

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

# AccessAbility

Fall 2016  
Number 124



## Fluffy

## Editorial

by

Maria Dibble

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When I read editorials from other newsletters, I'm sometimes put in mind of a soft fuzzy rabbit I had as a child, a very short-lived pet named "Fluffy", which left about as much impression on my life as those aforementioned editorials do.

They are comfortable and safe and tell us, for example, about how lovely the spring weather is as the seasons change and we all move forward hand-in-hand.... or about the "wonderful picnic we held for people with disabilities". The wonderful segregated picnic. About the only thing you could call even close to integrated was that they ate the same hotdogs and salads, and drank the same soft drinks that other picnics consume. They all stayed in the same space for two hours, didn't get to really experience the park because they might get hurt, and in the end, had a very sterile experience.

You might also see an article that vaguely mentions that regulations have been released by a state agency and comments are being sought,

but in most cases you get little else. Certainly, not a strong opinion or a harsh word that might offend someone, be in opposition to someone else's opinion, or potentially threaten funding. The latter is a real possibility, which STIC has experienced. We lost a program that provided about \$300,000 in annual revenue years ago, primarily because a state-level administrator was angry about our continuous systems advocacy. I was furious. I was sorry. But I still felt that the integrity of the agency, and the needs and rights of the people we served, were more important in the long run, even though the cut was painful.

And why would we expect any challenges to the status quo? We teach our children that "everyone is a winner", and every child gets a prize for a contest, because they might be upset if they lose, or even worse, the parents might get angry.

We can't even teach about the real world any more, for fear of offending. Someone I know

who teaches a college-level course said he must warn the students of any violence, or mention of anything that might be upsetting, and let them opt out, before he goes on to present the facts.

With this kind of reasoning in our history classes, we'll raise a generation of holocaust deniers, because we must not risk upsetting the students with information about the horrific Nazi death camps. Those students *should* be upset, because how do we ever learn not to repeat our mistakes if we don't ingrain into people's minds that those things must never ever happen again?

# AccessAbility

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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.

Parents these days call college professors to plead for a better grade for their child, because if they get a bad grade it might have an impact on their future job prospects. If my parents had ever called a professor, I would have been mortified; I would have wished I could just melt into the ground, never to be seen again. My parents would have said, "Did you do your best? If so, you need to try even harder."

Soft-and-fluffy offers "protection" and insulation from reality, but it also robs people of a basic human right, the right to make a mistake and learn from it. It's not just a right, it's a necessity. We learn from adversity, from struggle, from dealing with small slights and

major insults, just as our bodies grow stronger from pushing ourselves through pain to run long distances or lift heavy weights. Sometimes that's the only way we can learn. Without those experiences, we do not grow and we do not gain wisdom. Instead, we remain dependent on overseers and rescuers to provide constant reassurance and direction.

I wonder what the next generation will learn, and I wonder how they'll grow if they're never allowed to experience the pain of a bad mistake. They might be all warm and fuzzy, but they won't have the knowledge or the fortitude to solve tough problems on the fly, to hunker down and weather a crisis, to perform great deeds, or to change the world.

# THIRTY YEARS OF BEAUTY

by Charlie Kramer

August 16, 2016 made my thirty years of being an employee of STIC. The years have flown past.

Today I would like to look back and forward.

When I started, one of the concerns was that people with disabilities were not somehow "normal". When Maria sent Frank Pennisi and Peer Counselor Connie Head to meet with me, it became a relationship of a lifetime. My views on people were then, and are now, those of seeing individuals, not a diagnosis or a disability. We all have issues of varying seriousness and intensity. This is what makes us human, and sometimes we need someone to be there to really hear us in a non-judgmental way.

STIC's philosophy matches mine in the beauty of believing that each individual knows what is best for them. Yes, sometimes we offer thoughts and suggestions or possibilities without demand. The gift of allow-

ing people to fail, fall down, and make mistakes is showing respect for that individual. We all learn our most valuable lessons from making mistakes.

I have been lucky enough to be at this for this long, and yet each new day brings new insights and learning. I have been able to accompany people with rare and unusual disabilities. There is no greater learning experience.

We have come a long way since the eight employees that were here when I started. We were a small band of people prying open doors and removing barriers—physical, psychological and political. We had to be able to know things about each program and help out. Now we are so big it is too much to know every program and difficult to know all the staff. (I am working on it.)

STIC is the place for comradeship, caring and competence. I am honored to be here, and enjoy each day I get to work here.



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.

[www.stic-cil.org](http://www.stic-cil.org)

# SYSTEMIC MIS-MANAGEMENT

In July, Medicaid advocates issued a groundbreaking report showing that New York's budding Medicaid managed long-term care system is already systematically cutting people's services, threatening their health and independence. The report, *Mis-Managed Care*, was co-sponsored by Medicaid Matters NY, a coalition of over 140 organizations that work to protect and enhance New York's Medicaid system. STIC is a member, and STIC's Health Information Advocate, Elizabeth Berka, played a big role in collecting the information that appears in the report.

The report looked at Medicaid Fair Hearings involving attempted cuts to personal care services by Medicaid managed long-term care plans (MLTCs) from June through December of 2015. There were two key findings. First, the number of such hearings grew by 600% from the beginning to the end of that period, showing that attempted service cuts are increasing rapidly as more people are required to enroll in managed care. Second, when some of the largest MLTCs in New York cut people's personal care services, in over 90% of cases the cuts were overturned if the person challenged them. According to *Crain's Health Pulse*, a respected trade journal, the New York Health Plan Association, a lobbying group for health insurance companies, "defended the practice, saying the state shift to managed care was specifically intended to reduce the cost of treating high-needs patients."

You might read this and say, "But that means the system is working, right? Mistakes happen, and they get corrected." But here's what it really means:

Under managed care, an insurance company gets a standard payment to provide medical services to a person, whether it actually provides them or not. So the fewer services the company provides, the more money it gets to keep for itself—and its well-paid executives, and shareholders if it's a for-profit company.

Federal Medicaid law only allows the provision of "medically necessary" services and supports. Objective evaluations—exams, tests, etc.—are used to decide what is "medically necessary." If a service or treatment is medically necessary, it can't be reduced or eliminated unless the person's needs change in a way that justifies the service change. Under federal Medicaid law, New York's "need" to cut spending is not a legal reason to cut anyone's Medicaid-funded services.

When a MLTC wants to cut a service, it must send a notice explaining the reason for the cuts to the person. The reason can only be either that the person's needs were found to have changed, or that the previous assessment of needs was mistaken. The notice must arrive in time for the person to be able to file an appeal and to request "aid continuing" while the appeal goes forward.

In many of the cases reviewed for the report, the MLTCs did not provide a legally allowable reason for the cuts. As revealed in a lawsuit filed in January of this year, the plans cited wrong interpretations of state regulations, or simply said "a mistake was made" without explaining the mistake (see page 7).

When people requested a Medicaid Fair Hearing to appeal the cuts, they won 64% of the cases because the MLTC didn't bother to show up for the hearing. This suggests that the MLTCs knew their reasons were bogus and were banking on people not appealing their decisions. In another 26% of cases, the hearing actually took place and the MLTC lost.

The MLTCs only won these cases outright **1.2% of the time.**

As for "the system," it only partially works. Typically people have less than a week to file an appeal and request "aid continuing" when they get a notice about a service cut. Sometimes they have to exhaust an "internal appeal" with the insurance company before they can seek a Medicaid Fair Hearing.

Lots of people who depend on these services have cognitive disabilities, such as dementia, and/or limited education and literacy. They have trouble understanding the notices they receive, and may not have anyone who can help them. Many of these people never file an appeal, and we don't really know what happens to them, but we can make a sound educated guess.

Federal law provides that people can ask to have services be continued while they appeal, and that request must be granted. However, in New York the request has to go to a state agen-

cy, which must process it and issue an order to the insurance company to keep paying for the service. That process usually takes much longer than a week, which means it is typical for people to have their essential, health-preserving services deeply cut or completely eliminated for days or even weeks—all for an appeal which they are overwhelmingly likely to win. Meanwhile, people have been forced to spend days in bed, or risked their lives to get out of bed and have fallen and been injured because they had no attendant to help them. In at least one case, the stress of having services cut and trying to get them restored put a woman in the hospital for three days with a heart attack. People may have already died as a result of these practices, and if not, they will if this continues.

This reminds us of *Strouchler v Shah* (*AccessAbility* Winter 2012-13), a suit in which New York City had been routinely cutting personal care for people who needed 24/7 coverage. The reasons cited for the cuts were bogus, and those who appealed them won 97% of the time. The city lost in federal court. Unfortunately, that's not the first time New York State got hauled into court over similar behavior. The landmark *Mayer v Wing* case, which established the medical necessity rule, was argued, and lost, by NY in 1996. Today, the state is transferring the blame to MLTCs, but in the process it is systematically violating federal law, which requires the state to ensure that MLTCs do not do this stuff. The state has

the ability to financially penalize MLTCs that engage in patterns of misbehavior like this, but somehow the state never seems to get around to doing that—or doing anything else that could be effective in preventing abuses before they happen.

All of this adds up to a pattern and practice on the part of New York State that explains why the insurance lobbyists were so indignant.

*Under managed care, an insurance company gets a standard payment to provide medical services to a person, whether it actually provides them or not.*

Regardless of what Governor Cuomo or his spokespeople say about using managed care to "improve" healthcare for people, their intent is to cut healthcare spending. When you're cutting spending, every dollar not spent is a little

victory. When service cuts are overturned, many days, weeks, or months have already passed while those dollars went unspent. It doesn't matter, for Cuomo's purposes, that almost everybody wins on appeal, or that he loses case after case in court. The money wasn't spent, and it will stay unspent. There is no retroactive repayment for services that were never delivered. This goes into his budget calculations, and it fuels his crowing about "bending the Medicaid cost curve."

Now you might ask, "Didn't you say that the state pays the same rate to the MLTC whether it provides the services or not? Then how does the MLTC cutting services save the state money?"

That's a good question, and apologists for managed care like to point that out. The thing is, under federal regulations, the state can't just make up a rate and pay it to MLTCs. The rate has to be based on actual costs and expenditures, and it has to be adjusted annually. So if MLTCs succeed in significantly reducing spending, and

keeping it down, their rates are eventually reduced to match. The evidence nationwide is that managed care doesn't work well for long-term care on either the human side or the financial side, and some states have actually dropped it and returned to "fee for service" Medicaid. But some people just have to hit bottom before they are convinced, and our politicians, after all, are only gambling with the lives of low-income people, many of whom don't vote and all of whom certainly don't make campaign contributions.

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# SCRUTINIZING THE PLAN

New York State is required to produce a plan to explain how its Medicaid-funded community-based services will be changed to comply with new regulations that were issued by the federal government back in March 2014. We've been following this issue for several years (for example, see *AccessAbility* Summer 2014, Spring 2016, Summer 2016).

## Integration for All

The state's Office of People with Developmental Disabilities (OPWDD) serves the largest group of people who use these services, so we've focused mostly on that agency's plans. But there are two other state agencies, the Department of Health (DOH), which administers the TBI and NHTD waivers, and the Office of Children and Family Services (OCFS), with its Bridges to Health waiver, that are immediately affected. Also, new federal managed care regulations issued earlier this year expand the requirement to any community long-term services or supports (LTSS) that the state offers through Medicaid managed care. Since the state is moving to require Medicaid "Managed Care for All," the regulations will apply to just about every community support service for people with disabilities in the state.

So the state has to produce a statewide plan. DOH, NY's official Medicaid Authority, has been given the job. They took a run at it back in March of 2015. The federal Centers for Medicare and Medicaid Services (CMS) called it completely inadequate and told them to try again. DOH published its second try for public comment this summer. The massive document includes the most recent draft of OPWDD's transition plan, along with "plans" from all of the other affected state agencies.

Aside from the OPWDD section, the statewide plan is still lacking in detail, and gives the impression that neither DOH nor any of the other state agencies understands what is required, why it is required, or what really needs to be

done about it. Part of this impression comes from the fact that the "plan" is a hodgepodge of separate forms and narratives prepared by each agency on its own, with little evidence that they communicated with each other about it. The agencies have differing views on what the regulations mean and which programs will be affected. They do not seem to be up to date on the managed care changes and show no inkling of the profound impact they will have.

The new regulations that the plan must address are known as the Home and Community Based Services (HCBS) rules, and they contain three important changes:

1. A new definition of "Home and Community Based Settings," which excludes the use of Medicaid community LTSS funds in most segregated settings, and requires changes to other settings to ensure that they don't interfere with the civil rights of people with disabilities and that they maximize their participation in all aspects of ordinary community life.
2. New Person Centered Planning regulations requiring that all services be provided in response to plans developed through a process that is controlled by the individual and responds fully to that person's preferences for meeting her objectively-determined needs.
3. New conflict of interest rules that separate organizations that inform people about their service options and help them develop their plans, from organizations that provide direct services to those same people. (The conflict of interest rules could have a major impact on many of the people STIC serves. See page 14 for more.)

The new managed care regulations apply these changes to any Medicaid long-term service or support except for a few specific institutional settings, such as hospitals, nursing facilities, developmental centers, or ICFs. Thus, they apply to all of the new support services the state Office of Mental Health is rolling out

through its HARP program, all forms of "supportive housing," any sort of "adult day program," and other residential programs that are not technically nursing facilities, but seem like them, such as "assisted living" programs and "adult homes."

The regulations also prohibit using Medicaid community LTSS funds for any service for people whose residence does not comply with the regulations, even if those services are not provided in that residence. So they may apply to people living in 100%-state-funded OMH "community residences" or Office of Alcohol and Substance Abuse Services (OASAS) "treatment centers."

We don't think DOH, OMH, or other state agency officials see all of this coming.

## The Central Scrutinizer

If a program or facility does not comply with the "settings" rules, the state has two options: It can make plans to close it and transfer people to programs that do comply, or it can try to convince CMS, by presenting evidence in a public process, that despite appearances to the contrary, it does comply, and hope it will "pass." This is called "heightened scrutiny."

Around the US, and especially in states that, unlike New York, long ago did away with their reliance on segregated programs, there are today some programs that use buildings or grounds of old institutions but which are completely integrated. There are no more segregated or "institutional" activities going on in those places, and the people who use the programs have full freedom to come and go and participate in their communities.

CMS has said that ordinarily a place that is on the grounds of or next to a public institution, or has characteristics that tend to isolate people with disabilities from the community or limit their freedom of action or association,

will be in violation of the “settings” rules. The agency offered the “heightened scrutiny” process to this small number of programs that are fully integrated but use facilities that were once segregated. Those programs can provide evidence of full integration to CMS and get an exception.

Unfortunately, people in OPWDD and DOH have misinterpreted this as a license to try to preserve hundreds of programs and facilities that are, and will remain, largely segregated and restrictive. They think they only need to come up with a clever justification to convince the feds to allow those places to stay open. OPWDD is planning to submit every sheltered workshop that applies to be “converted” to a bogus “integrated employment setting,” every so-called “community” ICF (a highly institutional group home) to be “converted” to an IRA (“Individual Residential Alternative,” a somewhat less institutional group home), every cluster of small group homes on a former developmental center site, and oddball institutions and day programs, including those cute “special villages” and “farms” that keep people with disabilities separate from the rest of us, for “heightened scrutiny.” DOH seems to be gearing up to submit several former nursing facilities that were “converted” to “assistive living” but still look and feel like nursing facilities. We don’t think that CMS will buy all of this, but we are concerned that they may be vulnerable to manipulation, or they may simply be overwhelmed by the sheer numbers of applications they will have to review and might let a lot of them slide due to fatigue.

CMS requires that the state publish the names and locations of every site that is submitted for heightened scrutiny, and members of the public must have the opportunity to present their own evidence that these places are segregated, isolating, and/or unnecessarily restrictive and should be closed. Please stay on the lookout for public notices about this, coming up late this year or early in 2017, and be prepared to come out in big numbers to prevent a travesty.

### **Screaming and Kicking**

The new OPWDD draft plan contains some “admissions” and some new statements that we haven’t seen before. We get the impression that the agency was forced by CMS and determined integration advocates to cough these things up against its will. There is also a mixture of pleading and weary defiance in some of the agency’s statements.

For example, there is this: “for NYS OPWDD the requirements of the heightened scrutiny

process ... drives a tremendous workload in staff time and resources for both OPWDD and our providers with uncertain value in our progression towards a more person centered system in full compliance with the intent of the HCBS settings rules,” because “It is unclear what the CMS ‘test’ is for overcoming the presumption that settings in these circumstances are institutional and/or isolating.”

The workload is “tremendous” because the process was never intended to be a loophole to allow a state to get its entire segregated, congregate, restrictive and isolating infrastructure past the new regulations. The state is supposed to close those places and move people elsewhere. As for the “test,” here’s what we told OPWDD:

“We don’t think the CMS ‘test’ is obscure. It is stated very clearly in the regulations, which can easily be summarized as two points:

1. People’s freedoms of legal action, movement, and association must be no more restricted by their circumstances of needing and receiving support services than are those freedoms for people who do not need to receive support services.
2. People’s proximity to, and level of interaction with, nondisabled people who are not paid to serve them, and the amount of time they spend in ordinary places in the community, whether ordinary homes or workplaces, or any sort of public venue, must be the same for people who are receiving support services as they are for people who don’t need or receive support services.

Both points require a comparison between the lives experienced by people with disabilities receiving services and those of people who do not need those kinds of services. If they are not virtually the same in any respect, and if the manner in which necessary services are provided is the reason why they are not the same, then you have a noncompliant situation.”

One of the most striking admissions is this: “While OPWDD recognizes that CMS has not specified a limit on the size of [residential] settings, the national data and OPWDD’s assessment data indicates that people have better outcomes in smaller settings. The agency’s baseline systemic residential assessment data indicates that the smaller the residential

setting size, the higher the degree of overall HCBS settings compliance.”

Because of that, the agency says it will stop developing new group homes with more than four “beds” at some point in 2019, except in special cases in which the OPWDD Commissioner grants an “exception.”

That’s better than nothing, and just a year ago the agency’s response to advocates on this point was that limiting the size of group homes isn’t “feasible.” However, we’re opposed to the granting of any exceptions, and OPWDD has unwittingly provided hard evidence to support us: If, as the agency says, a larger facility will be unable to fully comply with the HCBS rules, then it can’t legally be funded with Medicaid money, so it can’t be allowed, even as an “exception.”

OPWDD also said, “OPWDD recognizes that a range of support is needed in the Supportive IRA model to make this residential option appropriate for more individuals and responsive to individuals as their support needs change.”

We’ve pointed out that the agency needs to stop bundling habilitation services with buildings via group rates. That’s what makes IRAs inflexible: If you’ve already been paid a group rate for a day’s worth of service to cover everybody who lives in an IRA, and one or more of the residents needs something else that the typical short-staffed IRA can’t provide, like being accompanied to a community location to do volunteer work, you can’t bill for it because you’ve already been paid; it’s double-dipping.

If instead you bill hourly for each individual service provided to each individual resident, whether in or out of the residence, then you can add or subtract as much service as each person needs without creating an accounting problem.

OPWDD also says that for people seeking new “day” services, the default will be one-on-one community supports.

Congregate “site-based” services will only be offered if they are justified by the person’s needs and person-centered plan. That is very good news indeed—if the “needs” are objectively assessed by professionals, and not merely the opinions of overprotective relatives.

However, the agency also asked for more time: “We do recognize that much of our facility based programming will need to evolve



to ensure that the majority of supports are provided in everyday community settings rather than a segregated facility. However, for some programs, this evolution will take time beyond March 2019 and will likely result in increased costs ... We ask that CMS understand that a system as complex and large as New York's requires a thoughtful and deliberate transition and more time than the five year deadline allows."

OPWDD is counting from March 2014, when the final regulations were issued. Actually, most of the new regulatory requirements were published in 2012 and everyone with expertise in the field knew they would be finalized, so the agency was actually given seven years, not five, for its transition. We also pointed out that OPWDD and New York have deliberately dragged their feet on adopting best practices for people with developmental disabilities for almost three decades, and if they had not done so, the task they're facing would be easier today. It's only the fact that there is now a deadline, and a cut-off of funds for failing to meet it, that has forced the state to make the changes it is making. They're going to have to really hustle, but we believe they can make it, and we are opposed to any extension of the deadline.

We agree that compliance is going to cost more. But NY is not a poor state by any stretch of the imagination. Further, if OPWDD divests itself of its extremely expensive state-operated direct services, and transfers the funds to lower-cost not-for-profit providers, then even if not-for-profit rates are raised by 25%—which is necessary to solve staff shortages and recruitment and retention problems—there would still be a huge pot of money freed-up to expand services. That's going to have to be part of the solution, and it's time to recognize that reality.

## **Kicking UAS and Other Stories**

As the state brings its Medicaid community support services into compliance with new federal regulations, the Department of Health (DOH) wants to convert the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid waiver programs to managed care by mid-2018. The first task was imposed on the state by the feds. The second is a problem the state created for itself; nobody is forcing New York to adopt Medicaid managed care.

We've covered this issue previously (see *AccessAbility* Winter 2015-16, Spring 2016). Early on, the problem was getting DOH to acknowledge that the specific services available from those waivers, like Home and Com-

munity Support Services (HCSS), Positive Behavioral Intervention and Supports, Home Delivered Meals, Community Integration Counseling, Independent Living Skills Training, and more, are still needed and must be offered by managed care plans. We got most of that ironed out, and over the summer DOH released a draft plan for public comment. The deadline for comment passed as we went to press, but we made an effort to let people know about the opportunity by other means. Now all we can do is summarize the situation.

The main issue with this plan is the same "conflict of interest" issue that the state is confronting with all of its community-based programs that involve "service coordination." DOH originally planned to separate "service coordination" from "care management" and "person centered plan development," which we support (see page 14). But their plan was too vague to pass muster with the feds. We supplied a more detailed version that will work with all of the state's community long-term service and support (LTSS) programs, not just the TBI and NHTD waivers.

Another important issue is the roll-out of the Community First Choice (CFC) option. DOH has proposed simply to run the existing state Personal Care service (which includes CDPA), and the waivers' HCSS option, which provides "cueing and supervision," through the CFC mechanism. However, the state's definitions for those services are very restrictive, and the federal CFC regulations require a lot more. For example, personal care attendants are not allowed to shovel your walk, mow your lawn, feed your pet, or make simple repairs to things that break in the house. The CFC regulations say that you must be able to get attendants to help with any "essential household chores," which includes all of those things and more. So we've asked DOH to supply a clear statement that restrictive lists of tasks that attendants can perform will not apply to personal care-like services delivered through CFC.

A third issue concerns the state's standardized screening tool to determine eligibility for the services. The tool is called UAS. It's a set of questions that a trained nurse-evaluator asks people with disabilities, and the answers add up to a final score. Like any such "functional assessment," the process is subjective. The quality of the results depends on the knowledge, experience, and carefulness of the evaluator. The questions alone are not, and cannot be, specific enough to pinpoint various types of cognitive limitations that people with brain injuries, Alzheimers, and other disabilities have. Many of these people are embarrassed about their limitations and instinctively try to

hide them when questioned by strangers; they don't understand that by doing so, they risk being denied the very services they are asking for. It is recommended that the evaluation be done in the presence of someone who knows the person well. Although evaluators get a lot of training, some of them just don't understand how to observe people as they answer questions, or what to ask their friends or relatives, in order to ensure accurate results. So there are many eligible people who aren't getting served, and more training will not "fix" mediocre evaluators. We asked DOH to require an automatic reassessment for anyone who fails the first one, and that reassessment must be done by evaluators at the highest level of competency.

There are other issues that we told DOH about as well. For example, nearly four years of uncertainty about the future of TBI and NHTD services has caused the loss of service coordinators and direct service providers as agencies stopped hiring or dropped out entirely. There are now long waiting lists of people who have been determined eligible but can't get services because there are no openings with the providers. DOH is required to make sure that the managed care plans have adequate networks of providers to meet the need. That's going to require a lot of attention to the scarcity problem, which needs to be in the plan. Also, the new federal managed care rules require DOH to have a permanent "stakeholder" group, including people who use the services, their representatives, and service providers, to oversee the operation of any managed LTSS program. DOH's plan doesn't say anything about this, and it must. And there's more, but we're out of space here.

We'll stay on top of this issue as it evolves.

## **Federal Legislation Notes**

### **Mental Health Funding**

In July, the House of Representatives passed a version of the so-called "Murphy Bill." There are actually two Murphys, both involved in mental health legislation in Congress. In the House, Congressman Tim Murphy (R-PA), or "bad Murphy," was pushing a bill that would have weakened privacy protections and legal advocacy for people with mental health disabilities, while requiring states to increase the use of forced treatment. His bill became known as the "Murphy Bill." In the Senate, there is also Senator Chris Murphy (D-CT), or "good Murphy," who supports legislation that would increase funding for a variety of mental health services.

The House bill that passed seems to have been merged with a competing bill that would have beefed up mental health parity law enforcement, among other things. The result has bad Murphy's name on it, but none of his bad ideas in it. It's weaker on parity but still would provide increased funding for things like Assertive Community Treatment (ACT), training for police agencies and psychologists, and funding to enable communities to develop crisis response plans and/or "bed registries" for temporary inpatient crisis stabilization. The bill also codifies a change already made to Medicaid regulations that lets states authorize managed care plans to pay for up to 15 days of inpatient mental health services per month in a psychiatric hospital, as an alternative to outpatient crisis services, if those plans choose to do so.

Over in the Senate, good Murphy's bill would do much of the same except for the managed care piece. However, the bill seems to have run aground over an argument with Texas Republican John Cornyn on whether to include a section that would make it easier for people who have a significant mental illness to get guns. At press time there had been no further movement on the bill.

### Disability Integration Act

We reported on this bill last time (*Accessibility* Summer 2016). It takes a radical approach to trying to guarantee that people with disabilities can get necessary supports and services in integrated settings. Its more striking provisions include a requirement that states ensure there is adequate accessible integrated housing for people with low and very low incomes, and a prohibition on states from limiting or eliminating services that are necessary for people to live in the most integrated settings on grounds of cost. Unfortunately, it tries to do all this without changing anything related to Medicaid, which is the only realistically available federal funding source for community supports for people with disabilities.

We didn't expect much to happen with the bill following its introduction by NY Senator Schumer this past January. So we were surprised to learn that it was introduced in the House of Representatives by Representative Chris Gibson (D-NY) in July.

We do not expect this bill to pass. But there is a clear need for federal legislation that reverses the "institutional bias," and it is important to keep ideas for doing that alive in the public eye. If you are interested, the House bill is HR.5689, and the Senate version is S.2427.

# courts watch



### *Caballero v Senior Health Partners: This Again??*

New York State keeps getting hauled into court for violating federal Medicaid law by cutting people's services without having legal reasons or providing adequate advance notice. Here's another one, this time involving managed care.

This class-action suit was filed in January 2016 in federal District Court, on behalf of all people who receive personal care services provided through several Medicaid managed care plans (MCOs), all of which seem to be provided by the same company, or by companies operating under a single holding company. The particulars look awfully familiar:

Olga Caballero, age 67, has diabetes, osteoarthritis, asthma, COPD, depression and dementia. She lives alone, speaks only Spanish, and is illiterate in any language. Due to her disabilities she has an unsteady gait and is at risk of falling, even with her cane, so she needs assistance to do anything involving moving around her apartment. She had been authorized for 35 hours a week of personal care services but the MCO cut her to 8 hours.

Jie Du, age 96, is blind and has dementia and osteoarthritis; she experiences restlessness and agitation. She can't walk without assistance but due to her dementia she sometimes tries; during one such episode she fell and broke her wrist. The MCO cut her personal care from 42 to 30 hours per week.

Alejandra Negron, age 71, has diabetes, COPD, osteoarthritis, asthma, and coronary artery disease. She has severely deformed hands and knees due to arthritis and can't walk without assistance. One of her diabetes medications is a strong diuretic that requires her to use the toilet between 1 and 3 times per hour. The MCO cut her service from 55 to 50 hours, and then to 25 hours a week. She experienced severe anxiety over the cuts that triggered a heart attack and an emergency room visit, followed by 3 days in the hospital.

The plans have a pattern of refusing "time span" services; that is, they won't let attendants stay on the job to provide services that can't be scheduled. They also impose unrealistic limits on services. For example, they allow

assistance for a maximum of 3 trips to the toilet per day, which they will "generously" extend to 6 trips for people who are "incontinent," but they also allocate a small number of minutes per trip, and will only schedule attendants to work those minutes as one block of time. So if you're allocated 10 minutes per toilet trip, and you get three trips per day, they'll schedule your attendant to work a single half hour to help you in the bathroom; they won't have her there throughout the day to help you when you actually need to go.

Now, I apologize to the squeamish, but even 6 bathroom visits per day is no longer enough for my enlarged prostate, and 3 a day was what I did 20 years ago. If I couldn't get to the bathroom on my own, this MCO would expect me to wear a diaper and frequently wet myself even though I am not "incontinent."

Ms. Negron's plan gave her just two hours a week of help to prepare her food—that's 21 meals, or an average of less than 3 minutes per meal. And again, that did not mean that the attendant would actually be there at mealtime.

Federal Medicaid law requires that all medically necessary services be provided, and that services may only be reduced if the person's needs change, or if their needs assessment was in error. The law also does not permit a state to use Medicaid managed care to apply limits to services that it does not place on its non-managed, or "fee for service" Medicaid program.

The plans are required to explain in writing why the services are being changed. The MCOs frequently claimed that the plaintiffs' previous higher numbers of hours were authorized by "mistake," without explaining the mistake.

In several cases people's hours were wrongly cut because the services were classified as "Level I Personal Care." Unfortunately, the plaintiffs' lawyers did a poor job of explaining this.

Level I Personal Care is assistance with tasks that aren't essential for personal hygiene or ambulation. It includes meal preparation and housekeeping, and New York State law limits Level I services to 8 hours. Level I does not include toileting, bathing, dressing, or help to move around; those tasks are called "Level II."

There is no statutory limit on Level II services, which all of the plaintiffs were receiving.

The complaint argues that because the plaintiffs were in MLTC plans, with Level II services authorized, there can be no arbitrary limits placed on any of their personal care services. But that's not true; the 8-hour limit always applies to any Level I service, regardless of how much Level II service a person gets. What the lawyers were trying to say is that the 8-hour Level I limit can't be used as an excuse to cut Level II services, such as toileting.

The plaintiffs also showed that when the MCO nurses assessed people prior to these service cuts, they often recorded that they had "deteriorated" and needed *more* services, yet they also recommended cutting the services to some unrealistic level. Or at least they signed off on those recommendations. Or maybe the recommendations were added after the nurses signed the assessments, which we hope is true, since anything else would be unethical and might result in them losing their licenses to practice.

But that's not all. When you receive a notice of a service change, you have the opportunity to appeal, and to have your services continue unchanged until the appeal process ends. In New York, people win these appeals over 90% of the time (see page 3). But the state office that deals with appeals mishandles them, resulting in people going days or weeks without service. For example, Ms. Caballero's daughter verbally requested an internal appeal from the MCO and asked for aid to continue. The MCO was supposed to communicate with the state to get authorization to continue providing services in such a case, and perhaps it did. Nevertheless, Ms. Caballero's services were cut shortly after her daughter called, and she spent several weeks in bed to avoid falling while her appeal was processed. The plaintiffs showed that the state has a pattern of not promptly authorizing "aid continuing," so it is common for people to go without services they are entitled to receive for days or weeks until the authorization comes through.

Now, everybody makes mistakes, but if an MCO has a pattern of cutting people's services for bogus reasons, the state is supposed to do more than rely on the individual appeals process to rectify the problem. MCOs that have patterns of bad behavior are supposed to be ordered by DOH to stop them, and if they don't, DOH is supposed to take money away from them as a penalty, and if they still don't stop, DOH is supposed to cancel their contracts. But DOH never does this. Not to

mention that DOH itself has a clear pattern of failing to deal with "aid continuing" requests effectively, and never does anything about it. Further, the state has been sued several times for similar issues over the last 20 years, and has lost every single time.

In cases like that, it is the federal Centers for Medicare and Medicaid Services (CMS) that are supposed to step in and sanction the state—but they never do that either.

One wonders what we will have to do to get somebody to enforce the law around here.

### ***Eason v New York State Board of Elections: The Tangled Webs We Weave***

This suit was filed on June 9 of this year in federal District Court in New York City. The plaintiffs charged that websites operated by the Board of Elections and the state's Department of Motor Vehicles (DMV, which issues driver and non-driver ID cards) are inaccessible to blind people who use the JAWS screen-reader software, in violation of the federal Americans with Disabilities Act, among other laws.

The Board of Elections website uses PDF forms to enable people to register to vote or update their information. The PDFs are largely inaccessible. The DMV site has a web-based form system to allow users to enter data without having to deal with a PDF document. It works better than the PDFs, but still not very well.

These sorts of problems are common at all kinds of websites, whether operated by government agencies or private businesses. There isn't anything particularly remarkable about this lawsuit, except for the fact that it was filed at all. Most people don't complain about inaccessible websites, which means they stay inaccessible. So this is a "teaching moment," and we hope that people involved with operating websites at various agencies and businesses will read further.

The complaint says that "the means are readily available to ensure that websites such as the voter websites maintained by Defendants are accessible to individuals with disabilities."

The phrase "readily available" is unfortunate because it doesn't convey that in order to make a website or any computer application fully accessible, the programmers and site developers must be well-versed in the details of how to do it.

Various software vendors, including Adobe, which makes the commonly-used Acrobat software in which most PDF forms are creat-

ed, tout their products as "accessible." People and organizations that want to have accessible websites typically hire web developers to create those sites, and many of those developers don't know anything specific about accessibility, only what the vendors claim. Web developers assume the site they create is "accessible" because software vendors claim their software is "accessible," and that's usually as far as they go.

The reality is that the software can be used to make accessible websites, but only if the developer knows how to design the pages, and tweak the software, specifically to get accessible results.

It's not just about the software; design and page layout is fundamental to accessibility. Certain types of website elements or designs can't be made accessible, or they create confusion for blind users (such as suddenly appearing and disappearing videos or "helpful" pop-ups between paragraphs of text), and they should not be used, no matter how fashionable they may be.

In some cases the software is buggy, which means the developer must apply additional "work-arounds" to make it function properly, as is the case with recent versions of the Adobe software. There are international standards for website accessibility (see <https://www.w3.org/standards/webdesign/accessibility>), lots of on-line training materials, and even a website that can scan your web pages and evaluate their accessibility for free, but a lot of web developers don't know how to use them.

If an organization has used a web developer with expertise in accessibility, the organization still needs to have people who use screen-reading software actually test the finished site to determine how well it works. JAWS is not the only screen-reader software in common use; there is also a product called Window-Eyes, and there is built-in screen-reader software in various Apple devices such as iPhones and iPads, and the website has to work with all of them. Testers need to use all of these products to fully test a site.

Accessibility can't be achieved as an afterthought. It must be an integral part of the planning and execution of every website or software application, and the experts must be involved in every stage of development. Advocates need to insist that accessibility is as necessary and valuable as anything else people expect from a website, and that those who commission websites need to devote an appropriate level of attention to achieving it.

In August, the parties reached a settlement in the case. It provides detailed instructions on what re-design and programming steps will be taken to make the site features accessible. Some of the steps will be easy to do; others will require considerable “behind the scenes” programming. Everything is supposed to be completed by the time you read this. The plaintiffs have a team of “experts” ready to test the results, and we’ll let you know if they pass muster.

### **Michael Anderson v The Franklin Institute: Free Folding Chairs!**

Here’s one we weren’t expecting.

The Franklin Institute is a museum in Pennsylvania. It has exhibit halls as well as movie theaters that show educational films. Michael Anderson uses a wheelchair and has extremely limited movement of any kind. He needs a personal attendant to accompany him everywhere he goes to help steer his electric wheelchair, open doors, and to help him drink, eat, and use restrooms. He even needs the attendant to position his head for him so he can look at something.

Anderson loved the Franklin Institute and he bought an annual membership, which entitled him to admission to all of its exhibits and films. However, he balked when the Institute insisted that his attendant had to pay for admission as well, particularly when Anderson wanted to see a movie in the Institute’s IMAX theater.

Well-loved disability rights attorney Steve Gold argued and won this case in federal court. The legal reasoning is simple: Under the Americans with Disabilities Act (ADA), the Franklin Institute is a “public accommodation.” Public accommodations are required to provide “auxiliary aids or services,” and to modify policies or procedures, when necessary to ensure that people with disabilities can fully access their programs and services, unless doing so would “fundamentally alter” the organization.

A pretty standard requirement that fits into this category is allowing service animals to accompany people to places in the community. Although we wince at comparing attendants to animals, the case turned on this point. A personal attendant is an “auxiliary aid or service,” necessary to enable the person with a disability to use the facility. S/he isn’t there to watch the movie; s/he’s there to help Anderson get into and out of the movie, turn his head to see the movie, help him drink water while at the movie, and use the restroom after the movie.

The Franklin Institute argued that letting attendants in free for movies would impose a substantial cost that might even force it to curtail its programs. They were unable to show any figures to demonstrate this, but their argument hinges on the notion that letting an attendant in for free uses up a seat that could have been paid for. Yet that’s not how the Institute’s theater works. It has a single row, devoid of fixed seats, for people in wheelchairs. If an attendant comes with the person, the attendant is given a folding chair. This empty row, and the folding chairs, are not counted as sellable seats by the theater, which does not use the space for nondisabled customers even when an event is “sold out.” So an attendant never gets a seat that could have been sold. Also, IMAX performances at the Institute are rarely more than 50% full, and attendants accompanying people with disabilities to them are a rarity. The argument that the Institute’s funding and continued operation would be jeopardized by once in a while letting someone in for free to occupy a seat that would never otherwise be used was ridiculous.

The Institute cited federal Department of Justice (DOJ) guidelines in its defense. DOJ issued specific guidelines on event ticket sales that say that providing free tickets or seats is not required by the ADA. However, that guidance only applies to numbered seating at events like football games or stage plays. It was a statement made in passing as the agency explained that people with disabilities who want to buy reserved seats must be allowed to purchase them in contiguous sets so they can sit with their friends if they wish. The Institute’s IMAX theater doesn’t sell numbered seats; people can sit in any open seat—except for people who use wheelchairs, who have to sit in the one seatless row.

This decision clearly applies to all cases where a paid worker accompanies a person with a disability solely for the purpose of providing services to that person. But advocates are suggesting that, for example, habilitation workers should refuse to pay for movie tickets.

They would be justified in doing so, but they are also very likely to have a fight on their hands, and to be thrown out of the theater, or worse, until some organized effort is made to educate the operators of venues that charge

admission. We would like to see suggestions from advocates on ways to make use of this decision that don’t put individuals at risk of getting involved in highly unpleasant confrontations with ticket sellers, especially in light of what happened to Ethan Saylor, a man with Down syndrome who was killed by police because he didn’t want to leave a movie showing for which he did not have a ticket (see *AccessAbility*, Summer 2016).

### **DRNY v Justice Center: All Means All**

We’ve covered this case previously (*AccessAbility* Summer 2015). As we said then, this was an airtight case for Disability Rights New York (DRNY), which is the state’s designated Protection & Advocacy (P&A) oversight agency under federal law. That law grants P&A agencies broad authority to demand that state agencies turn over all kinds of documents, records, and reports that the P&A needs to investigate not only specific instances of abuse or neglect of people with disabilities, but also to determine whether the state agencies conducted their own investigations properly.

DRNY lawfully requested records in four cases in which serious neglect and/or abuse was alleged, and was stonewalled by the New York State Justice Center for the Protection of People with Special Needs, which first delayed providing any response, and then later provided only its own heavily redacted reports, without any of the supporting documentation it had collected.

DRNY sued the Justice Center in federal court in January 2015.



On March 18, 2016, the federal District Court judge denied the Justice Center’s request that the charges be dismissed on the grounds that DRNY failed to state a claim. The judge’s decision is not a final ruling. Rather, he summarized DRNY’s arguments and, assuming, for the moment, that DRNY’s allegations were factual, he showed that the agency does have a case that can go to trial. His brief and succinct decision easily demolished all of the Justice Center’s arguments.

The Justice Center claimed that the word “report” only means final reports written by the Justice Center itself, and appeared to claim that the

word “record” only specifically means “medical record,” among other verbal contortions that remind us of Bill Clinton (“that depends on what the definition of ‘is’ is”). The agency also argued that it was justified in hiding the names of the people who were abused or neglected, as well as the people who may have done the abusing and neglecting, because it is obliged to protect the privacy of people with disabilities.

The plain language of the relevant federal laws, the Protection and Advocacy for People with Mental Illness Act and the Developmental Disabilities Act, clearly says that the Justice Center should have turned over “all records” (that’s A-L-L, “*all*”, meaning every, as in every single document, handwritten note, video or audio tape, and computer file) that the agency had collected in the course of investigating those cases, along with any first draft, preliminary, and/or final reports that anyone, whether the

Justice Center or any state agency that it was investigating, wrote about them, with all of the names and other identifying information intact. Further, anything in state law that allows the Justice Center to limit what information it provides is clearly overridden by the federal laws, according to the basic principle, over 200 years old, that when there’s a conflict between state and federal law, the federal law always wins.

The Justice Center refused to see the writing on the wall and is still fighting the suit. So DRNY will have to go back to court on this, but in the meantime, on July 18, 2016, the agency issued a public response lambasting the Justice Center and demanding that New York State government take action to rein it in. They asked the state legislature to hold hearings on the Justice Center’s conduct, and also that the agency be moved out from under the Governor, who oversees the state agencies

that the Justice Center is supposed to investigate, and be placed under the authority of the Attorney General, a separately-elected, independent state official.

As we’ve reported, the Justice Center initially hired several staff of other state agencies, including OPWDD, who failed in their duty to detect and stop systemic abuse and neglect of individuals in their care and who may have been culpable in those events. The Center’s flat refusal to accept the federal judge’s ruling in the face of easy-to-understand reasoning suggests that the Center is doing whatever it can to delay the final administration of justice on behalf of these people, perhaps long enough to ensure that those responsible are out of reach.

It is difficult to see any other reason for the agency to continue to cling to its absurd parsing of plain language into fantastical structures of farcical meaning.



## STIC’s Honor Roll

Our 2016 Annual Awards Luncheon was held on June 23. Once again we were proud to recognize people who have gone beyond the call of duty to support people with disabilities, demonstrate what can be achieved through grit and determination, or to help STIC accomplish our many goals. Thank you to all!

### COMMITMENT TO COMMUNITY SERVICE

#### **Leonard Hilldale**

*Coats-N-Clothes-4-Kids*

Mr. Hilldale is the founder of Beds 4 Kids and Coats-N-Clothes-4-Kids. When he adopted a family for Christmas and a child’s only request was a bed, he began a program to give them away. At first he donated 200 a month, but due to some regulations, it is now 60 a month. He also opened a 12,000-square-foot warehouse filled with free clothing for people who need it.

a local resource for families that cannot obtain needed supports for their family member through existing programs.

#### **Michelle Roody**

*First Ward Action Council*

Michelle is tremendously helpful in the rental assistance program and works closely with our Housing Specialist. She goes beyond the call of duty to ensure quality service to people with disabilities, working to ensure that even those who have many issues don’t get evicted.

### OUTSTANDING ACCESSIBILITY ACHIEVEMENT

#### **Jennifer O’Brien**

*OurSpace*

Jennifer’s fantastic community project revitalized Recreation Park in Binghamton in a way that put a focus on accessibility for individuals with disabilities. As a result of her efforts, the

#### **Lori Martin**

*Alive with Autism*

Lori is one of the founders of “Alive with Autism,” a support group in the Binghamton area whose mission is to advocate for, support, and encourage individuals and families affected by autism. She collaborates with our Parent Technical Assistance Center (PTAC) to provide

park is now an outstanding example of an inclusive environment for community members and children of all ages.

### OUTSTANDING CONSUMER ACHIEVEMENT

#### **Lisa Loveland**

Lisa showed extraordinary perseverance and assertiveness in her quest to leave Broome Developmental Center and join our community. She encountered and conquered many obstacles as she moved first to a group home and then to her own apartment. She can now live the life she has chosen for herself, rather than the life that others believed she was meant to have.

### OUTSTANDING CONSUMER SUPPORT

#### **Joan Henry-Gates**

*Liberty Resources*

Joan, a Service Coordinator for people in the TBI waiver, is a tremendous advocate who works tirelessly to ensure that people with disabilities achieve their goals of community integration.

#### **Kay Hogan**

Kay is an extraordinary Service Coordinator with an unshakable commitment to people who receive NHTD waiver services. She goes way beyond expectations, working at all hours to meet people’s needs so that they remain in the community with the best quality services possible.

## Rhona Johnson

Corning AIM Independent Living Center

Rhona is an outstanding Service Coordinator who never gives up on people, even those with significant challenges and behavioral issues, including those who have threatened her, because she knows that no one else would serve them if she doesn't. She has a strong belief in community integration, working to ensure that people can get out of nursing homes or avoid going into them.

## Sue Michaels

The Kitchen Store

Sue goes above and beyond with the people with disabilities who visit her small business while working to learn how to cook through STIC's Community Habilitation service. She is very compassionate, and she takes plenty of time to teach kitchen skills in a personalized atmosphere.

## OUTSTANDING VOLUNTEER SUPPORT

### Steven & Shannon Freer

These folks are very active volunteers with our Haunted Halls and Xscapes fundraisers. Among many other things, Steve helped build and portray "Bloody Face" last year, and Shannon sold merchandise and worked on other Haunted Halls tasks.

## Special DSP-ensation

by Maria Dibble

The week of September 11, 2016 was National Direct Service Professionals (DSP) Week. Those dates have passed as this newsletter hits the streets, but the commemoration deserves attention.

DSPs are the core of our Habilitation and Supported Employment services. They work directly with people with disabilities to assist them in achieving their personal and employment goals.

I have found them to be caring, supportive, compassionate individuals who work diligently with and on behalf of the people they serve. Many of their efforts are invisible, because most DSPs aren't based at STIC, but rather work one-on-one with individuals in the community. Their workplace could be a gym, park, store, restaurant, mall, or library. DSPs assist people to learn or improve skills including cooking, cleaning, personal hygiene, sports, socialization, money management, interviewing, finding a job, workplace etiquette, and so much more.

When a person succeeds, so do the DSPs who empowered her. I can't stress enough their hard work, their contributions to people with disabilities, and their value to STIC.

I want each and every DSP who works for STIC to know that you are a crucial part of the work we do. Because of your efforts and dedication, we have an excellent reputation in the community and are in high demand from people with disabilities and their families. Every STIC employee in some way works to ensure that those we serve discover their dreams and make them come true.

Please accept my heartfelt thanks for a job well done.

## Jellicle CAT

by Emily Neville

*"When you fall on your head, do you land on your feet?"* – "Jellicle Songs for Jellicle Cats," from the Broadway musical *Cats*

The Collaboration Action Team (CAT) holds a monthly meeting in which a variety of community agencies come together to discuss and problem-solve challenging case scenarios. The focus is on issues related to individuals with mental health and/or developmental disabilities, with an eye toward learning about what other agencies offer and to see "what else is out there" when the agency isn't sure how else to help or what to do next. Any agency is welcome to join us and discuss/present a scenario on which they are working.

The CAT meeting is held at Southern Tier Independence Center (135 E. Frederick St., Binghamton) on the fourth Tuesday of every month from 11:30 am until 1 pm. Lunch is provided.

Participating members must sign a confidentiality statement, and notes are taken and distributed via a password-protected ZIP file. One or two scenarios are presented, depending on the size of the group and the number of scenarios we receive. We ask that people RSVP by the Friday before the meeting so that we can have a head count for lunch. Also, if you have a scenario you would like to present, let us know by the Friday before the meeting as well.

RSVP to Emily Neville at [emilyn@stic-cil.org](mailto:emilyn@stic-cil.org) or by phone: (607) 724-2111. Upcoming meeting dates: September 27 and October 25.

## In Memoriam: Vitaliy Aleksandrovich Sirotkin

by Maria Dibble

It is with the deepest sorrow that I announce that Vitaliy Aleksandrovich Sirotkin of Owego, NY passed away suddenly on Monday, June 20, 2016. Fondly known as Vito here at STIC, he was our much valued and loved Facilities Manager for eleven years.

Born in Russia on March 19, 1975, he is survived by his beloved wife and five cherished children.

June 20 was a day like all others, busy and hectic, until I heard that Vito had collapsed in the back hallway. Although he received help within three minutes or so, he could not be revived. It was possibly the worst day of my 33 years at STIC.

Vito was a truly fine human being: kind, generous, thoughtful and considerate, with a tremendous sense of humor, which we all experienced in different ways. I've never known anyone with the same capacity for connecting with people of all ages, ethnic backgrounds, disabilities, gender, etc., because he never cared about those things. He used to say, "people are people"—that's all that is important. It wasn't until we were sharing our experiences and thoughts about Vito that I truly realized the depth of his empathy and compassion, the core of who he was. He loved a good practical joke, often carrying them out as well as being on the receiving end. His work ethic was beyond reproach, with a strong sense of responsibility. He'd do anything for anyone, even if it wasn't in his job description. I can't remember how many times I heard him say, "We're all family. You help family. That's all there is to it."

We seldom encounter people of his quality and character. A deeply religious person, he practiced his beliefs, but never preached. He thought that he should be the living example of what he believed, and he was.

While we've perhaps gotten over the initial shock, his voice still sometimes seems to resonate throughout the building, and our grief will be with us for a long while to come. Vito, may you rest in peace. Your memories are alive, which means you will never die for us either.

## In Memoriam: Betsy Giannicchi

by Sheila Loftus

Betsy J. Giannicchi, 57, of Endwell, passed away peacefully at home after a brief courageous battle with cancer with her loving family by her side, on August 4, 2016. Betsy was a valued and beloved employee of Southern Tier Independence Center for five short years. Her hard work, kindness, generosity and high spirits will be greatly missed by her co-workers and friends alike.

Betsy was a devoted single mom with two daughters, and she sometimes had to work

Southern Tier Independence Center's Parent Technical Assistance Center (PTAC) is pleased to announce a FREE training

## **CREATING SUPPORTS FOR STUDENTS WITH MENTAL HEALTH AND BEHAVIORAL CONCERNS**

October 28, 2016

9:00 am to 12:30 pm

(Registration and Coffee/Tea at 8:30 am)

The Doubletree  
225 Water St., Binghamton

*Keynote Speaker*

**Dr. Agnes Whitaker,**  
Psychiatrist

*Also Featured*

**Anne McNamara,**  
SED Regional Associate

*Panel Discussion and Q&A with*  
**Dr. Whitaker**

**Jim Lucenti,**  
School Psychologist and  
former CSE Char

**Maria Rizzo,**  
School Psychologist

**Rachel Schwartz,**  
STIC Behavior Specialist

This mini-conference will provide concrete tips and resources for school personnel, as well as parents and interested others, about successfully supporting children with behavioral issues.

**Register at:**  
**register@familyrn.org**

If you require a sign language interpreter or other accommodations, please notify STIC by October 7, 2016 so arrangements can be made.

(607) 724-2111

We hope to see you there.

two jobs to support them. As the girls grew up, Betsy didn't always agree with their choices, but she loved and supported them, and they always knew they could count on her. In 1996, Betsy unexpectedly lost her sister, Barb. She felt this loss deeply and afterward wore Barb's initial "B" pendant every day. Betsy was a true friend who always listened and selflessly offered comfort to friends and family alike. At her funeral, it was said that in life there are givers and there are takers, and Betsy was definitely a giver. Very seldom would she let you help her unless you insisted. In the condolences, several people indicated Betsy was their best friend. I think that speaks to the type of person she was, making each person she met feel special. Betsy never complained about being ill or asked, "Why me?" She remained positive and upbeat until she passed. Her family and her dog, Molly, remained at her side throughout her illness. In typical Betsy fashion, she waited until everyone she loved left the room and passed quietly in her sleep. Rest in peace, Betsy.

### **One More Time...**

by Bill Bartlow

As horrifying as it might be to contemplate, and though the news induces tears, wailing, and gnashing of teeth, 2016 is our final performance.

As STIC expands, offering more services to more people, the demand for office space increases and sadly displaces the haunt space. We have looked for a new location but have not found a suitable venue within our budget. HHH has been a spectacular fundraiser for STIC and great entertainment for the community, but STIC's commitment to those we serve is our top priority.

The show must go on in 2016, and we are determined to make it a memorable experience for all who come to see it. We have added a number of new features that are bound to be crowd pleasers. The dedicated troop of volunteers on our Scream Team will be ready to meet you and greet you with their usual enthusiasm.

Come meet Harry, HHH's new ambassador. He's an irresistible ladies' man who was introduced to throngs of adoring fans at Spiedie Fest. Like a rock star, he was swarmed for "selfies" and overly excited by all the hugs and kisses his celebrity status garnered. We're sure you too will swoon when you meet him.

If your business or organization would like to help sponsor or advertise at this fully accessible event, please contact us at STIC.

For entertainment year round we invite you to our newest attraction for fundraising: XSCAPES. Our initial two months of operating *The Valley of the Kings* has been a gratifying time for us. Our patrons rave over this absorbing new adventure and tell us that ours is just as good as others in larger cities. Players as young as 6 have successfully engaged the room and revealed things the adults missed. Grandparents, too, are enjoying finding the clues and solving the puzzles of this exercise in teamwork and critical thinking.

Our next Xscape room, "Pulse," will open soon. With the technical expertise of our media specialist Matt Wolfram, and our event coordinator Matt Wightman, this room's theme centers on the very real concerns of today's national security. For more information on Xscapes and the plots behind the rooms go to the Xscapes web site: <http://www.xscapes-stic.com>

Meanwhile enjoy the rest of summer, and we look forward to seeing you in October when the leaves are colorful, frost is on the pumpkin, and thoughts turn toward All Hallows' Eve.

### **Veterans Peer Outreach Program Closed**

by Maria Dibble

It is with much regret that, effective June 30, 2016, STIC's Veteran Peer Outreach Program was voluntarily ended by STIC.

When we first conceived of this program, our plan was to provide peer support and other services to veterans with disabilities. Though we believed it was a much-needed program, and despite extensive outreach, very few people participated.

That being said, all of our services are open to all veterans with disabilities if they wish to take advantage of them. Veterans have always been welcome here, and that, of course, is still the case.

We thank everyone who worked with STIC to publicize our program and we thank ACCESS-VR for giving us an opportunity to put our ideas into practice.

HAUNT FINALE



# HAUNTED HALLS OF HORROR

SOUTHERN TIER INDEPENDENCE CENTER

BLOOD CREEK  
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Oct. 1st through 29th Fridays & Saturdays  
7p - 10p

New this year "Swamp Hag"

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607 724-2111 www.hhh-stic.com

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*Seventh Annual*

## HAUNTED HALLS OF HORROR

Every Friday  
and Saturday

October 1 –  
October 29

7 pm – 10 pm

Admission:

**\$15.00**

PULSE

VALLEY OF THE KINGS



# SELF HELP

## Resolving Conflicts of Interest

A big change that will come with New York's new plan to comply with federal regulations for community-based services involves "conflict of interest." It's very important that you understand why this change is coming and what it means.

### What is conflict of interest?

A "conflict of interest" happens when a person or organization that is supposed to tell you about all of your options has something to gain by not telling you everything, or by not telling the truth.

When we're talking about services for people with disabilities, there's a conflict of interest when an organization that serves you can make more money by not telling you about the services that its competitors offer, so that you will get all of your services from them.

### What is the new rule?

The new rule is that if an organization provides direct services to you (such as habilitation, supported employment, respite, etc.), that organization cannot also provide "case management" to you, or be responsible for developing your service plan. Further, there can be no "interlocking" control between separate organizations that do those things for you (they can't have the same boards of directors or any of the same management staff).

It's important to understand that the rule applies to situations in which the person with a disability gets direct services, and also either "case management" or service plan development, from the same agency. A single agency can provide both of those types of services—but it can't provide both of them to any single individual, with one exception: when only one organization in the geographic area can do all those things for you.

This is a federal rule. It is final. It cannot be changed. So New York State, and all of its agencies that serve people with disabilities, have to figure out how to follow this rule in the future.

### Who does the rule apply to?

It applies to anyone who receives or provides any community-based long-term services and supports that are paid for with Medicaid.

The feds finalized new regulations for Medicaid managed care earlier this year. Those regulations specifically apply the HCBS conflict of interest rule to any and every community long-term service and support provided through managed care. The rule cannot be "waived."

So the rule applies to any organization that provides any kind of "service coordination," and that also operates any kind of housing for people with disabilities, including IRAs, so-called "assisted living centers," "supportive apartments," and "adult homes," or also provides any kind of individual or group "day service," from Community Habilitation to Adult Social Day Care. We believe the rule also applies to any form of "personal care," including CDPA.

New York doesn't provide all of these services through HCBS waivers now. However, New York has a "Managed Care for All" process that is slowly moving all recipients of all of these services into Medicaid managed care. As that process goes forward for each service, the key question to ask is, would the feds have let New York provide that service through an HCBS waiver, if New York had asked them to? If the answer is yes, then the conflict-of-interest rule will apply to that service when it's under managed care, even if it doesn't apply to it now.

### Why was this rule made?

People place a lot of trust in the folks who help them pick out and receive their important support services. Sadly, a lot of service providers have violated that trust. They have deliberately failed to tell people everything about what their options really are. They have refused to tell people about the services that their competitors provide, or they have lied about how effective those services are. We know this happens because many people with disabilities and their family members have told us. We also know that this was not a "mistake." It was a deliberate policy, established by top management, and we know that from unimpeachable sources.

And it is still happening, not just in our community, but throughout New York and other states.

Some states, however, started their HCBS programs with independent "enrollment brokers," whose only job was to tell people about their options and help them develop their service plans. The enrollment brokers did not provide any direct services, or service coordination, to anyone, so they had nothing to gain by lying to people.

After hearing many complaints about corrupt self-dealing in NY and other states, the feds finally said, Enough! Every state that lets service provider agencies be a single point of contact must end that practice. There must be complete separation between those who tell people about their options and help them plan their services, and those who provide those services.

You may be thinking about the OPWDD "Front Door." The Front Door is a kind of enrollment broker. However, even the Front Door can violate the new rule, because OPWDD also provides direct services. So OPWDD can't continue to conduct business this way either.

### What does this mean for me?

We want to be clear and up front about this. It ***COULD*** mean that you will not be able to get both Service Coordination and any other Medicaid-funded service from STIC at some future point.



But don't panic yet. All of the state agencies, including OPWDD and DOH (which handles the TBI and NHTD waivers), have to present a plan to the feds on how they are going to deal with this. The State of Ohio recently reached an agreement with the feds on this issue, and the good news is that Ohio has been given until 2024 to bring their system into compliance.

The final plan for New York may preserve your relationship with the person who is your service coordinator today. But it also may not. We are not making any promises.

### **What are we doing about this?**

Today your Service Coordinator does "case management." That means things like keeping track of your paperwork and making formal referrals to other Medicaid service providers. Your Service Coordinator also does service plan development: S/he schedules your annual planning meetings and reviews, chairs the meeting, writes down everything in your plan, and makes sure that everybody who should get a copy of the plan does.

But we all know that Service Coordinators—at least, those who work with people who live in their own homes and participate in ordinary community activities—do a lot more than that. Here are just a few examples: Attending IEP meetings with family members; taking your phone call right away when you're worried about something; finding a backup when your Hab worker doesn't show up; helping you understand the complicated forms that state agencies send you; coming to your home and "pitching in" if you're having a crisis, and on and on and on.

None of that is "case management," nor is it "service plan development." It's something else. Call it Personal Advocacy.

We think that Personal Advocate is a job title, and we've just given you the job description. Importantly, it fits the definition of a direct Medicaid service. We believe that it will be legal for the same agency that provides your other direct services to also provide your Personal Advocate.

But that means that some other organization must do your "case management" and help you develop your service plan. Under managed care, that organization can be the Managed Care Organization (MCO) that provides your managed care plan. That's because MCOs are insurance companies; they only authorize and pay for services.

DOH is going to move the TBI and NHTD waiver services into managed care beginning in 2018. Also, for those services there is a severe shortage of service coordinators and provider agencies. Most people in those waivers don't really have a choice of two or more providers in their geographic areas, so this issue is less urgent for them.

OPWDD is different. There are a lot of providers, and OPWDD isn't going to do managed care any time soon. In fact, the feds have specifically told OPWDD that they have to come up with a conflict-of-interest plan now, before they start doing managed care.

We think that OPWDD would be an ideal location for both "case managers" and service planners. However, that would mean that OPWDD would have to stop providing direct HCB services. We think the agency can come up with a ten-year plan to slowly transfer state-operated residential and day programs to private providers, and at the same time transfer case management and service planning functions from those private providers to itself.

We don't know if OPWDD, the state, or the feds will agree with our idea. We hope they do.

Because there are only two other options, at least for OPWDD, before managed care takes effect.

One would be to require Service Coordinators to leave their current employers and start completely new and separate organizations that only do "case management"/service coordination and service planning. There are a lot of great service coordinators out there. But not very many of them are suited to start and run businesses—especially businesses that have to comply with the huge set of complex requirements to be approved by OPWDD and to bill Medicaid. Starting such a business is a daunting task—and would require quite a bit of seed money because it would probably be a couple years between creating the business and receiving the first Medicaid check.

The other option would be to devise a plan that will separate most of you from your current Service Coordinators and assign you to other Service Coordinators that work for other agencies. Nobody wants that to happen. So we will work hard to get OPWDD and the state to adopt our ideas, and we'll keep you informed.

# **Walk-In Mental Health Services**

Tioga County Department of Mental Hygiene now offers Open Access Walk-In Services. The service has been accessible since November 1, 2015 and includes a wide variety of treatment options (crisis, assessment, referral, etc). Walk-In services do not require an appointment and are provided on a "first come, first serve" basis.

## **Open Access Walk-In:**

Monday – Friday

9:00 am – 5:00 pm

1062 State Route 38

Owego, New York

(607) 687-4000

## **24-Hour Crisis Line:**

(607) 687-1010



This newsletter is also available in large print, on cassette, and online, at: [www.stic-cil.org](http://www.stic-cil.org)

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## Free Access Is Not Free

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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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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!**

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