



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

AccessAbility

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THROUGH THE KEYHOLE

by Maria Dibble

No exact picture exists to print in these pages, but a photo is etched on my mind, forged from the dreams of thirty years ago, the image so vivid that even the edges are curling with age, as are the memories of those early years—a hand holding a key reaches for the door of a small storefront, the key sliding effortlessly into the keyhole, turning smoothly to swing wide the door, revealing the entrance to 232 Clinton Street in Binghamton, our first home.

Two idealistic people step into the building, the bare room holding only a counter and a few folding chairs, their footsteps echoing across the hardwood floors. Those people were Frank Pennisi and myself.

The combination of our idealism, inexperience, and ability to dream, was the foundation of our beginning. Others thought we were being unrealistic in our vision of an accessible world and of an agency that could serve people of all ages and disabilities. They were

sure we'd become jaded and give up our dream within a few years.

Certainly time and experience have taught us to be a bit cynical about government's promises (well maybe more than just "a bit"), but the vision of a world where people with disabilities could be on a level playing field with nondisabled folks has not diminished.

In 1983 you seldom saw people with disabilities on city streets, at the mall, in movie theaters or at concerts. Now we are everywhere, including TV commercials. In 1983, closing sheltered workshops was only a distant fantasy, but it looks like soon it is going to come to fruition. In the early 80s it was unheard of for people with disabilities to be part of the process of developing their own plan for personal care services, and Consumer-Directed Personal Care wasn't even on our radar screen. Now consumers are an integral and required participant in the planning process, and CDPA is a flourishing reality. Civil rights legislation for people with disabilities was thought to be a far reach in the late 80s, but in less than three years the Americans with Disabilities Act went from some thoughts and hopes on paper to the law of the land in 1990.

No matter how cynical I may become as I get older and see more of the world, so to speak, I will hold to my still strong and fervent belief that people can make

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change, and that empowered people can make it happen even faster. I'm not so naïve or self-centered as to think that these changes wouldn't have occurred without STIC, but I do believe that we have made a difference. That because STIC exists, the lives of people with disabilities that we've touched are better, and that most importantly, people have been empowered to believe in themselves as much as we believe in them.

Sometimes we get too caught up in the minutia of day-to-day life, and trapped by the belief that more money will fix things. Sure it helps, don't get me wrong, but it can't buy the most important things, life with dignity and equality, lived in an integrated community where a disability is just another part of who we are. I feel honored that I've been part of the first three decades of STIC and look forward to being a part of at least some of the next 30 years.



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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.

www.stic-cil.org

Free at Last!

This past August saw the 50th. anniversary of Martin Luther King's immortal "I Have a Dream" speech. And so it is fitting that, after decades of broken promises and intensive advocacy by people with disabilities, New York State has finally announced a plan to close all of its remaining developmental centers. Here's the schedule:

OD Heck (Schenectady) – March 31, 2015

Brooklyn – December 31, 2015

Broome – March 31, 2016

Bernard Fineson (Queens) – March 31, 2017

After the recent closures of the West Seneca (near Buffalo), Monroe (Rochester), and Wassaic (Hudson Valley) DCs, these four are the last remaining "developmental centers" in the state.

New York first announced that it intended to close all of its developmental centers (DCs) by the year 2000 way back in 1991. The state made an agreement on special Medicaid rates with the federal Centers for Medicare and Medicaid Services (CMS). The rates were intended to support creation of smaller residential and day programs for people leaving those institutions. However, they became a perverse incentive to keep the facilities open, and the closure plan was dropped. It wasn't until a series of articles began appearing in the *Poughkeepsie Journal* in 2010 that the state was embarrassed into resuming the closures. Those articles showed that the rates being paid to keep people in DCs were more than 4 times the actual cost of the service, and that much of the extra money appeared to have been funneled off for unauthorized purposes only slightly related, if at all, to serving people with developmental disabilities.

A "developmental center", it's important to remember, is not a building. It is a type of residential program for people with developmental disabilities. New York's Office of People with Developmental Disabilities (OPWDD) operates other institutional programs known as "Intensive Treatment" and "Multiple Disability" units, and some of these are located in the same buildings or "campuses" as DCs.

A few years ago, in its "People First Waiver" proposal, OPWDD said it planned to close all of its DCs while retaining "institutional capacity" for about 300 people. This past April, OPWDD announced a "transformation agreement" with CMS which required OPWDD to provide a plan for closing all remaining DCs *and* ICFs/DD (Intermediate Care Facilities for people with Developmental Disabilities) in the state and reduce its institutional population to 150 people in temporary crisis-oriented programs. All DCs are ICFs, but not all ICFs are DCs. There are over 5000 people living in ICFs run by OPWDD or its subcontractors; the facilities range in size from 6 to 24 beds (and larger in some cases). Although federal Medicaid regulations deem ICFs to be transitional placements whose residents all must have realistic plans to move to more integrated settings, NY has, for decades, violated those regulations and treated ICFs as permanent homes.

The transformation agreement that mandates these closures is part of NY's pending amendments to its "Partnership" Medicaid waiver, which covers Medicaid managed care services. These amendments have not yet been approved by CMS (see page 9), but OPWDD has been pushing hard to meet various deadlines in the agreement anyway. We assume they'll continue to do so—unless certain state employee unions and politicians get in the way.

The unions have been campaigning against DC closure plans ever since there have been such plans, for obvious reasons. As these unionized state-operated facilities are closed, the people they house move to "community based" services provided by private not-for-profit agencies, which are largely not unionized.

This is presented as a "jobs" issue, but that's not what it is. At least as many jobs will be created in the private sector by these moves as are lost in the public sector. In fact, there will be more, because these moves reduce service costs by between 30% and 80% per person served, freeing up funds to serve more people, leading to more jobs. But in the process, of course, public employee unions will lose membership, dues revenue, and influence in state government.



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.

Broome Developmental Center is on the list for closure. Interestingly, the OPWDD press release states that the four closures, including Broome, will be of “institutional campuses”. The Broome campus houses not only Broome Developmental Center but an Intensive Treatment Unit. Because Broome is the newest physical “campus” in the state, it was long assumed that it would be the last to close, and might not close at all. This is apparently not the case.

State Senator Tom Libous has been opposing the closure of institutions as long as the unions have. According to the website VoteSmart.org, in the 2012 campaign cycle, “General trade unions” were the fifth highest contributing category to his campaign, and “Public sector unions” came in sixth.

In August, Libous launched a petition drive to oppose closure of Broome Developmental Center. The petition was originally targeted at closure of the Greater Binghamton Health Center (GBHC), which is a different issue (see below), but was expanded to include BDC when OPWDD announced its closure. Information on Libous’ website at press time said that “While I usually support collaboration between State agencies, I’m totally opposed to seeing this bad idea spread from OMH to OPWDD. It saves less money than some in Albany may think and it does so at the expense of those who can least afford it. Nor is it required by the federal courts. So I’ll fight just as hard, through meetings and hearings and more, to keep the Developmental Center open along with GBHC.” News reports emphasized the number of state jobs at the center. One source quoted Libous as saying, “You have to protect jobs. You have to protect residents.” Another source reported that Libous said, regarding both closures, “But we’re talking 1,000 jobs. We can’t afford to lose ... and until they convince me that there will be jobs saved and how they will be saved, I’m not giving in to that.”

We think, and hope, that there is room to work with Libous on the GBHC issue (nobody thinks the GBHC is a “home” for anybody, and the intensive temporary crisis-management services it provides are essential for keeping people with severe and persistent mental illness in the community). But institutions for people with developmental disabilities must close, and no one should prey upon the fears of the public, or the worries of the people who work in them, in order to keep them open.

Still No Justice

As we predicted in articles discussing the creation of the NYS Justice Center for People with Special

Needs, the Center has had no effect on whether state employees guilty of abuse get fired.

According to an August 8 New York *Times* story, NY has “made no discernible progress in firing abusive and derelict workers. Not counting workers ultimately cleared of all disciplinary charges, the state still manages to fire only about a quarter of those recommended for job termination, a rate that has not budged.”

The *Times* and the Cuomo Administration have both blamed the problem on public employee unions, principally the Civil Service Employee Association (CSEA). Union contracts for state employees include an arbitration clause. Any time an employee is to be fired for cause, the employee has an option to go to binding arbitration. The arbitrator is the final authority on what will happen, and most arbitrators view their role as enabling compromise—even when dealing with abuse. Since the employee won’t agree to be fired, any possible compromise must involve the employee keeping his/her job. A couple years ago, as the state was negotiating a new contract with the unions, Cuomo proposed a new “table of penalties” to be given to arbitrators. This was promoted by OPWDD and Cuomo as including “mandatory” firing in some cases. OPWDD and Cuomo claimed they had an understanding with the unions that the table would be accepted. Two years later, it hasn’t been.

Cuomo claims the union has held up the agreement because of a dispute about health benefits. The *Times* story reported that the CSEA has consistently opposed the idea of mandatory firing even for abuse. However, just as we predicted that abusers would not be fired, we also predicted that the root of the problem is not the unions, but the elected officials who cater to them.

The proposed “table of penalties” was never “mandatory”; it was a set of “guidelines” for arbitrators. Arbitrators have authority to make their own decisions, and ignore “guidelines” if they wish. The “table of penalties”, even if adopted, won’t stop arbitrators from compromising with abusive employees and letting them keep their jobs. Think about it. If a worker is accused of abuse and OPWDD wants to fire him/her, and there is an actual mandate that, regardless of arbitration, such an employee must be fired, what is the point of letting the employee go to an arbitrator, who will order him/her to be fired? Don’t let the politicians’ press releases fool you; they never intended to mandate firing in the face of union opposition.

The legislation establishing the Justice Center was promoted as ensuring swift responses against

abusers, and included a new “do not hire” list to keep people who are fired for committing abuse from being rehired. The original bill clearly stated that it would have no effect on disciplinary procedures in union contracts. And the final law actually made it harder than ever to accuse a state worker of abuse or neglect. As for the “do not hire” list: it was empty the day the Justice Center opened. It will only contain the names of the people whom the state manages to get on it from now on, after jumping through all the hoops set up by the new law and union contracts. It cannot, by law, include people who have already been fired (and in some cases, jailed) for abuse.

As the Justice Center bill was being debated, advocates were asked for input by some of the politicians who today are expressing outrage at the state’s failure to fire abusive employees. We said that the proposals regarding the “table of penalties”, and the language of the Justice Center bill, were inadequate. We suggested that the legislature enact a law stating that in all future contracts with unions, no language permitting arbitration of decisions to fire employees for documented abuse or neglect can be allowed. This law would take effect as current contracts expired, and would provide a real solution for the problem. Our suggestions were ignored.

Federal and state law provide that signed union contracts can’t be violated by employers. But no law prevents a state from defining limits on contract terms to which it will agree before they are negotiated. So we offer the suggestion again, in the hope that this time, somebody will listen.

An Excellence Adventure

As part of New York’s move toward managed care and more integrated long-term care services in natural settings, the state’s Office of Mental Health (OMH) announced a plan this spring to close state psychiatric hospitals and transfer resources to community services.

OMH wants to consolidate state-operated services into “Regional Centers of Excellence”. Each center will have downsized inpatient facilities and local community service “hubs”. The state facilities are supposed to offer high-quality specialty services for small numbers of the most difficult-to-serve people. Community services are supposed to be expanded to address service gaps for people with more typical mental health disabilities.

Of course, this is big talk, and the devil is in the details. Meanwhile, press coverage has

been dominated by state employee unions and politicians wailing about “job loss” and “putting dangerous people on the streets.” So we’re going to give you the details and explain what STIC is doing about this, and what you can do yourself.

What’s the Problem?

OMH knows there aren’t enough community services for people with mental health disabilities.

By comparison, the OPWDD services that we often criticize are widely available. Some people with developmental disabilities do end up homeless or in jail, but not often (and usually they also have a mental health disability). But for people with severe and persistent mental illness who don’t have well-off, and very patient, families, jail or the streets are likely stops on the way to a psychiatric hospital, or after leaving one. Homeless shelters, county jails, children’s detention centers, and state prisons are full of people with mental health disabilities. Nearly all of them could stay out of those places if they got enough community services, both when in crisis and as they begin to recover.

Severe mental illness is a disease process. It has acute phases where intensive treatment is needed, followed by recovery, then remission, and then, sometimes, relapse. People with these conditions do need to go in and out of hospitals at times, just like people with congestive heart failure, kidney disease, severe seizure disorders, and other people who live ordinary lives among us most of the time but sometimes need intensive medical help.

The difference is that stressful situations, including, in many cases, poverty, trigger the acute phase and make recovery harder. So ongoing more or less intensive support services are needed to keep them as healthy as possible. Without them, people end up in homeless shelters or jail. And if they don’t get quickly hooked up with enough services after they leave those places, they relapse and go back into them.

OMH is not set up to provide adequate community supports for two reasons. First, almost 2/3 of its \$3.3 billion budget is spent on state psych centers. Those centers today house relatively few long-term residents. In the last fiscal year, they served around 10,000 people, but at any given moment there were only about 3300 people in them. The number of people served grows every year, while the number of people housed at any one time shrinks. These places are basically short-term acute treatment centers. In other

words, they do what ordinary hospitals do for people with physical injuries or illness, and what some of them do for people with mental illness but for less cost. Why less cost? You might say, because state psych centers are union shops and ordinary hospitals aren’t. But that’s not always true, especially in New York City. It’s more because these huge facilities have a lot of unused buildings and grounds that must be maintained, as well as duplicative administrative staff.

Second, unlike the developmental disabilities service system, or the physical healthcare system, New York’s mental health system doesn’t make much use of Medicaid dollars. Accessing Medicaid could bring a huge amount of new money into the state to pay for community services.

What’s the Plan?

There are five OMH “regions” and 24 state psych centers. When the plan is done there will be 15 Regional Centers of Excellence, some of which will have more than one inpatient facility. There will be no “catchment areas”, so people anywhere in the state can use any Center’s services.

The plan lays out a 3-year process that began this July. This fall and winter the details will be fleshed out. Each OMH region (ours is the Central New York Region) has a committee to figure out how community services should be expanded. Each committee has three co-chairs, already appointed. OMH is supposed to appoint 15 more members, representing consumers, families, and service providers, “shortly”. STIC has applied for membership. These committees will meet three times this fall, and then make recommendations to a Steering Committee.

The Steering Committee includes the regional co-chairs, plus several people representing consumers, service providers, and advocates. The advocates that we at STIC know are: Kate Breslin, Schuyler Center for Analysis and Advocacy; Glenn Liebman, Mental Health Association of New York State; and Harvey Rosenthal, NY State Association for Psychiatric Rehabilitation Services. Roger Bearden, Cuomo’s “Special Counsel for Olmstead”, considered a good guy but lately unheard-from (see page 8), is also a member. The Steering Committee will look at the regional recommendations and produce a final plan for expanding community services, transitioning inpatients, and closing facilities, to be carried out starting next July.

That’s only part of the plan though. The other big piece is Managed Long Term Care

(MLTC). We don’t have space to explain that in detail, but here’s a summary: OMH is rolling out a form of managed long-term care called “Behavioral Health Organizations”. Meanwhile, “special needs” Medicaid managed care plans (now called “Health and Recovery Plans” or HARPs) have been available to some people with mental health disabilities. They include a lot of specialized psychiatric services. OMH wants to apply for a new Medicaid “experimental” 1115 waiver to cover a range of rehabilitation, employment, and community-based support services for adults and children with mental illness. If the feds approve this, it could bring in hundreds of millions of new dollars for services. HARPs would be expanded to include acute health care as well as HCBS-like services including care coordination, supported employment, respite, “peer support” and “habilitation”. Like all Medicaid managed long-term care in NY, these plans must be person-centered and offer self-direction. HARP providers, whether BHOs or other MLTC organizations, must work with police, jails, and prisons to ensure smooth and safe transitions. If approved, expanded HARPs would be offered to adults beginning in 2015, and to children in 2016.

OMH says the new waiver HARPs are one of three main ways that community services will be expanded. The other ways include enabling existing state workers at psychiatric centers to move into community service jobs, and directly increasing funds for community service providers.

There are also several state initiatives to make more affordable housing, including “supported” housing, available to people with mental health disabilities. Much, but not all, of that is related to settlements of lawsuits involving people in adult and nursing “homes” (see page 8.).

What’s Going to Happen Locally?

That depends on what ends up in the final plan. Here is all we know for sure right now:

The Greater Binghamton Health Center (GBHC) is to be “merged” with Hutchings Psychiatric Center (Syracuse), Mohawk Valley Psychiatric Center (Utica), and St. Lawrence Psychiatric Center (Ogdensburg) into the Empire Upstate Regional Center for Excellence. When this merger is complete, there will be an inpatient facility for adults in Syracuse with 185 beds, and an inpatient facility for children in Utica with 90 beds. The first three facilities are supposed to be merged between July 1, 2014 and June 30,

2015; the remaining childrens' inpatient services from Ogdensburg will be moved to Utica after that. Meanwhile, the region is to get several local "state-operated community service hubs", which are to provide "administrative support".

What Can We Do about It?

As you can see, so far this is not much of a plan. It's only an outline. Over the next several months there will be opportunities for concerned people to help finalize the details.

This spring's OMH "listening tour" collected a lot of input. You can view it at OMH's website. OMH officials were told, very clearly, that there aren't enough community services, not enough services for children, and that families shouldn't have to travel long distances to visit children in inpatient facilities.

In the Greater Binghamton Region, we can expand on those points. Local emergency response services are very poor, and ongoing supports are extremely limited.

When somebody has a psychiatric crisis, here is what should happen: Immediate intensive intervention to evaluate the person and deliver effective treatment comes first. Once the person is stabilized, his/her situation must be examined to figure out what triggered the emergency and how to make it less likely to happen again. A service plan needs to be developed to address those issues. The person should not be discharged from the emergency treatment center until that plan is developed and those services are in place. Over time, as the person recovers, the amount and frequency of services can slowly be reduced, but probably only rarely completely removed.

What happens in our region, though, typically, is this: A person goes to a local psychiatric emergency program in crisis. If the person has a developmental disability in addition to a mental illness, s/he is most likely turned away without any services. Most of those not booted out the door get some quick "counseling" and/or medication, and are sent back home without any serious plan for long-term support. Sometimes people are sent to the GBHC or another state psych center. They are usually released after a few days, again without many, or even any, long-term supports in place. People can get on a waiting list for a limited list of rigidly-defined support services offered by a tiny number of providers. If they don't quickly relapse and end up on the street, in jail, or in a psych center (again), they may eventually start getting those services.

When they do, they're in for a rude awakening. Although community services funded by

OMH are supposed to be flexible and based on individual needs, as provided locally they are not. When it comes to residential supports, if you're in "supported living", you can get one hours-limited level of specific services; in "supervised living" you get another level of services; in a "community residence" you get a third level. Those levels are based on the name of the program you're in, not on your individual needs. If you need an hour or two more of service per day or week than the program provides, you're out of luck. If you need an hour or two less, but not enough less to go to a different program, and you say so, you're labeled "noncompliant". And, as you recover and your needs are reduced, when you reach the magic threshold for the program you're in, you have to physically move to a new place to get the lower level of service.

As for crisis-response supports: In theory, Assertive Community Treatment (ACT) is available. ACT is a service model that, according to OMH, has a staff-to-consumer ratio of 1-10, and is provided at whatever intensity the person needs, 24/7, on-call. A person has a "team" of people with various specialties, each of whom is supposed to directly serve the person to troubleshoot problems and prevent crises, and be accountable for the person's well-being. Team members are to be "aggressively proactive" in working to ensure that the person fully participates in his/her treatment and recovery plan. In practice locally, ACT is not always immediately available, and when it is, it doesn't provide a true individualized 24/7 response. Like all of the other services, it rigidly limits the amount of contact people can have with people who are supposed to help them.

Certainly a lot of this is due to lack of funding. Along with that, there's a local shortage of psychiatric practitioners who specialize in children. There's also a severe shortage of clinicians and administrators who have kept their continuing education up to date and understand that people can have both developmental and psychiatric disabilities, and that the treatment for the latter does not necessarily change because of the former.

People are scared of OMH's plan to close the GBHC, because as far as they can tell, an already terrible service system will get much worse, especially for kids, whose only real local option for medication management and stabilization when in crisis is the GBHC. They are sick and tired of having family members with developmental disabilities denied psychiatric crisis services, and they don't want their kids shipped off to Utica for days at a time, where they can't visit them.

People who work at GBHC don't want to lose their jobs, or leave the area to keep them.

People don't trust OMH, and for good reason. OMH's website and public pronouncements claim to provide services that just don't exist—at least, not around here. New Yorkers in general don't trust any plan to close psych centers and provide community services instead, because NY is famous world-wide for promising to do that in the 1970s and instead condemning thousands of people with mental illness to homelessness and prison. They think that's going to happen again.

So while we're glad that OMH says the purpose of this whole thing is to expand community services, we would be happier if there were hard numbers attached. For example, something like: "Today, OMH's annual budget is \$3.3 billion, 65% of which is spent to run 24 psychiatric hospitals. Three years from now, OMH's annual budget will STILL be AT LEAST \$3.3 billion, PLUS 3% cost-of-living increases, and AT LEAST 67% of that budget will be spent to provide adequate levels of integrated personalized support services that serve people with mental illness whether they also have developmental disabilities or not, and which include local short-term inpatient crisis treatment." Sadly, there is nothing like that in the plan. That's why we at STIC, along with other advocates, and some state legislators, want to pass a law to require that ALL of the money saved by closing psych centers will be reinvested directly into community services.

The next step is to work with the regional and steering committees to get these complaints translated into action. Our Regional Committee co-chairs are: Vickie E. Perrine, COO of Claxton-Hepburn Medical Center in Ogdensburg; Dr. Matt Catalani, Clinical Director at Hutchings Psychiatric Center in Syracuse; and Otsego County Community Services Director Susan Matt. We hope that our application for membership on the committee is accepted. Whether it is or not, we'll be talking with regional committee members from our area, as well as the advocates on the Steering Committee, to make sure that we are heard.

What Do We Want?

1. Temporary inpatient crisis-management and stabilization treatment IS a community service. It must be available in local hospitals, not 70 to 100 miles away. By all means, close the antiquated, oversized buildings at GBHC. But also make sure that UHS Hospitals and Lourdes Hospital will provide those services instead.
2. Get rid of barriers for people with dual developmental and mental health disabilities.

OPWDD's People First Waiver DISCO proposal at least talks about serving this group, though vaguely. It's not mentioned at all in OMH's plans. We need to retrain clinicians and program administrators, emphasizing current research in this field, and then mandate redesign of their programs. We also need to offer early retirement to those who won't accept modern thinking.

3. Establishing Binghamton as a local "hub" for services provides an opportunity to beef up recruitment efforts. There is a severe shortage of psychiatrists, especially those specializing in children, locally. Although small towns will never attract large numbers of top medical people, we could do better locally if funding allocations take recruitment into consideration.

4. Another way to expand service availability is to pay better rates for those services, so more people will offer them, and funding allocations should take that into account.

5. Peer support has to be paid for. The local "health homes" are refusing to do so. They think that agencies that offer this service, which are already overtaxed and have waiting lists, should do it for free. The HARP plans are supposed to offer this service. Make sure it's paid for, or it won't be available.

6. Make services flexible. With person-centered planning should come truly personalized services. Residential support levels should be based on individual need. As those needs fade over time, the person should be able to stay in the same place. Move the workers, not the consumers. And make ACT services live up to OMH's promotional materials, with real 24/7 crisis support that responds to individual needs and fades only if and when the person recovers.

7. Make discharge from crisis centers contingent on availability of adequate follow-along support. Nobody who is credibly threatening suicide should be sent home without being accompanied by someone who will make sure the person won't do it as soon as they are alone.

8. A new Medicaid waiver for mental health services is a great idea. We know, though, that the feds aren't very happy with how NY handles its current waivers, and haven't been enthused about approving new ones. If it turns out that they won't approve this one, then OMH absolutely can't move ahead with the rest of the plan until it comes up with the money from other sources.

You'll have opportunities over the next few months to influence this process. We suggest you contact members of the Steering and Regional Committees (once they are appointed) to let them

know what you think. And you can keep up with what's happening at the OMH website:

www.omh.ny.gov/

The full "OMH Regional Centers for Excellence" plan is at:

www.omh.ny.gov/omhweb/excellence/rce/rceplan.pdf

The Steering Committee has a page at:

www.omh.ny.gov/omhweb/excellence/rce/steering_committee/

Important resources include:

"Overview of RCE Progress" document: www.omh.ny.gov/omhweb/excellence/rce/steering_committee/description_of_RCE_teams.pdf

"Resource Base Discussion" document: www.omh.ny.gov/omhweb/excellence/rce/steering_committee/resource_base_discussion.pdf

"Managed Care and Centers for Excellence Planning" document: www.omh.ny.gov/omhweb/excellence/rce/steering_committee/interaction_of_RCE_with_managed_behavioral_health.pdf

OMH definition of Assertive Community Treatment (ACT):

<http://bi.omh.ny.gov/act/index>

COURTS WATCH

US v Florida: The Children's Hour

(Warning to the humor-impaired: This article contains sarcasm.)

The US Department of Justice (DOJ) has been investigating Florida's use of nursing homes to house children with disabilities for some time. Now they're suing the state, and challenging a particularly ugly brand of healthcare so-called budget-cutting.

Florida has a Medicaid Home and Community Based Services (HCBS) waiver program for children with disabilities, including developmental disabilities. However, it's been very limited. As a result, children who are eligible for it spend a long time—years, in fact—on a waiting list to get the services. They often spend those years in nursing homes. The average length of stay is 3 years, and some children have literally grown up there. Sometimes the children sit around in the same deadly boring, TV-droning day rooms inhabited by elderly inmates. Some go out of the

facilities for school, but some get no more than 45 minutes of schooling per day.

This is bad enough. What's worse are the recent activities of the state's politicians. Allegedly in order to cut costs, they enacted a state regulation that requires that HCB services "be furnished in a manner not primarily intended for the convenience of the recipient or recipient's caretaker." Guidelines for this regulation state that children should be "weaned off" paid in-home nursing services, and parents and other family members should be trained and required to take on those tasks. Then, every six months, at needs reassessment time, the state cuts service hours for those children even if their needs haven't changed. Many parents, unable to cope with the increasing burden of providing care themselves, eventually give up and send the children to a nursing home.

Families have complained about this for years. Somebody listened, because the state applied for, and won, a \$37.5 million "Money Follows

the Person" Medicaid expansion grant under terms extended by the Affordable Care Act. This money could have reduced the HCBS waiting list significantly. Instead, the Republican-controlled state legislature decided that accepting the grant was inconsistent with its opposition to the hated "Obamacare", and refused to take the money.

Instead, they increased the day rate for nursing homes that house children, and removed a rule limiting the number of children in a nursing home to 60. And they cut fees for community service providers, with the inevitable result that fewer services became available.

Let's just digest this for a minute.

First, as noted in DOJ's complaint, Medicaid pays only for services that are "medically necessary". That is, they help cure a medical condition, or keep it from getting worse, in order to maximize the person's ability to function in all the ways that we expect from a human being. Now, when your functional abilities are maximized, all kinds

of things become more “convenient” for you. In fact, making things “convenient” in this way is the goal of all medical services. So the Florida regulation mandating that services can’t be “primarily intended for the convenience of the recipient” is a startling display of ignorance of basic medical principles.

But then they added “or recipient’s caretaker”, an obviously deliberate shot at single working mothers. Of course! If you have a disabled child, you should stay home and take care of him/her instead of going out and earning a living so the child can eat and sleep under a roof as well as have his butt wiped by his mom instead of some stranger at the taxpayers’ expense, because that’s your moral duty as a parent, and if you don’t like it, you should have thought more carefully before you had a kid. That’s pretty much what went through these people’s minds, right? On top of startling ignorance we have astounding judgmentalness. (If that’s a word. Spell-check says it isn’t. It should be.)

Suffice it to say that federal Medicaid law doesn’t allow this. “Medical necessity” means you need it to improve or maintain your health and functioning because your physical condition and/or functional limitations justify it. And if that’s true, then Medicaid has to pay for it. End of discussion. The things and people in your environment are irrelevant. And this is important to us because already at least one Medicaid long-term managed care insurance company in NY has tried to tell some parents that their kids can’t have homecare because they, the parents (and their live-in significant others) should be taking care of the kids instead of going out to work.

Now for that rejected \$37.5 million “Obamacare” grant and the increased rate for nursing homes. Clearly this isn’t really about saving money, because if it was, they’d take the grant and use it for cheaper homecare instead of boosting spending for highly expensive nursing facilities. No, this is a matter of *principle!* The principle that the federal government has no right to demand that a sovereign state use its money to treat its citizens both humanely and sanely! “Its money”? Whose money? Well, in FL, 55.4% of Medicaid is federal money (and the grant would have had a higher federal match). Ah! But “its citizens”? Whose citizens? Well, the United States’ citizens, actually. Only countries can have citizens, and define their civil and human rights. States can only have “residents”, and they must respect those rights for those residents as provided by the federal government. Didn’t we fight a war over that? And then didn’t we pass

constitutional amendments, and, later, federal civil rights laws, to enforce it? Some people never learn.

But now we come to a real problem with this case. The facts are largely about whether kids can get “nursing services” in their homes rather than in nursing facilities. The families that started the lawsuit in which DOJ has now intervened claimed that they need real genuine nurses to do things like feed their children and maintain their ventilators, and DOJ accepted that argument. The waiver, for those who can get on it, provides home nursing services. The thing is, nurses are horrendously expensive. Most of the things they do can, in fact, be done by trained homecare workers for considerably less cost. Such workers do those kinds of things all the time in NY’s Consumer Directed Personal Assistance program. Given the other facts of the case, it isn’t very likely that Florida’s politicians would have behaved differently if they understood how much money could really be saved by deprofessionalizing HCBS services. But disability rights advocates seeking to use this case as precedent should be cautious.

And there’s another reason for caution. We need to avoid endorsing the notion that medical professionals should provide attendant services not just because of cost, but because we want real community integration. Absolutely, at home, when parents need to go to work, nobody should demand that they instead learn to insert catheters and clean ventilators so they can do that for their kids all day long. But when those kids get out into the world, nobody should demand that they be followed around by nurses and physical therapists and who knows what other obviously-out-of-place medical professionals simply so they can eat lunch or go to the bathroom. In natural settings, we *want* people with disabilities to get help from natural supports—friends, co-workers—for at least some of these things. Not because it’s cheaper, but because it takes away the stigma of being “special”, “fragile”, separate from others and in need of expert handling. So again, let’s pause before we charge ahead to do battle with the facts of this case.

DOJ filed its complaint in federal district court on July 22, alleging violations of the ADA’s prohibition on discrimination on the basis of disability by state government. They might have been better off citing Medicaid law, or even the Individuals with Disabilities Education Act (for the 45 minutes of school per day thing). But we’ll let you know what happens.

Forziano v Burke: Together Again

Last time, we reported on Paul Forziano and Hava Samuels, a married couple with developmental disabilities whose group “home” providers would not let them live together. One agency reportedly claimed it wasn’t specifically required to support married couples; the other, operated by the Catholic Church, said it didn’t believe Samuels was capable of consenting to sexual activity. So the families of the couple sued everybody they could think of, including OPWDD Commissioner Courtney Burke, in federal district court, alleging ADA violations.

We weren’t able to see the actual complaint, but some news reports said Forziano and Samuels were arguing their case under ADA Title II, which covers state and local government. The group “home” agencies are cited as defendants even though they are private organizations. They get government money, but it’s the responsibility of NY State, and its Office of People with Developmental Disabilities (OPWDD), to enforce the rules among subcontractors.

Various news reports were confusing on OPWDD’s response to the suit. However, shortly after we went to press another provider agency offered the couple a “one-bedroom apartment inside a group home” that had been used by live-in staff. They moved into the apartment in early July.

Meanwhile, the couple’s parents made a settlement offer to OPWDD, which the agency rejected. The contents of the offer were not disclosed.

Therefore, the lawsuit continues, though it’s hard to see how it can survive once a judge hears that the couple has their apartment. The parents say it’s important to force OPWDD to clarify what requirements group “home” operators must comply with, in case something goes wrong with the couple’s situation in the future and they have to move again.

As we reported, group “home” operators must provide individualized supports to meet the needs of each resident. They aren’t allowed to refuse to support married couples merely because they are married. On the other hand, they can’t be forced to move other people who don’t want to move to different group homes to enable a couple to live together, and they probably can’t be forced to physically modify a facility to provide larger living quarters for a couple, at least, not without getting additional funds.

But a judge is likely to say the case is moot because the couple no longer has anything to complain about. We'll keep track of this and let you know.

DAI v Cuomo: The Dust Settles

In July a settlement was announced in this long-running lawsuit regarding people with mental health disabilities living in adult "homes".

The suit was filed in 2003 as *DAI v Pataki*, in the wake of a New York Times' expose of inhumane and abusive conditions in several adult "home" facilities in and around New York City. The facilities are very large (80 – 200+ "beds") single-room-occupancy boarding houses that provide minimal support services to residents. Disability Advocates, Inc. (DAI) and several other plaintiffs alleged that the state was violating the Americans with Disabilities Act (ADA) because adult "homes" are institutional settings and the residents could be better served in more integrated settings.

Nearly 6 years and 2 governors later, federal District Court Judge Nicholas Garaufis agreed and ordered the state to move 4500 residents with mental health disabilities out of the facilities and into "supported" living within 3 years. The state slowly began making plans for the moves, while appealing the ruling. (See *AccessAbility* Winter 2009-10.)

Three years and one governor after that, during which the federal Department of Justice (DOJ) got involved, a federal appeals court overturned the decision on the technical grounds that DAI did not have standing to sue. (See *AccessAbility* Summer 2012.) At the time, DAI was a subcontractor of the Commission on Quality of Care (CQC), a state agency that ran the federally-funded Protection and Advocacy for people with Mental Illness (PAMI) program. The authority to bring certain types of lawsuits was vested in CQC, the court said. However, the court did not dispute the facts in the case, and while it suggested that Garaufis' order was a bit extreme, it urged the parties to settle, since there were clear grounds for someone else, like DOJ, to file another lawsuit that wouldn't have the same technical problems. Settlement talks got under way.

Meanwhile, the CQC became the subject of a blistering report by the federal Department of Health and Human Services for failing to be an effective independent watchdog on other state agencies.

As a result of this and the OPWDD abuse scandal, the state abolished the CQC and designated DAI,

now known as Disability Rights New York, as the official administrator of Protection and Advocacy programs for the state. (At the same time, it created the Justice Center for People with Special Needs to take on the CQC's other duties.) This removed the appeals court's technical quibble.

In January 2013, NY's Department of Health (DOH) announced that large adult "homes" were no longer appropriate housing for large numbers of people with mental health disabilities. A so-called "Transitional Adult Home" is an adult "home" 25% or more of whose residents have mental illness. DOH said that adult "homes" with 80 or more beds that are under 25% can't admit anyone with a mental illness if it would cause them to reach 25%. DOH also prohibited local hospital psychiatric in-patient units from discharging patients to transitional adult "homes", and "advised" the state Office of Mental Health that its psych centers should not do so.

Finally, this July, a settlement was announced. It is less sweeping than Garaufis' original order. Now the state has 5 years to "assess" the residents of the affected adult "homes" and decide whether to offer them the option of moving to supported living. 2500 residents must be assessed within 4 years. The settlement states, "community integration and self-determination shall be key considerations in the assessment process." Also, assessors must assume that every adult "home" resident is able to move to a more integrated setting. Only those with "significant dementia", who need "nursing care" that can't be provided in the community, who are "dangerous" to themselves or others, or whose needs can't be met by a Medicaid-funded, or suitable other, program (Meals on Wheels was the cited example), won't have the option. The settlement assumes that all of the affected people already are, or will be, enrolled in either a "health home" or Medicaid Managed Long Term Care, and will, as a result, get person-centered planning.

The state is committed to develop at least 2000 "scattered-site" supported housing settings (including 1050 already in progress), and as many more as needed to meet the needs of those who opt for it. The state is also required to provide an array of community-based services, including but not limited to psychiatric rehab, assertive community treatment (ACT) services, employment services, homecare, and care coordination, to people living in the affected adult "homes", whether or not they opt to move to a more integrated setting.

Clarence Sundram, last seen as the Governor's "special consultant on vulnerable populations", who prepared an excellent report on abuse and

neglect in the state's institutional settings (he was a CQC chairperson in the previous century), was appointed Independent Reviewer for the settlement, with a budget to hire staff and issue annual reports on compliance.

At press time, Judge Garaufis still needed to approve the settlement. Nobody expected that he would not.

This is a pretty good result. The requirements to provide person-centered planning and specific community services, including ACT, should force the state to actually budget for, and assure availability of, those services (see page 3 for another new way to pay for them). The mandate for scattered-site housing is very important, because up to now, many "supported housing" projects funded by Cuomo's various projects haven't met that requirement. But there are some quibbles.

The settlement lasts for 5 years, after which NY's obligation to provide the mandated services ends. The specific requirements to assess and offer more integrated services to residents only applies to a specific set of adult "homes" in and around New York City. (The new DOH regulations affect the entire state, but adult "homes" with 80+ beds are rare outside NYC.) And most galling, the state still denies that its adult "home" policy ever violated the ADA.

What Happened to Olmstead?

Earlier this year, with much fanfare, Governor Cuomo announced creation of an "Olmstead Cabinet" to finally produce a "real Olmstead Plan" for the state.

The 1999 US Supreme Court *Olmstead* decision said it's illegal for state governments to refuse to provide services to people with disabilities in the most integrated settings appropriate to their needs if they serve people with disabilities at all. The decision also said states would have a defense against lawsuits on this issue if they had an "effectively working plan" to ensure that the most integrated settings are an option for all who want them. If the state has waiting lists for those services, people must move off them at a reasonably quick and steady rate.

In 2002, under heavy pressure, Governor Pataki signed a law to create the Most Integrated Setting Coordinating Council (MISCC), a committee of state agency heads and some people who

represented people with disabilities, advocacy organizations, and service providers. The MISCC was supposed to produce a plan to transform services to more integrated models. The committee had no power, and was deliberately dysfunctional as run by OPWDD Commissioners. It was supposed to produce its plan within one year. It still hasn't done so, 11 years later.

When Cuomo came into office his staff basically just laughed at the MISCC, but there was some pressure from advocates to keep it going. New (and some better) people got on the Council and began making plans to make the process more public and more controlled by people with disabilities instead of state agencies. That's when Cuomo announced his Olmstead Cabinet.

The Cabinet includes only state agency heads and members of Cuomo's administrative team. There is no formal role for any people with disabilities or advocates. Roger Bearden, formerly a well-regarded disability rights lawyer, and then, for a brief period, Chairman of the now-defunct Commission for Quality of Care, was appointed Cuomo's "Special Counsel for Olmstead", and he has an (at least publicly) undefined role in the Cabinet.

The Cabinet was supposed to produce the "real Olmstead Plan" sometime this summer. So far, it has been completely silent. It is not acknowledging input from the disability

community, and is refusing to tell anyone what is going on. Advocates, who were suspicious of the Cabinet from the start due to its lack of representation from people with disabilities, are very frustrated about this, and growing moreso by the day.

What Happened to the Partnership Waiver?

Many years ago, the NY State Department of Health (DOH) started an 1115 "experimental" Medicaid Waiver to bring managed care to the state. This waiver grew to include the "F-SHRP" waiver, which, among other things, committed NY to "recover" steadily increasing amounts of money from so-called "Medicaid fraud" (mostly just accidental billing errors).

When the Cuomo Administration came in, with its push to make all of Medicaid "managed", it renamed this waiver the "Partnership Plan" and proposed amendments designed to get another \$10 billion in federal Medicaid money to support its various managed care/supported housing/service expansion ideas. The amendments are a hodgepodge of things, some of which are good ideas, and others of which read like they were cooked up by a bunch of idealistic college students who never worked a day in their lives with real people with disabilities.

Negotiations with the federal Centers for Medicare and Medicaid Services (CMS) over the amendments went even worse, if that's possible, than they did over OPWDD's "People First Waiver" proposal. And a few months ago CMS demanded a "Transformation Agreement" be added to the amendments. The Agreement mostly sets aggressive, specific goals for OPWDD to meet over the next year, including stopping referrals to sheltered workshops (already done), and producing a plan to downsize and close ICFs (coming next spring). Along with those things, the Agreement requires that all forms of Managed Medicaid Long Term Care in NY provide person-centered planning, offer individual budgets and self-direction to all recipients, and emphasize integrated services.

The Transformation Agreement is a definite good thing, and the state is proceeding as though it's already been approved—as far as it can, without actually having any money. But CMS says the state hasn't adequately explained how it's going to spend all of the money it's asking for, and until it does, no approval will be forthcoming. If this goes on much longer, it will affect things like the roll-out of managed long-term care upstate and for people who are dually eligible for Medicare and Medicaid, as well as development of more supported housing units. So we're all waiting on pins and needles here....



STIC's Honor Roll

Every year we hold a luncheon to honor those who have furthered the cause of people with disabilities through advocacy, helping individuals, or supporting STIC. This year's event took place on June 27.

These are no ordinary people; each one of them has gone well beyond the call of duty to make a difference. We never get tired of saying it:

THANK YOU!

COMMITMENT TO COMMUNITY SERVICE

Christ the King Lutheran Church

This congregation provided very generous support for people with disabilities and their families after both recent floods, and during the holidays each year.

The Impact Project

Jim Willard III, Director

The program organizes volunteers who build ramps, make bathrooms accessible,

repair roofs, and any other construction projects that people with disabilities need. This awesome group gets supplies donated or deeply discounted, and can put 30 to 50 volunteers on a project and finish it in a day.

Joe Santacrose Foundation

Jim Santacrose

Jim Santacrose created the foundation in memory and honor of his son Joe. It supports children in sports, and collects and distributes donated items such as furniture. It has been very generous to people with disabilities.

LIFETIME ACHIEVEMENT IN INDEPENDENT LIVING

Greg Jones, Attorney

NYS Office of Advocate for People with Disabilities

Greg is retiring after a long career of intense dedication to disability rights. His expertise on the Americans with Disabilities Act, and

ability to provide critical information on a range of issues, will be sorely missed.

OUTSTANDING BUSINESS SUPPORT

BAE Systems

Steve Kraly

Steve is a longstanding, strong STIC supporter who has organized other BAE employees to volunteer for our fundraising events, support families during the holidays, and make cash donations.

Miller Auto Team

Steve Miller

Steve provided substantial advertising support for our Haunted Halls of Horror fundraising event.

Warehouse Carpet Outlet

The company generously donated huge quantities of carpet to help construct the Haunted Halls in our basement.

Wegmans Food & Pharmacy

Donna Cook

Donna and the company have provided ongoing cash and in-kind support for our major fundraising events and many other smaller events.

OUTSTANDING CONSUMER SUPPORT

Debra Brunette

Debra has adopted seven children with disabilities. Her wonderful family has made sure all of the children are included in general education classes. They are great advocates for children and kind, supportive, generous people who are an example for us all.

Jill Coleman

Binghamton High School

Jill, an Autism Consultant and Work Study Coordinator, is highly supportive of students with disabilities. She goes the extra mile in her work for inclusion and integration.

Debbie Grassi

Achieve

Debbie works in the Family Empowerment and Respite programs. She goes above and beyond to provide services, and is extremely accommodating no matter how short the notice.

OUTSTANDING SYSTEMS ADVOCACY

Maureen Lee

Maureen is an ADAPT member who is committed to disability rights and works tirelessly on many issues.

Lillian Wozniak

Lillian has spent a lifetime advocating on a variety of issues.

OUTSTANDING VOLUNTEER SUPPORT

Dennis Guzalak

Dennis has supported our Haunted Halls of Horror since it began, donating many of the scary things you see there.

JoAnn Kieffer

JoAnn is a multi-tasking volunteer who takes on the hard job of cleaning our loan closet equipment, helps with events like our Carnival last June, and works to get adapted bikes to children with disabilities at very low cost.

James Lynch

James volunteered at our Carnival and other events, and he got Security Mutual to help support families of people with disabilities during the holidays.

Anthony Paradiso

Anthony is a dedicated Haunted Halls of Horror volunteer from BAE. He keeps the sound systems running, provides security, and takes on many other tasks.

C. J. Scharfenstein

C. J. is a makeup artist who has helped with donations and getting people “uglified” for the Haunted Halls of Horror for several years. She also helped out with our Carnival last June, including getting people to agree to be dunked.

Find the Way to a New York State of Health

by Maria Dibble

STIC is pleased to announce (pending the fulfillment of contract requirements) that we’ve been awarded a grant to assist individuals to obtain insurance through “New York State of Health”, the state health benefits exchange.

The health benefits exchange is a new concept created by the Affordable Care Act, whereby people can choose from among several affordable health insurance plans. Our project, the “In-Person Assister Navigator Program” (no, we didn’t name it), will provide information to people about their health benefits options, and assist them to select the best plan for their needs and enroll in the plan of their choice. STIC will offer this service in nine counties, with the help of our two subcontractors, Corning AIM and Catskill Center for Independence (CCFI).

STIC will have offices in Cortland, Chenango, Tioga and Tompkins Counties; CCFI in Schoharie County; and AIM in Allegany, Chemung, Schuyler and Steuben Counties.

Our three agencies will conduct intensive outreach to all parts of our 9-county region by offering daytime, evening and weekend hours at a wide variety of locations in addition to those offices. People will be able to enroll beginning in October 2013, with the actual plans going into effect in January 2014.

For more information, contact STIC at (607) 724-2111 (voice/TTY) or toll-free at (877) 722-9150.

Even More Health Information

by Elizabeth Berka

We have a new department at STIC: the Health Information Program!

Hello, my name is Elizabeth Berka, and I am the new Health Information Specialist. I have a Bachelor of Arts in Psychology from Le Moyne College and have experience working with OPWDD and long-term care.

I am passionate about finding answers to your healthcare related concerns. As many of us have come to realize, healthcare is multifaceted and far from transparent. I am here to guide you through it.

There are many upcoming changes to the NYS healthcare system, including changes to the Medicaid program. I am happy to explain these changes to you and give you informational handouts so you may reach a better understanding. Training materials on the Affordable Care Act, Medicare, and Medicaid managed care are available upon request.

Please feel comfortable contacting me Monday through Friday 9 am - 4:30 pm. My contact information is as follows:

healthinformation@stic-cil.org
(607) 724-2111 extension 304
Toll free: (877) 722-9150 (voice/TTY).

No Place Like Home: Integrated Housing Coalition

by Maria Dibble

STIC is forming the “No Place Like Home Integrated Housing Coalition” to bring new housing options to our region for people with all types of disabilities.

The need for affordable accessible housing that is integrated in the community has never been greater than it is now. As people are leaving nursing, group and adult “homes”, developmental centers, and other segregated environments, they are looking for homes that are physically accessible, near bus lines, and convenient to services but not tied to them.

Options in our area are limited, as is funding. Yet there are creative resources and programs being developed around the state and the nation that could benefit our community. This coalition will explore them in more detail, and develop action plans to bring new alternatives to the area.

Our first meeting was held September 4. There is lots of work to be done and the more different agencies, consumers and advocates that can join the process, the better our chances for success.

I know that other housing coalitions exist for a variety of purposes, but none has the sole focus of addressing the needs of people with disabilities. And it isn't just about a place to live, it's also about making sure that support services exist in the community to meet the needs of people with significant disabilities. Just as none of us would want services based in our homes, neither do people with disabilities, so these services must be separate from people's apartments or houses.

STIC wants to collaborate with others to develop a comprehensive housing plan for our community to meet the unique circumstances faced by people moving out of more segregated settings. Alone, this task would be daunting, but with your input, we can make it happen.

If you would like to participate in an action-oriented group working to meet the ever-growing housing needs of adults with all types of disabilities, then this coalition is for you.

Just click your ruby slippers together three times and say, “There's no place like home.” Then email Maria Dibble at mdibble@stic-cil.org or call me at (607) 724-2111 (voice/TTY) to be added to the mailing list and find out more details.

Haunted Halls

by Bill Bartlow

The Southern Tier Independence Center's “Haunted Halls of Horror” Fundraiser will, in 2013, unveil its fourth season of Halloween fun for our visitors.

In the previous three years we have watched and listened to the reactions of attendees as they emerged from the attraction. We have done our reviews, our post-mortems, and are always brain-storming with the intent to make it a bigger and better haunt. We aren't satisfied with the overwhelming acclaim that ours is the best haunt experience in the area. We attended the 2013 National Haunt Convention in Philadelphia to hobnob, consult and cavort with our fellow wizards of “ween”. We were proud to find ourselves right on track and up to speed with other Halloween attractions. It was clear that the ultimate thrill for all was in seeing the reactions of those who visit our haunts.



Haunted Halls of Horror

October 11, 12, 18, 19, 25, 26, 31
6:30 pm – 9:30 pm

Matinees!

October 19 & 26
2:00 pm – 4:00 pm

Tickets

Advance Sale: \$6.00 through
October 8
At the Door: \$8.00

STIC
135 E. Frederick St.
Binghamton

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

We're out to get you. We're out to startle, surprise, scare, make you squeal, give you that adrenaline rush, out to give you that “fight – flight” fright. We're always looking for something new and even better each year.

So that's why we found ourselves driving a 24-foot U-Haul north on route 81 on a dark snowy February night. That truck was filled with the contents of an Ocean City, NJ “Zombie House”. Yeah, we've brought a professional Boardwalk haunted house attraction to Binghamton. Our drivers may have been a little white-knuckled on the steering wheel at the time, but the satisfaction of seeing visitors lose all color as one of our new characters lurches out from the darkness is our reward.

Our 13,000 square foot Haunt is indoors, so don't worry about the weather. We're on: Rain, Blow or Halloween snow. Our creatures will be below awaiting your arrival. The facility is fully accessible. Be cautioned that this is no “Happy- Jack-O-Lantern-Cute” format and is not appropriate

for the very young or overly sensitive. An alternate location at STIC for age-appropriate holiday fun will be available for your supervision of the youngsters.

Pre-event tickets will be \$6.00 each through October 8. After that, and at the door, tickets will be \$8.00. More information is available on our web site: www.HHH-STIC.com.

STIC Tuesdays!

Southern Tier Independence Center has gratefully partnered with Ruby Tuesday in the Oakdale Mall. Ruby Tuesday has a "Community Give Back Program". Enjoy a meal at Ruby Tuesday on any Tuesday during August and September; mention the Give Back Program to your server, and 20% of your purchase total will be donated to STIC to support our fall fundraising efforts.

We encourage you to patronize local businesses that are truly participating community members and generously give back to help meet the needs of those in our area.

Hey, you gotta eat. Treat yourself and your friends and family to a great meal, superb service, and help out your neighbors all at once. See you on Tuesday!



Who says the Mayor's all wet??

Life's a Carnival

by Maria Dibble

On June 1, 2013 the sun shone on a scene of fun and excitement as people of all ages lined up at our gates to attend the first major event celebrating 30 years of service to the community.

Carnival music played in the background as 700 or so children and adults consumed free hot dogs, cotton candy, cookies and other goodies and played games, had their faces painted, were amazed by a juggler and magician as they performed their arts, and watched Mayor Ryan and others get plunged into the dunk tank. And what a day to be dunked! The temperature was in the 90s, the humidity was high, though there was a breeze, and luckily for us, not a drop of rain fell.

We were gratified to see the public enjoying the day's activities, while they gathered information about STIC, met many of our staff, and in some cases made contributions in recognition of the work we do. Some old friends we hadn't seen for years came from as far as 50 miles away to join in our celebrations, and we thank everyone for making it a very successful event.

Q & A: Service Coordination and DISCOs

In August, STIC hosted an informational meeting for people with developmental disabilities and their families to tell you what we know, and don't know, about the changes that are happening. Here's what we said, plus some stuff we didn't have time to say:

What the F...ront Door!??

Recently the NY State Office of People with Developmental Disabilities (OPWDD) rolled out a new process for people who are new to the "system", or are asking for new services. This is called "The Front Door". Why did they do this?

OPWDD has been pushed by the federal government to strongly promote "self-direction" and choice in services. The agency was told it must have more than 1200 "new" recipients of self-directed services by March 31, 2014. OPWDD was also told that it can't monopolize federal Medicaid funds the way it has in the past. It must do more with less.

Is this fair? We think it is.

OPWDD, for decades, has been the most expensive DD service system in the nation, and it has distributed most of that money unfairly, on the "squeaky wheel" principle. That is, money flowed to people who either created a public crisis (Willowbrook, the lawsuit resulting in NYS CARES), or had the most effective advocacy (such as people admitted to developmental centers after such admissions were officially "closed", because their families twisted somebody's arm).

Also for decades, OPWDD has resisted giving people with disabilities control over their lives and their services even as most other states have done so. In the late 90s, other states began offering "Self Determination" programs: People with developmental disabilities, working with people they chose, set up real individual service plans that met specific needs in creative ways, using funds that they budgeted themselves. These programs were flexible and user-friendly. NY didn't have this, but after years of frustrating discussion with advocates, OPWDD created "Community Support Services" (CSS): a perverted, rigid version of the concept that is the opposite of user-friendly. The agency also refused to pay for much help for people to navigate the program. For these reasons, agencies tend to discourage people from using it. That's no accident. We

ENJOY A MEAL WITH US AND WE'LL GIVE BACK.

RubyTuesday

COMMUNITY GiveBack PROGRAM

100% OF THE GIVEBACK AMOUNT IS DONATED DIRECTLY TO THE ORGANIZATION.

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were involved in the program design. OPWDD's lawyers and accountants were clearly afraid of it, and wanted to limit it to the smallest number of people possible.

Then came the scandal over abuse and neglect in facilities operated, or paid for, by OPWDD. Old bureaucrats were fired, and new leaders who weren't part of "the system" came in. These new leaders were actually not cynical about disability rights. They meant it when they said that people with disabilities should be as integrated as possible in their communities. And they didn't owe anything to service agencies that make their living from segregation, or to politicians who support those agencies. They also weren't prepared for the firestorm they were stepping into.

When these new leaders asked for public input, they heard the same thing over and over: Provider agencies don't offer real choices. They "self-deal"; that is, they only tell people about the services that they themselves provide. They won't tell you that a competitor down the street offers something different. We had heard that locally for decades. Now OPWDD leaders were hearing it, and if they still didn't quite believe it, they couldn't ignore it.

OPWDD had to do something about all this. But their first try didn't cut it. The "People First Waiver" plan talked about increasing person-centered planning, self-direction, choice, and community integration—but very slowly, over 5 or 10 years. Officials at CMS (the federal Centers for Medicare and Medicaid Services) were on the hotseat over OPWDD's Medicaid-hogging (which may yet amount to criminal fraud; the investigations aren't over), and they were extremely upset about the abuse scandal too. Plus, CMS had been working for years to change the rules for Medicaid waivers like OPWDD's, to require real integrated resident-controlled living situations instead of cookie-cutter group "homes", and the Justice Department was suing states for failing to serve people with disabilities in the most integrated settings. No, CMS didn't like a lot of things about the People First Waiver, and as negotiations dragged on, they put their foot down. No, they said, you won't take 5 to 10 years to reform your system. You'll do it RIGHT NOW.

Not only does OPWDD have to deliver results on self-direction, it has to stop violating the federal rule that ICFs (including small ones) are transitional facilities, not permanent homes, and produce a plan to close most of them. It must emphasize real jobs, for real wages,

not "workshops" or "day programs". And it must make sure that all of these things happen everywhere in NY, not just at progressive agencies that like the idea.

So they created the "Front Door", which is supposed to do the following:

1. Ensure that people can't get expensive segregated services that aren't justified by real need.
2. Before anybody talks about services, make sure a person's interests, preferences, abilities and life goals are thoroughly understood in an objective, verifiable way.
3. Encourage people to use self-direction to define custom services instead of being plugged in to rigid, pre-defined service categories with limits on hours, locations, or types of activities, so the services will not be too little, or too much, but "just right" to achieve their goals, which will save money as well as be more effective.
4. Provide the same exact—and complete—information to every OPWDD consumer.

The concept of the "Front Door" is a great idea and sorely needed. But OPWDD has botched it in a huge way. What did they do wrong?

Poor Prior Planning Produces Poor Performance

At around the same time CMS lowered the boom, OPWDD Commissioner Courtney Burke, the new leader with the vision and courage to really change the system, left. She is now Cuomo's Deputy Secretary for Health, responsible for overseeing the state's entire Medicaid "reform" process. That is likely a good thing. But she was gone for several weeks before it was publicly announced, and that kind of stuff rarely bodes well.

For whatever reason, the people she left behind responded to CMS's demands not in a calm, organized way, but by issuing frantic memos demanding wholesale change to the service system without first figuring out, step-by-step, what they were going to do. As a result, OPWDD employees were told to stop doing business as usual and do things the "front door" way without having even been trained on what that is. If we didn't get the story from people at the agency whom we trust, we would have thought it was an excuse for foot-dragging and sabotage by people who don't like these changes. But it's not. That's actually what happened.

In Memoriam: Milrene Smith

by Maria Dibble

Milrene Smith, a founding board member of STIC, passed away on August 23, 2013. Milrene was strongly committed to the pursuit of disability rights, community integration and the concept of self-direction of all services. She was the first person in Broome County to participate in our Consumer Directed Personal Assistance Program, after spending several years advocating for its establishment and implementation. I have never met anyone with as sunny a personality as Milrene. Ever ready with a joke, she was equally ready with her support of STIC, CDPA and people with disabilities. She will be sorely missed. Our deepest condolences go out to her family in their time of grief.

So then they trained some staff, but kept changing what they told them. And they began doing public trainings for consumers and their families.

In August we hosted one of those trainings. Some of it was good. The message that self-direction is good and people should go for it was well-presented. The videos are excellent. Other things—not so much. We aren't blaming the presenter. We know the presentation was canned, passed down from above. But if this is going to work, then there are things that have to be fixed.

Maybe the biggest problem is that all we've got for self-direction is CSS. OPWDD has to realize that it can't meet its self-direction goals if it doesn't make that program much simpler and more flexible. Such changes were hinted at as part of the People First Waiver planning process, but the agency hasn't committed to anything. It needs to fix this sooner rather than later.

It sounded like they tried to make the language of the presentation simple to understand, but they didn't really succeed. There is still too much service-agency jargon, and some of it just sounds condescending. The text needs to be edited by an experienced adult-education writer.

The presentation is too long. It needs to focus on the things that are most important to people who

are seeking pretty-near immediate help. They should drop the history of OPWDD as well; frankly, nobody cares.

The issue of eligibility is harder to deal with. That's because the definition of "developmental disability" is really complicated, and so are the Medicaid hoops people have to jump through. People do need to understand why they get denied services and what they can do about it, but this part needs some polishing.

We understand why we at STIC aren't allowed to provide this training. Unlike many other agencies, we promote self-direction and integration, and we truthfully tell people about all of their options, at STIC and the other programs in the area. But OPWDD doesn't know that and can't make different rules for different providers. We hope they get better at the "Front Door" thing, but until then, if you choose STIC services, when you get here we'll explain it better.

What's the Difference between a DISCO and the "Front Door"?

Biggest difference? The Front Door is here, but DISCOs aren't, and won't be for a while.

The essence of reform is that people with developmental disabilities should:

1. Be objectively and carefully assessed to find out what they really want, can do, and need
2. If found eligible for help from OPWDD based on that assessment, next go through person-centered planning to figure out how to translate those wants and needs into action, with the person controlling as much of that process, and making as many decisions, as possible
3. Have a plan that is not limited by rigid service definitions and meets those preferences and needs in very specific, individual ways, using a budget that the person controls
4. Get help to carry out the plan from people who are best equipped to get the specific things done that the person needs

The order of those steps is important. We don't start with a menu of defined services anymore; customizing services specifically for you only happens once we know if you really need anything at all, and if so, what the facts are about that. Gone are the days when you could come to OPWDD and say, "I want a 24/7 community residence," and just get it, or at least get on a waiting list for it. Instead, we're going to ask

things like: Can you make a simple meal? Show us how. When you aren't at work, do you find other things to do that you enjoy? How long does it take you to get ready for work in the morning and what help do you need with that? What kind of people do you like being around? What kinds of people annoy you? Once we have all of that very detailed information, then we can figure out what sort of help you really need in the places where you really want to be, and then we go from there to make that happen.

This process is what the People First Waiver plan intended to use, many years from now. When DISCOs get started, it's what their "Care Coordination Teams" will do. Until then, we have the "Front Door".

DISCOs will start as pilot projects, not earlier than next April and probably a lot later than that. They may not be available everywhere in the state, and as long as they are pilots, nobody will be forced to use them. They will only serve people who volunteer to take part in this experiment, and that's going to be true for at least 2 or 3 years. If DISCOs are done right, you will benefit by volunteering. But it's too early to say.

The other different thing about a DISCO is that it's managed care. But that's in the future, and it's not clear how the final product will work, so we won't spend time on that now.

Can You Keep Your Service Coordinator?

Short answer: We don't know.

Let's try to expand on that. You're probably asking, "My Service Coordinator is Joe Smith. Can I keep him?"

The old system is going away. Services and how they are delivered will change. This cannot be stopped. It is beyond the power of anyone in NY to stop it. The state has abused (and perhaps literally stolen) billions of federal dollars over 20+ years, and there is no sympathy in the federal government for us. Rightfully so, because that money was taken out of the hands of people like you who can't get many of the services that you take for granted.

The job title "Service Coordinator" is dead; it just hasn't fallen over yet. We will have Service Coordinators on staff until the new DISCOs roll out. "Joe Smith" will probably be one of them. After that? In the place of service coordination as we know it, there will be something different—something that hopefully gets the same results, but in a different way.

At first, DISCOs will be experimental. We joined iCircle, an organization that will apply to "demonstrate" a DISCO. We don't think OPWDD will tell us how to do "care coordination", including both allocating funds and helping develop and carry out service plans. iCircle's application will say how we want to do it, and then we'll see if the state likes it.

We at STIC would like to keep all of our current service coordinators on staff and involved in providing the kind of help that they do now. We hope that will be possible. We intend for iCircle's application to show how it can work.

We do know that DISCO "care coordination" is supposed to be a team effort. We think that means different team members could have specialized knowledge to help you with different things. A real customized service plan for someone with a lot of needs will require that; it won't be possible for one person to be the "go-to guy" for everything. We also know that today's service coordination rules are rigid. Everyone will have a plan, but some people can manage their own plans, except for the most technical stuff. They shouldn't be forced to accept someone looking over their shoulder, and that means that those who need more help should get it.

And that's all we can tell you about that right now.

What Can You Do about This?

If you're concerned, you need to contact the new OPWDD Commissioner, and Deputy Secretary for Health Courtney Burke, and tell them, as specifically as possible, what you need.

Don't say, "I want to keep my service coordinator". Instead, tell them the specific things your service coordinator does for you, and why you need those things done under the new system.

Be candid about what you need. If your family member needs supervision while you go to work, say that. There's no shame in that. Don't say they need "day hab" or a "workshop" if the real problem is that somebody needs to watch them. Quite frankly, day hab and workshops are expensive; just watching somebody is much cheaper.

If your family member wants something more than just to be "watched"—and we hope they do; nearly everybody does—then of course explain that too. But understanding, and then fulfilling, people's real life goals doesn't happen quickly. You need both a short-term and a long-term

view. In the short term, make sure the person gets the supervision they need, because you have to go to work and you certainly can't provide it. It's a very simple service. It doesn't require a lot of education or training, or special tools or facilities. It should be possible to set up very quickly. Our state officials don't understand this. They need to hear it from you, honestly and simply.

Then, in the long term, listen to what your loved one really wants. If he wants "a job", he means a real job that has meaning and value, like you have, not a fake one that just occupies his time and attention. If he wants "my own house", then that's what he wants, not a house owned by an agency, where he doesn't make the rules or even decide who lives with him. Accept that this will take time, work with the person-centered planning process, and have faith that it will succeed.

Contacts

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OPWDD
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Albany, NY 12229

Deputy Secretary for Health Courtney Burke
(518) 408-2500

Trouble Getting Durable Medical Equipment?

A decade ago, Congress passed a law calling for competitive bidding for so-called "durable medical equipment and supplies" paid for by Medicare. That includes wheelchairs, blood sugar monitors and testing strips, canes, hospital beds, commodes, suction pumps and the like.

The program has been rolling out slowly. In July 2013, the federal Centers for Medicare and Medicaid Services (CMS) finalized Round 2 of the bidding program in 91 areas of the country, with 9 of those areas being in New York State. As a result of bids being awarded, some providers are no longer available. Since then, people have reported problems finding new providers for their durable medical equipment.

If you've had a problem with this program, email Fran Wishnick at the New York Association on Independent Living. They're keeping track of the problem and working with the New York Association of Medical Equipment Providers to resolve it. Email Fran at: fwishnick@ilny.org.



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