.) Over the summer, the agency released written responses to these comments, and also published the actual Medicaid waiver renewal application that it is submitting to the feds.

A remarkable thing about the agency's response on the new HCBS regulations was, they quoted or paraphrased STIC's comments at length, in a way that seemed to acknowledge their truth. Now, OPWDD only got five sets of comments on this subject before their deadline (they are still accepting comments though), so they didn't have a lot of quotes to

choose from. Still, we're flattered. We're not entirely won over, but we *are* flattered.

Specifically, they said that the new HCBS conflict-of-interest rules will likely require "restructuring" the service system. Those are the rules that forbid the same person, agency, or group of agencies controlled by the same people to provide both service coordination and specific direct services to the same individual. They also acknowledged that some of OPWDD's regulations for service providers, which are somewhat similar to the new HCBS rules, are often ignored, and that the agency can't solve that problem merely by issuing tighter regulations. It will have to put more "boots on the ground," improve its monitoring system, and apply tougher sanctions for noncompliance. OPWDD also acknowledged that it has a regionally uneven service system; the preferences of individual service provider organizations in various communities, rather than the needs and preferences of the individuals who live there, govern the kinds of

services that are available, and providers that currently offer only segregated programs may need to be forced to offer integrated alternatives as well. The agency agreed that blanket "house rules" in group homes that restrict individual rights are "impermissible," and that any individual restrictions in behavior plans may not be applied unless more positive behavioral supports have been tried first and shown to have failed.

OPWDD reactivated its Regulatory Reform Workgroup to address these issues over the summer, and STIC Executive Director Maria Dibble was heavily involved in this process. At press time, the agency was working on a brief "administrative memo" about new HCBS requirements that will be sent to service providers, and a detailed review protocol that OPWDD will use to assess whether group home providers are in compliance with the new federal HCBS regulations. Actual revised state regulations will come later.



## A Shot across the Bow

The memo is a “shot across the bow” for provider organizations, making clear that big changes are required and those organizations need to start thinking about how they will comply right now. We’ve seen a second draft of the memo that looks good. It hits hard on the most immediately important issues, including two that STIC has identified as especially problematic in group homes: not enough staff to ensure that people can really have individualized activity schedules in the community (the notorious tendency to offer residents a choice of “van ride,” “group bowling,” or “stay home” as the only evening or weekend activity options); and “house rules” established for the convenience of staff or to suit their personal biases (including rules forbidding overnight visitors, private telephone access, and access to preferred foods at any time). The agency will begin using the review protocol this fall to inspect individual group homes across the state. The early version we’ve seen also focuses heavily on those two big issues. It also addresses whether staff treat residents with respect instead of patronizing condescension, and whether residents have true privacy. It inquires whether provider organizations have adopted a recognized person-centered planning model but does not adequately address the new requirement that people must direct their planning process to the extent of their capability. And while it specifies that most information must be collected by interviewing or observing residents directly, it does not explain how house staff will be prevented from influencing residents’ responses.

OPWDD is not ignoring the new requirements for non-residential HCB settings, but because CMS has said it will issue “guidance” on that topic at a later time, the agency is not proposing anything concrete right now. It did request more public comments on its plan to increase integrated employment, including how to assist sheltered workshops to convert to programs that would comply with those requirements. That gave us an opportunity to restate our view that those requirements will prohibit use of HCBS waiver funds for “enclave” or “mobile work group” supported employment models, and for so-called “affirmative businesses,” and that the state needs to provide whatever assistance is necessary,

including purchasing and reselling buildings, to quietly usher sheltered workshop operators out of existence completely.

## Let’s Make a Video!

The workgroup was also shaping a policy for the use of video surveillance cameras in residential programs. OPWDD has been pressured by some people, including Michael Carey, the father of a boy who was killed by two OPWDD employees while riding in an agency van in 2007 (the “Jonathan” in Jonathan’s Law), to install such cameras to detect abuse. Almost everyone thinks this is a terrible idea. First, it is not possible either to completely hide the existence of such cameras, or to have them everywhere, so therefore they will not prevent abuse but only relocate it to places outside the view of the cameras. Second, people are supposed to have privacy in their homes, and the cameras will inevitably themselves be abused to spy on, and control, the people who live in those facilities. Third, the staff will use them as an excuse for not doing their jobs, which are supposed to include a lot of direct personal interaction with the residents, and provider agencies will use them as an excuse for hiring fewer staff, because one worker can just sit in an office and stare at a bank of video monitors to ensure “safety.” OPWDD clearly heard that there is no support for use of cameras among actual people with disabilities, and the agency staff themselves aren’t too keen on it. They say they will issue some sort of policy on this topic, but we don’t know what it will contain. The draft review protocol for group homes clearly defines surveillance cameras as undesirable though.

## Let’s Make a Plan!

OPWDD’s response on the person-centered planning issue is still not adequate; our impression is that the officials involved are having a hard time understanding the problem. The regulations are very clear: they say the individual WILL direct the process to the extent they are capable, and will receive assistance as necessary to do so. They also say that the individual will choose who does, and does not, participate in the process. OPWDD officials keep dodging this; they say the person “can” direct the process unless they “choose” not to; they say the person is “at the center” of the process; they say that

“input” from the person is required; they say the person “can have people of their choice” involved. We have to keep repeating that **this is how it should work**: the individual is given the opportunity to run the process at every step. If they demonstrate a need for help during the attempt, then it is provided. That includes putting together, or approving, a list of the people who will be involved, and nobody who is not on that list will be invited to attend meetings, provide input, or participate if they show up uninvited. The individual is expected to chair planning meetings, and will do so even if s/he needs coaching for the process. The individual is expected to set the priorities for discussion and service planning, and issues not of interest to the individual will not be part of the plan. Individuals who are non-verbal will be extensively observed in a variety of settings prior to any service planning in an effort to understand their interests and preferences, and their likes and dislikes, as to people, places, and activities. These observations will then govern the service coordinator as s/he conducts the planning process, with the individual present. This will require much more time than the typical service coordination caseload allows, a problem that OPWDD appears to acknowledge but offers no solution.

OPWDD also does not appear to have an adequate process for ensuring, as required by the new regulations, that every person receiving HCBS services gets to make the following choices:

Whether to live in an institutional setting OR get HCB services, AND which service coordination agency to use from among ALL of the service coordination agencies in the region, AND which services to use from among ALL of the defined service options, AND which service PROVIDERS to use from among ALL of the available providers of services.

The agency’s written procedures on this are vague, and they do not require proof that the individual made informed choices on each of these points. A signature above a line that says, “I made an informed choice,” on a form that only includes the institution vs waiver question, and the name of a single service coordination agency, is not proof. Until OPWDD figures out how to comply with the new requirement that service coordination and direct services cannot be provided to the same person by the same

agency, people need to be given written lists of ALL of the available *services*, *service coordination providers*, and *direct service providers* by somebody who is NOT ON ANY OF THOSE LISTS (in other words, an impartial “enrollment broker”), and sign them in the presence of that person, in order to prove that there was no conflict of interest, “marketing,” self-referral, or coercion involved in the process of making choices.

### **Mi Casa is NOT Su Casa!**

Another aspect of the new HCBS regulations that OPWDD does not seem to understand, or is deliberately resisting, is the requirement that people be able to choose their preferred place to live, and to receive the services and supports they need in that place, no matter how intensive their needs are.

The agency is still holding onto its separate “supervised” and “supported” IRA concepts. “Supervised IRAs” are traditional group homes under the control of staff. “Supported IRAs” can be similar to what people call “supported apartments,” where you’re more or less in charge and staff come in and out as needed. OPWDD says if you need more than about 3 hours of residential support daily, you can’t live in a supported IRA, so if you don’t own or rent your own home, you’ll be stuck in a group home with people looking over your shoulder 24/7. OPWDD statements suggest that you can seek “alternative services,” including a live-in caregiver or “paid neighbor” as well as more traditional “residential habilitation” options, but those first require you to have your own place to live. This isn’t always feasible, and the new HCBS regulations clearly say that one of the choices you have to be offered is a “provider-owned or –controlled setting” where you can live alone or with one housemate. So you should be able to live alone or with your significant other in an apartment owned by the service provider, with any amount of paid support up to 24/7 there if necessary, or in your own home, with the same amount of paid support, as you choose.

The agency also continues to endorse the concept that if you live in a provider-owned or –operated residence and your needs change, whether behavioral or physical, that provider can throw you out of the house—and potentially into a more segregated institutional setting—rather than be required to adjust your services and supports to meet your individual needs.

We will keep trying to get OPWDD to explicitly acknowledge that its current approach to these issues is wrong and must be changed.

### **Questions, Questions, and More Questions**

OPWDD also tried to answer some questions commenters posed about the new waiver.

On the topic of *mandatory managed care*, the agency confirmed our speculations: New York State still intends that all disability services, including those provided by OPWDD, eventually will be delivered through managed care systems. However, OPWDD did not think CMS was ready to digest both the new DISCO model and mandatory managed care at the same time. Therefore it is only proposing a two-year renewal of the existing HCBS waiver right now. That renewal is supposed to take effect on October 1 of this year—if CMS approves it by then, which is not likely, since at press time in late August, OPWDD hadn’t yet submitted it. For the foreseeable future, DISCO enrollment will remain voluntary, and is now projected to begin sometime in the fall of 2015. The unstated implication is that CMS may never approve a mandatory managed care system for OPWDD, depending on how well or badly the agency’s other reform efforts turn out.

OPWDD has heard many complaints about its *“Front Door”* system for bringing in new consumers or providing them with new services. It has ascribed most of the problems to delays in the processes of getting people approved for Medicaid, then getting them approved for the HCBS waiver, then getting a person-centered plan written and approved, and then, finally, getting services delivered. The agency has promised several changes to speed up these processes, and also says it will retrain its staff. We’ll see how that goes.

One point not addressed is the need for simple *individualized supervision services*. We think that such services can be offered to those who need it very quickly, without a lot of assessment or planning, and that they should be available to people facing immediate service gaps, such as people aging out of school, so they won’t be dumped into segregated congregate day programs. OPWDD still refuses to offer this as a waiver service, even though the state’s HCBS waiver for people with brain injuries has successfully done so. We will continue to push this issue; this service needs to be available, not only to address service

gaps, but so that people won’t have to spend every hour of their waking lives doing “constructive goal-oriented” work.

On the questions related to *self-direction*, the response was still somewhat confusing. OPWDD clarified that not only Community Habilitation, but also Supported Employment and Respite services can be self-directed according to the new, simple “agency with choice” model that STIC’s habilitation programs have always followed. That is, you can choose who works with you (if the person meets certain minimum qualifications, and your choices are not based on illegal discrimination), schedule your service hours, and train and supervise your worker(s). However, this model doesn’t offer budgetary control. For that, you still have to become involved in what used to be called the CSS program. You will need a formalized circle of support that accepts responsibility for service plan, budget development, and oversight. You will have a Fiscal Intermediary (FI) that handles the usual billing and payment processes, but you can choose to take on some other tasks involving staff recruitment, formal training, and management that some CSS FIs now handle. The new “Individual Directed Goods and Services” (IDGS) waiver service category will not be capped at \$5,000 annually as initially proposed; OPWDD is trying to negotiate a cap somewhere around \$30,000. IDGS can cover transportation costs, though vehicle purchasing or leasing will not be allowed. “Live-in Caregiver” is an available waiver service today, though only for those who choose CSS-style self-direction. But the waiver renewal application says that the “service delivery methods” for this service will include both “participant-directed” and “provider managed.” IDGS is listed only as “participant-directed” in the application, so we hope this means you will be able to have a live-in caregiver without going the full circle-of-support/budgetary control route. Some information seems to suggest that it may be easier to use a Support Broker to do clerical recordkeeping and reporting than it has been, but we aren’t sure about that. It is also still not clear whether the new system, which requires discrete budget and hours allocations, and more frequent billing, for habilitation and respite services, will be as flexible as the old system in terms of staff scheduling.





## STIC's Honor Roll

Each year STIC recognizes a select group of people and organizations that truly exemplify excellence in supporting disability rights, STIC as an agency, or people with disabilities as individuals. There are many people and organizations in our community that do a good job in these areas, and we are grateful to them. The people below deserve special recognition because they have far surpassed "doing a good job"; they are our role models.

We honored them with a luncheon back in June. They have our eternal gratitude, and here we say it again. THANK YOU!

### OUTSTANDING AGENCY SUPPORT

#### James and Pamela Vincens

This couple has tirelessly supported STIC with funds and participation for countless years.

### OUTSTANDING CONSUMER ACHIEVEMENT

#### Allan Walley

People with disabilities are often called "courageous" by nondisabled people simply for existing and doing what everybody else does. That's not courage. Allan exemplifies courage. He has faced the most imposing barriers imaginable to organize his own life, defend others with disabilities from bigotry and discrimination, get out of an institution, creatively design his own supports, and lead by example, with dignity, in the community.

### OUTSTANDING CONSUMER SUPPORT

#### Emily Gaudinier, General Manager, TR Events of Binghamton

Emily and her organization have consistently used their resources to benefit children with dis-

abilities and their families by helping with sensory-friendly Bounce House events, providing new social experiences for children, and offering discounts and meeting space for families.

#### Karry Gorman, Manager, Cost Cutters Salon

Karry has made a specialty of cutting hair for children with severe sensory issues. By going slowly, carefully explaining what is happening, and accommodating individual needs, she turns what could be a very stressful event into a positive experience.

#### Ann Marie Peterson, Deputy Director, Broome DDRO

Ann Marie has consistently been extremely supportive of the specific needs of individual consumers, helpful with issues related to movement from institutional settings to integrated community living in general, and highly responsive on issues surrounding the impending closure of Broome Developmental Center.

#### Trudi Zayac, Broome County Urban League

Trudi went well beyond the call of duty to provide support to a particular individual with disabilities, helping the person to overcome several problems and succeed in a work-study placement, and now plans to hire the person permanently.

### OUTSTANDING FUNDRAISING SUPPORT

#### International Brotherhood of Electrical Workers Local 325 (Tom Spicer)

Tom and his IBEW local have provided lots of in-kind help, both in materials and labor, for our Haunted Halls of Horror fundraiser, as well as a cash sponsorship, since the event's inception. We couldn't keep the lights on (and flickering spookily) without them.

## Plumbers & Pipe Fitters Local 112 (James G. Rounds)

These folks have been longstanding, consistent sponsors of STIC's fundraising events, both the Haunted Halls and our holiday light festival.

### OUTSTANDING LEGISLATIVE SUPPORT

#### NYS Assembly Member Richard Gottfried

Assemblymember Gottfried of Manhattan, who chairs his chamber's Committee on Health, has been a highly consistent and influential supporter of legislation that promotes community integration for people with disabilities. (See page 6 for details.)

### OUTSTANDING SYSTEMS ADVOCACY

#### Bruce Darling and Rochester ADAPT

Bruce is New York State's most well-known and fearless disability activist, on both local and national scenes. He and the dozens of ADAPT-ers he regularly mobilizes have made the difference on many issues over the years, and today they are tirelessly fighting for the Community First Choice option in our state. Bruce really is The Boss!

#### Steve Holmes, Administrative Director Self Advocacy Association of New York

Steve has stepped up to the plate in a big way to combat bigotry against people with developmental disabilities and support the goal of closing institutions.

#### Bryan O'Malley, Executive Director Consumer Directed Personal Assistance Association of New York State

Bryan has been a highly effective advocate, both publicly and behind the scenes, in support of Community First Choice, "aid continuing" during managed long-term care appeals, and various CDPA issues.

### OUTSTANDING VOLUNTEER SUPPORT

#### Dwight Adolf

Dwight has done excellent work with airbrush makeup for the scare-actors in our Haunted Halls fundraiser.

#### Neil Hendrickson

Neil is an exemplary all-around Haunted Halls volunteer, helping to build and set scenes and create artwork. He also scared more than his share of our visitors as "The Butcher."

#### Rick, Shirley & Chris Wheaton

This family has been an outstanding resource to the Haunted Halls, providing security services, scare-acting, and other performances.



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.





## **“WEEN”: The Fifth!**

by Bill Bartlow

Since our first year, when we began with 4,000 square feet and 800 attendees, we have grown to over 15,000 square feet indoors. We have added outdoor music with laser light special effects, live fire spinning and a juggling show, and our scary, staggering zombies. In 2013, 3,000 ticketed visitors enjoyed our Haunted Halls of Horror, Binghamton's premier haunted attraction. What a year! The community support is ever increasing as evidenced by our roster of volunteers participating in the event. Last year nine performances were staffed by a total of 148 scare-actors and support personnel.

The entire extravaganza would not be possible without the incredibly generous support of our community sponsors, which along with ticket sales have raised over \$98,000, helping STIC continue in its efforts to assist those with disabilities. We wish to extend our profound thanks and congratulations to all those who have made this amazing accomplishment a reality.

## **Haunted Halls of Horror**

Friday & Saturday 6:30 – 9:30

October 10, 11, 17, 18, 24, 25, 31 & Nov 1

Matinees 4:00 – 6:00

October 18 & 25

You don't have to wait in line: Get a VIP pass

Advance ticketing available on-line & at STIC

Only \$10 for admission

STIC

135 E. Frederick St., Binghamton

**For Information Call**  
(607) 724-2111 (voice/TTY)

We're busy with preparations for 2014's show.

Visit us on line at [www.hhh-stic.com](http://www.hhh-stic.com) or Google "Haunted Halls of Horror." We're high tech: even online ticket purchases and credit cards are accepted. Animatronics, synchronized laser, and motion-tripped special effects are becoming more sophisticated, and new attractions keep the Haunted Halls of Horror fresh every year.

Here's that Daunting Question, the one that each hesitating visitor is asks: do you dare? And: Do You dare?

There will be time to turn back and descend the stair, time to return to your safe zone before becoming immersed in our den of the macabre. Brace yourself. Hold on to your friends. It takes time to prepare to meet the faces and scenes that you'll encounter. Our mission is to startle, shock, and induce real fear and panic. Some have curled up in a quivering ball on the floor. Some have run screaming for the exit. The things that are housed in the deepest part of your subconscious will burble to the surface and freeze you in your tracks. Or worse.

This is make-believe, of course. Go with it. But be warned this is not for the impressionable young. You know your own kids and what they can take, but this haunt is not recommended for the very young and sensitive. Monster protection will be available, but if our haunt might is too frightening, the Kiddies' Show is upstairs. Age appropriate seasonal fun will be available there, provided by ECDC and PTAC.

### **There's Magic in the Night: Come See the Show!**

#### **'Ween 2014, Featuring:**

"Christine: The Cadaver Coach": Your Final Ride Awaits. A New Attraction This Year: There are some girls one just doesn't recover from. They are paralyzing, arresting classic elegant beauties, head turners, drawing everyone's attention as they pass. This long dark lanky lady is dressed up for the evening

and wants to take you for a ride: Your Last Ride.

Eric Carpenter's intricately carved collection of Jack-o-Lanterns. Welcome Witch Way. Directions from Buckey. The Ticket Terminal. Major General Mayhem and Dozer Central. Incarcerated Zombie. The Helevator to Zombie world, A post-apocalyptic treat.

Body Baggage Barrage. Play with the Clowns in Barker Bob's Psycho circus. "Ring-Around-the-Rosie" with the Creepy Kids in the Toy Box. Be the cut of the day at the Fresh Chops Butcher Shop. Hang out at the Head Shed. You've got an appointment at the Body Boutique with Dr. Dementia. Rearrange your thinking: Brain Salad Surgery. Crawl the Catcombs & Cemetery. Duck through the Terror Tunnel. Slithering slimly swamp creatures & Minions of the Mirkwood send you over the bridge and out to ease back into reality. Maybe one more.. exit. Followed by our outdoor entertainment, weather permitting: Carnevil 5

## **Deaf Services is Back!**

by Heather Shaffer

Hi readers! I want to introduce myself as the new Deaf Services Coordinator here at Southern Tier Independence Center, which I joined in late June.

I'm Deaf and was mainstreamed my entire life. I have two boys who have entirely changed my outlook on life. I recently graduated from Broome Community College, which has excellent services for Deaf students.

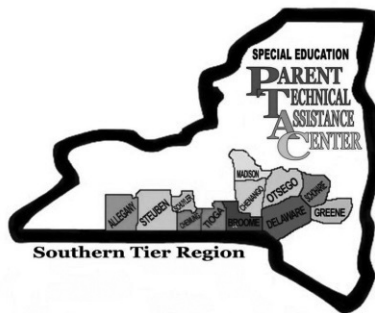
The mission of the Deaf Services program is to advocate for deaf communities in accessibility, promote self-determination, self-advocacy for rights to accommodations, independence, and celebration of American Sign Language (ASL) and Deaf pride among diverse Deaf communities.

The program supports this mission by providing services that give Deaf people the ability and confidence to empower themselves and live independently with full access to the

rights, privileges, and opportunities available to the general public.

Services include community education, peer counseling, advocacy, independent living skills training, communication assistance, and information and referral.

I look forward to being a strong advocate for the Deaf communities and a peer counselor, working with variety of people with hearing loss, including Deaf, hard-of-hearing, and late-deafened.



## Parent Technical Assistance Center (PTAC)

by Shannon Smith

PTAC is committed to providing parents and families of children ages 3-21 with special needs information and resources needed to navigate and work collaboratively in the educational system.

### What we do:

- Provide families with information regarding the special education CPSE, CSE process including referrals, evaluations, and transitions.
- Enhance families' skills and abilities to effectively advocate for their child's needs and work cohesively with the educational system.
- Educate families on their rights and options regarding: special education mediation, resolution sessions, due process, impartial hearings and appeals, state complaints, and other related training topics.
- Trainings for professionals and staff within the educational setting, provided upon request.

### Counties we serve: Services are provided to:

- Allegany • Delaware • Schoharie
- Broome • Greene • Schuyler
- Chemung • Madison • Steuben
- Chenango • Otsego • Tioga

### Where we are located:

We travel throughout the 12 counties, but our home base is located at the Southern Tier Independence Center in Binghamton, NY.

All services are free and confidential.

## Accessibility Advocacy Committee (ASAC)

by Jessica Hinton

The ASAC committee is an advocacy group at STIC that works with local business to help make our community more accessible. We focus on issues of parking, building access, accessible bathrooms and much more. We have been a committee for about two years now and have been working on several local issues on accessibility.

ASAC would like to recognize and thank the businesses that have made efforts to become more accessible.

Owego Free Academy – for their fully accessible pool

American Family Fitness – for their re-paved and marked parking lot

Down to Earth – for their ramp for the doorway

Number 5 – for their re-striped parking lot

Visions Credit Union - Upper Court Street – for their re-striped parking lot

We applaud your efforts and would like you to serve as examples to other businesses in the area. Thank you on behalf of people of all abilities.

## Annual Campaign Marches On

STIC extends our thanks to the following donors to our Annual Campaign who agreed to let us publish their names. If you haven't sent in your gift yet, there's still time!

THANK YOU!

American Legion Post 80

Bear and Mer Boel

Sharon DiGennaro

Terry O'Connell



## Addressing Student Anxiety

*A Forum for Parents and School Personnel*

**What:** FREE KICK-OFF EVENT for Southern Tier Special Education Task Force

**When:** October 2, 2014, 9 AM - 12 Noon

Registration from 8:00 - 8:45 am

**Where:** Southern Tier Independence Center

135 East Frederick Street,  
Binghamton, NY 13904

Schools are seeing an explosion of anxiety in their students of all ages. Experienced professionals will share essential information about anxiety, its impact on students, and effective strategies for intervention by parents and educational professionals.

### Guest Speakers/Panelists:

#### Jim Lucenti:

M.A. School Psychology, C.A.S.; Supervisor of Instructional Programs, Broome-Tioga BOCES; prior experience includes Director of Special Education, School Psychologist, and Behavioral Specialist.

#### Kathryn Moulton:

Family Psychiatric and Mental Health Nurse-Practitioner, Child and Adolescent Behavioral Health Center (CABHC) at Greater Binghamton Health Center. Doctoral candidate in Nursing Practices at School of Nursing at SUNY Upstate Medical Center.

#### Michael Rozalski:

Ph.D., Associate Professor, Binghamton University. Current research interests include classroom and school-wide behavior supports, legal issues related to students with disabilities, and violence prevention.

#### Rachel Schwartz:

LMSW. Has worked with children with developmental disabilities and their families in home, school, and community settings for over 15 years, offering understanding and supports for wide array of challenging behaviors.

Panel Moderator:

**Victoria Xlander:** B.S. Ed., M.S. Ed., C.A.S., Director of Special Education Services, M-E CSD.

**Please RSVP by 9/25/2014 to:**

**advocate@stic-cil.org**

**or by mail to:**

**Sue Ruff**

**STIC**

**135 E. Frederick St.**

**Binghamton, NY 13904**

The Southern Tier Special Education Task Force is a regional affiliate of the NYS Special Education Task Force.

# SELF HELP

## **VOTE! Now More than Ever**

by Sue Ruff

On September 23, STIC is joining with several local organizations to participate in a National Day for Voter Registration.

STIC, Southern Tier ADAPT, the Disability Vote Network, the League of Women Voters of Broome and Tioga Counties, the YMCA, Binghamton University Civic Engagement, and Literacy Volunteers are all participating. Voters can come to STIC's Helen Keller Room from 9-5 that day to:

- Complete a new voter registration form
- Complete a registration form with change of address or change in party affiliation
- Fill out an application for an absentee ballot
- Join the Statewide Disability Vote Network

The Disability Vote Network, housed at the center for Disability Rights in Rochester, is a project of the New York Association on Independent Living. Their goal is to sign up at least 5000 voters with disabilities over the next three years to create a voting bloc. Keeping voters current on disability issues, needs, and legislation, the Disability Vote Network hopes to harness the efforts of a large group of dedicated people who will send emails, make calls, and support changes in Albany that will affect our rights and freedoms.

Many bills we supported this past year didn't get passed (see page 4), and some, like the Lever Bill, passed despite our advocacy efforts to stop it. The Lever Bill disenfranchises voters with disabilities who need the new ballot marking devices in order to vote independently. While it won't affect voters in our region of the state (we got rid of the lever machines), it will hurt voters with disabilities in several counties downstate who want to vote in school, fire district, and other specific local elections.

### **Election Day is November 4, 2014.**

This is an important election year as members of the US House of Representatives, NY Governor, State Attorney General, State Comptroller, State Senators, State Assembly Members, Supreme Court Justice, County Sheriff, Family Court Judge, Broome County Legislators, Binghamton City Judges, and many local town supervisors, clerks, council members, and highway superintendents will all be on the ballot. The people we elect for state office will be the people we rely on next year for implementation of the Community First Choice option as well as other policies that directly affect our lives. Locally, Broome County legislators will decide the fate of local transit services as well as other community services. It is important to VOTE!

In addition, there are three statewide proposals for voters to consider: creation of an independent panel to draw district lines, allowing electronic versions of bills as opposed to paper copies, and a bond issue that would fund technology updating at schools.

### **Registration Deadline Information:**

- Last day to register for 2014 General election: **October 10, 2014**
- Last day for the Board of Elections to receive new registrations: **October 15, 2014** postmarked by **October 10, 2014**

- Last day to change your address: **October 15, 2014**

- Last day to change your party enrollment for it to be effective for 2015 Primary: **October 10, 2014**

Please note: as long as you will be 18 by election day (11/4/14) you can register to vote for this election.

The Board of Elections has openings for poll workers. If you are interested in working as a poll worker for the upcoming elections, please contact their office at (607) 778-2172 for more information.

We hope to see many people on September 23 and November 4.

## **Protect Your Rights!**

Do you live in a developmental center, intensive treatment unit, multiple disability unit, or ICF? If so, your rights have been threatened by the "deal" recently agreed to by Governor Cuomo, Senator Libous, Assemblymember Lupardo, and public employee unions.

You have the right to control your service plan, and to decide who does, and does not, take part in your service and discharge planning. You have the right to control who can see information about you. And you have the right to receive services in the most integrated settings appropriate to your needs. **DON'T GIVE UP YOUR RIGHTS!**

**DO NOT SIGN ANYTHING** until your advocate has looked it over.

There is **NO** deadline for signing papers; nothing bad will happen because you want to wait until your advocate has read them.

**YOU DO NOT HAVE TO ALLOW** county mental health or social services staff to be given your name or any other information about you as you work on your discharge plan.

**Hey!**  
**Did you find all the**  
**Springsteen references**  
**in this issue?**

**If so:**  
**Um.. no prizes or anything. It's**  
**just cool...**



YOU DO NOT HAVE TO ALLOW county mental health or social services staff to come to your meetings unless you want services from those agencies.

If your admission is “Voluntary”, DO NOT LET THEM CHANGE IT to “Involuntary” for any reason. It won’t get you better services and it won’t get you released sooner.

YOU DO NOT HAVE TO BE RELEASED TO A GROUP HOME. If you want services in your own home or apartment, you can get them. It takes longer but it can happen.

If you are unsure about any of this, talk to your advocate or lawyer.

STIC can answer your questions or be your advocate. Call us! 724-2111 (voice/TTY)

REMEMBER – DON’T SIGN ANYTHING until your advocate has looked at it.

## What is AT?

by Kevin Jackowski

As director of the TRAIID AT loan closet, I am often asked, what does AT mean?

AT is short for Assistive Technology. AT is commonly defined as an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

This is a deliberately broad definition, as AT includes a wide range of items, devices, and equipment. AT includes low-tech items such as large-handle eating utensils. AT also includes medium-tech devices like a handheld video magnifier, an electronic version of a magnifying glass. And AT includes high-tech equipment such as a computer mouse that is controlled by head movement.

Like the definition of AT, the TRAIID AT loan closet includes a broad range of items, devices and equipment available for individuals of all ages with disabilities, their family members, service providers, employers, and educators. Contact us to see what is available and for more details about our loan program.

[traid@stic-cil.org](mailto:traid@stic-cil.org)

(607) 724-2111 (voice/TTY) x214



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## 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.**

- |                                     |      |  |           |
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**MAIL TO:** Southern Tier Independence Center, Inc.  
135 E. Frederick St.  
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Name \_\_\_\_\_

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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

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Maria Dibble

### ASSISTANT DIRECTOR

Jennifer Watson

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