

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

AccessAbility

Fall 2012
Number 108

Through the Eyes of a Child

by Sue Ruff

As I write this, summer is waning and the new school year looms closer. Children would love the vacation to last. Some parents may actually be looking forward to the first day of school; but for some children, the educational experience may not hold good memories.

In April, Governor Cuomo established an Education Reform Commission “to recommend reforms to the state’s education system in order to improve performance in the classroom” (www.governor.ny.gov/press/4302012EducationReformCommission). While the needs of students with disabilities were not specifically mentioned in the Governor’s statement, one paragraph did mention at-risk students in high-need, low-wealth districts. In June the Governor appointed additional members to the Commission following criticism of the makeup of the panel. The Commission has been traveling the state for regional meetings (handled in much the same way as the Governor’s Medicaid Redesign Team—submit your written statement and you’ll have three minutes to speak before we ask you to stop).

On August 8, less than a third of the Commission members came to Binghamton University for three hours. From the Governor’s statement: “By Dec. 1, the group is supposed to produce a report with preliminary recommendations on a host of education topics that touches on nearly every major issue in education: teacher quality; test scores and graduation rates; funding distribution; parent involvement; technology; helping poor communities; and,

on top of all that, saving taxpayers money.” (<http://blogs.wsj.com/metropolis/2012/06/14/cuomos-high-powered-education-committee-gets-to-work>) The list of Commission members at the above link includes two former Citigroup chairmen, a billionaire hedge fund manager, two legislators, a teacher’s union president, a newly elected school board member, the CUNY Chancellor, the NYS Education Commissioner, and sixteen distinguished others. As I observed the presenters at BU I wondered how many members of the Commission either attended a “high-needs, low-wealth” school themselves or had children in such a district? One of the people who testified that day was a teacher who lived in a wealthy district but taught in a very poor small city system. Her comparison of the disparities was stark and very real.

We have all heard about high-stakes testing, the loss of teaching jobs and programs in many districts, and the shrinking of inclusive options for students with disabilities as the numbers of students in typical classes climbs higher every year. Several speakers at the hearing mentioned the loss of supports that keep children in school. That night I asked my three grown children who their favorite teachers had been and why. They described teachers who were caring, who were passionate about what they taught, who believed in their students while recognizing students’ gifts as well as their needs. My children mentioned teachers who were creative in helping them learn and figure out problems, who helped them appreciate the abilities of other scholars, who

INSIDE

STIC Housing Conference.....	pg 3
The MISCC Revives ... Again.....	pg 4
Medicaid Likes and Dislikes.....	pg 4
People First Waiver ABCs.....	pg 6
Final Justice.....	pg 8
CourtsWatch.....	pg 10
DOH Waives Telling the Truth.....	pg 12
Manage Your Smile!...pg	12
STIC’s Honor Roll.....pg	13
STIC Open House.....pg	14
Haunted History.....pg	14

were down to earth, who had good senses of humor, and who respected and treated them as peers. As those teachers’ names flashed in my memory, I recalled the times I had observed them in the classrooms and the comments they had made on report cards and in conference meetings. They were gems! I wonder if the educational environment for children today will result in their being able to say, as adults, “I had some favorite teachers and this is why they were my favorites.” I hope this criterion is on the radar screen of the Governor’s Commission.

Around the time (April) the Governor was appointing people to his Education Commission, Corey Foster, a student at a residential school in Yonkers, was restrained

AccessAbility

September 2012

EDITOR IN CHIEF: MARIA DIBBLE
EDITOR: KEN DIBBLE
LAYOUT: RUSSELL RICHARDSON

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

Our address is:

AccessAbility

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

Subscriptions

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

Advertisements

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

Reprints

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

Authorship

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

www.stic-cil.org



by five staff and died. His death was ruled an accident. Also in April, lawyers for another NY student, Andre McCollins, played a graphic video of the GED (Graduated Electronic Decelerator), a device that delivers electric shocks, that was used on Andre at the Judge Rotenberg Center (JRC) near Boston, MA. A judge had ordered the showing of this video that depicted seven hours of torture for Andre in one day. Andre's mother had found him in a catatonic state when she came to visit him. Within hours the video was all over news programs and internet sites. The family and JRC settled the family's lawsuit before the case went to the judge.

The day after I attended the Education Commission hearing at BU, I drove a few people to Albany to join some other groups who were demonstrating in 90-degree temperatures against the placement of NY students in the Rotenberg Center. All the speakers asked how the state could pay \$90,000 to \$220,000 a year to send NY children to the "only facility in the country, and likely the world that uses extremely painful electric shock to control the behavior of people with disabilities". One expert, James Eason, Professor of Biomedical Engineering at Washington and Lee University, has said, "Technically, the lowest shock given by Rotenberg is roughly twice what pain researchers have said is tolerable for most humans."

The majority of JRC's students come from New York State. "In the past, New York banned the use of contingent electric shock on any student from New York, but there is still a large student population at the JRC from New York supported by public funding." (www.change.org/petitions/the-governor-of-ny-stop-the-flow-of-taxpayer-dollars-to-support-torture)

It is currently impossible to find hard data on how many children in or from NYS are being subjected to restraint, seclusion, or various kinds of treatments that are very painful.

Last summer, Tim Harper wrote in *219 Magazine*, "New York's Boarding School of Hard Knocks", "At a time when New York State education officials are slashing programs because of budget shortfalls....

records from the New York City Comptroller show the city alone paid nearly \$32.5 million to the Rotenberg Center during fiscal year 2011. Of that, \$16.8 million came from the city Department of Education. The balance comes from the Administration for Children Services. Hundreds of thousands of dollars also come from other local school district funds to pay for students from elsewhere in New York State....these NY funds cover about two-thirds of the facility's annual operating budget. This despite the fact a top United Nations' torture investigator decried the institution's methods and called for further investigations." (<http://219mag.com/2011/08/24/controversial-mass-school-depends-on-ny>)

Harper's article mentions that over one hundred students from NYC attend JRC. JRC invests some of their tuition funds into promotional radio ads: "Is your child autistic or emotionally disturbed? Unmanageable, failing in school or refusing to attend or stuck in psychiatric or correctional setting?" I recall attending a BOCES CSE Chairs meeting a few years ago that featured a presentation from a JRC marketer. Very slick brochures were handed out to the CSE chairs. One chairperson who heard the presentation told me later, "If I had \$200,000 to spend on a student, I could do a lot right here."

While some children ended up at JRC via the foster care system, many have been placed there by parents. In some cases when schools disagreed with placement, JRC offered information to parents about lawyers that would help them fight school districts and get court orders for treatment.

New York Senator Martin Golden and Assemblywoman Joan Millman filed legislation (S.6294A-2011 and A.9084A-2011) that would revise the law to prohibit any form of public funding to any school or program that uses aversive interventions. Electric shock is specifically mentioned in this legislation. *As of this date, no other legislators have signed on to either bill.*

Efforts to pass legislation regulating restraint and seclusion in non-residential public schools in New York State have also failed; they



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.

Conference
**There's No Place Like Home:
 Integrated Housing Options
 for Seniors & People with
 Disabilities**

Wednesday, October 17

Two Identical Sessions!

8:30 am – Registration

9:00 am – 12 noon – Speakers

1:00 pm – Registration

1:30 pm – 4:30 pm – Speakers



Intended Audience:

People with Disabilities, Family Members,
 Professionals

Presenters Include:

- New York State Association on Independent Living
- OPWDD (Home of Your Own, ISS/CSS, Family Care)
- First Ward Action Council
- Binghamton Housing Authority
- Town of Union (invited) — (First Time Home Buyers, Section 8)

8:30 am – 5:00 pm

Booth Displays Featuring Housing-Related Services in Broome, Chenango, & Tioga Counties

**Free of Charge!
 Light Refreshments Provided**

You Must Pre-Register By October 1, 2012

Name _____

Phone _____

Address _____

Agency (if any) _____

I Need:

Sign-Language Interpreter: Y N

Documents in Electronic Format: Y N

Other Accommodations: Y N

If Yes, What? _____

To Pre-Register & Request Accommodations:

Mail To: STIC

135 E. Frederick St.

Binghamton, NY 13904

Email: office@stic-cil.org

Call: (607) 724-2111 (voice/TTY)

By October 1, 2012

For More Information Contact:

Jo Anne Novicky or Jessica Arnold

(607) 724-2111 (voice/TTY)

are opposed by school administrators and teachers' unions, and legislative leaders have chosen to listen to them instead of to the students and parents and advocates who have provided dozens of stories of abuse and neglect of students with disabilities in those schools. (See *AccessAbility*, Spring 2009.) However, Massachusetts advocates scored one victory against the JRC and a federal appeals court awarded another this summer (see page 10).

At the federal level, S.2020 and HR.1381, bills that would protect children from aversives as well as unnecessary restraint or seclusion, have not passed. In July, Senator Harkin held a public hearing, "Beyond Seclusion and Restraint: Creating Positive Learning Environments for All Students" (www.help.senate.gov/hearings/hearing/?id=28ddb0d-5056-9502-5dea-7197eb6434c8). The mother of Corey Foster (the young man who died in Yonkers in April) attended the hearing, and Senator Harkin had spoken with her before the panelists began. Educators from Georgia, Virginia, and Pennsylvania described the success of positive behavioral supports. Cyndi Pitonyak, Coordinator of Positive Behavioral Interventions and Supports, Montgomery County Public Schools, Christiansburg, VA, spoke with eloquence and passion about her district's more than two decades of experience with inclusion and positive behavioral supports. She cited 40 years of education research and spoke about how her district pours resources into on-the-job training for teachers, especially at elementary levels. And she said, "We drew heavily from Johnson City, NY, 23 years ago when we began to do inclusion—we took buses of teachers up there... inclusion and positive behavior supports go hand in hand and we had to develop them together..." (at 96:43 minutes into the hearing). I highly recommend the entire hearing to students, parents and teachers. There is a better way.

We talk about getting people out of institutions and we talk about *Olmstead* and the most integrated setting, but will the Governor's Education Commission suggest aligning NY dollars and NY policies with best practices in regard to the education of all students with disabilities? NY adults who started out as students at JRC are coming back to NY because they are aging out. But many NY students under 21 are still there. And we have decades of experience knowing what we could do for these students instead of segregation and abuse. What memories will we be giving them? Where will they find favorite teachers?



Third Annual
**Haunted Halls
 of Horror**

**October 12, 13, 19, 20,
 26, 27, 28, 31, 2012
 6:30 – 9:30 pm**

STIC
 135 E. Frederick St.
 Binghamton

Tickets:
 \$5.00 advance
 \$7.00 at the door

PG-13: Parental Guidance
 Advised
 Not for Immature Persons

Separate Non-Scary
 Activities
 Provided for Younger
 Children

Refreshments Available

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

STIC is on the Web



www.stic-cil.org

STIC and *AccessAbility*
 DO NOT endorse any claims made
 by advertisers in the newsletter.



The MISCC Revives ... Again

As the season approached when green things die and Halloween heralds the grisly reappearance of the walking dead, news came that the moribund MISCC would once again return from the grave.

During last spring's debate on Governor Cuomo's Justice Center, which arose from "Vulnerable Persons Advisor" Clarence Sundram's report on neglect and abuse in residential settings, advocates demanded that NY follow Sundram's recommendation to make the use of segregated congregate facilities the "last resort". Although the Justice Center doesn't do that (see page 8), Cuomo promised that we'd hear something within a month.

A bit over a month later, it was announced that the state's Most Integrated Setting Coordinating Council (MISCC) would be re-invigorated and charged with producing an Olmstead plan.

The "Olmstead plan" idea comes from the US Supreme Court's *Olmstead v LC* decision, which said that unnecessary segregation of people with disabilities using state funds violates Title II of the ADA, which prohibits discrimination on the basis of disability by state governments. The Court said that if a state provides services to people with disabilities, they are entitled to receive those services in the "most integrated settings appropriate to their needs", but no one can be forced to accept a setting they don't want, and the state must consider financial and procedural issues to ensure that needed services of various types remain available. The Court said that states that have an effectively functioning plan that moves people off any waiting lists for integrated services with reasonable speed will likely be immune from lawsuits on this issue.

That decision was issued in 1999, and between then and January 2012, NY claimed that its fragmented and conflicting set of disability

service agencies and policies added up to an effectively functioning Olmstead plan. This, of course, was nonsense. A typical adult with developmental disabilities who can't stay in his/her parents' home (perhaps because they are too old to provide care) and needs support or supervision for more than a few hours a day will either be placed in a segregated setting within a few months, or remain on a waiting list for integrated services indefinitely, even though integrated services cost three to five times less than the segregated setting. This is only one example of NY's noncompliance with *Olmstead*; people with mental health and/or physical disabilities face similar issues.

Then in January, Governor Cuomo finally told the truth. He called the present situation "fiscally irresponsible and morally unacceptable", and he said the state would have a real Olmstead plan.

The MISCC met in March. Celebrated Rochester disability rights activist Bruce Darling was appointed to the Council. He offered recommendations that included collecting basic data about services available and segregated people who want to be integrated, and he urged that MISCC membership be altered to ensure that a majority of members are people with disabilities. The resulting meeting summary, issued under the name of OPWDD Commissioner Courtney Burke, said some good things about producing a plan with measurable goals and timetables.

Then nothing happened. Silence reigned. MISCC meetings scheduled for April and August were cancelled. The Cuomo Administration's entire disability focus seemed to be on the OPWDD scandals and the Justice Center bill.

In late July, the MISCC announced a tentative schedule of public forums on an Olmstead plan for mid-August. But it wasn't until Friday, August 17, that they released a "media advisory" with actual dates and questions to be considered. The first events, including one in Binghamton, were scheduled for the following Tuesday, August 21. Another set was scheduled for the following day, and more for September 28. The MISCC asked 13 very good questions. Naturally, they didn't get many thoughtful answers on the first two days. Almost nobody showed up at all, in fact, so another date, October 2, was announced. Fortunately, written and online comments will also be accepted, and there's a new Olmstead Plan website where you can post the latter: www.governor.ny.gov/olmsteadplan.

The media advisory said the plan "will include

goals, strategies, performance measures, baseline data and quantifiable targets related to services that will assist individuals with disabilities and seniors to live in the most integrated community settings." If such a plan actually emerges, this would be an important step forward. However, if a center of authority to not only monitor progress on the plan but also enforce its provisions does not emerge, nothing will be gained.

The advisory and forum questions were posted on the MISCC website: www.opwdd.ny.gov/opwdd_community_connections/miscc. **PLEASE!** Visit that site and the Olmstead Plan site, read the questions, and send in your answers. **Your voice must be heard!**

Another MISCC meeting is scheduled for December 3. We'll keep you informed.

Medicaid Likes and Dislikes

In July NY Medicaid Director Jason Helgeson asked community groups around the state to organize "focus groups"—small groups of people who use Medicaid for different reasons—to meet with him and answer two questions: What do you like about Medicaid? What don't you like about Medicaid? This was part of DOH's hastily-assembled effort to convince CMS that it was serious about getting public input on its Medicaid 1115 waiver application (see page 12).

STIC hosted a focus group. It was attended by people who use our services and those of Citizen Action, Southern Tier AIDS Program, Mental Health Association of the Southern Tier, and Fairview Recovery Services, and we've collected people's remarks from some of the other regional meetings. Here's a summary.

What People Like about Medicaid

That it exists, and therefore they don't die. Also, the CDPA program got high marks. But the nasty implied subtext of this question was, "If you want Medicaid to continue to exist—if **you** want to continue to exist—then you're going to have to accept the state's proposed "reforms".

What People Don't Like about Medicaid

A big issue was Medicaid transportation. If you're on Medicaid and need to go to a doctor's office, hospital, or other place for medical services, and you don't have your own transportation, Medicaid is supposed to pay

for it. There have been abuses of this service in the past: for example, a corrupt official awards a paratransit service all the Medicaid transportation business, at, say, \$60 a round-trip, even for people whose disabilities don't require accessible vehicles or paramedical services, in return for a kickback. Or people who could use public transportation to get to appointments call for a cab or van instead because it's easier. So DOH wants to "manage" this, and has hired a statewide contractor, Medical Answering Services (MAS), to do it.

Before this, each county managed Medicaid transportation on its own, and the results were uneven. Some counties, such as Broome, did a fairly good job, in a cost-effective way. But MAS imposed a one-size-fits all system that was not familiar with local circumstances and did not make the most cost-effective decision in many cases. DOH claims the system is saving a lot of money. They have acknowledged problems, but also claim all of those problems have been fixed, at least in Broome County. This is false. After consumers reported lots of issues to Helgeson at the focus group, and Broome County Social Services reported similar issues, meetings were held between DOH, MAS, and DSS. Some problems appear to have been fixed, but others remain, and more meetings are scheduled.

For people with complicated or multiple needs, it's still very difficult to schedule transportation, especially if one needs to go outside the area or the state because there are no qualified local specialists. MAS has tightened up prior approval for such trips. Scheduling visits with multiple specialists at one hospital or clinic is very hard. A patient may need to stay at a site for a very long time to see all the specialists. Reimbursement for mileage takes many months, and new rate limits for hotels and mileage have left families scrambling to come up with funds that in the past they didn't have to pay up front.

It used to be that for people who had a lot of medical appointments, Broome DSS

would provide a bus pass so they could use regular buses or county paratransit services to travel as needed. Yes, the pass could be used

for non-medical purposes, but it was much cheaper than paying for cab or van service for each appointment. The bus passes are not available from MAS.

When you have an outpatient medical procedure with anesthesia, the doctor will say you *must* have someone with you to bring you

home safely. But MAS tells people who have nobody to accompany them, but do have their own bus passes, to take the bus home instead of approving cab rides.

Some people have reported that when they call MAS, they are told that supervisors have to be consulted and they will get a call back, but the call doesn't come.

People who have used local transport companies for years and know the people who work there have been told not to call the company if a ride is late or doesn't show up, but to call MAS instead—a needless waste of time since people can resolve problems quicker locally than MAS can.

DOH claims that Medicaid transportation services are supposed to be available 24/7. But MAS says there is no such requirement in its contract. People with an urgent medical need who call MAS after 7 pm or on weekends are told to call back during "regular business hours". Although walk-in clinics are open to 8 pm 7 days a week, DOH apparently expects people to call an ambulance to take them there. Medicaid will

pay for it, of course—to the tune of 5 times as much as a van ride costs and up to 50 times as much as a cab.

People who currently get high-quality support services from trusted people are very concerned about potentially losing those services. For example, DOH plans to convert programs serving people with HIV/AIDS to "health homes"—large case management programs that may not be run by small local providers. This is another case of "one size fits all". Helgeson says lots of New Yorkers can't get those good services, and health homes will make them more widely available. However, the rates to be paid are lower than what the good programs get, and case loads will be higher. Inevitably, while some people will get more services, others will get less than they do now, and it's likely that nobody will get services that are adequate.

Accessible affordable housing came up often but did not get a satisfactory response (see page 12).

An emerging issue is lack of accessibility in doctor's offices. As people in managed care are forced to use "in-network" doctors instead of those they used to see, they're finding that their offices don't always accommodate their needs. For example, a woman who uses a wheelchair and can't transfer to a gynecologist's examining table herself was refused treatment. The ADA requires doctors to make their practices (not just their offices) physically accessible when readily achievable and to offer alternate accommodations otherwise. Doctors could

buy (expensive) accessible motorized exam tables, or (much cheaper) Hoyer lifts and provide the small amount of training needed to use them to their staff, to address issues like this, but they mostly don't. DOH has a legal responsibility to enforce ADA rules, since it pays the doctors, but it ignores this issue, which advocates have raised periodically ever since the first conversions to

Medicaid managed care began in the 1990s. Yet DOH claims it never hears complaints about this (see box).

How to Use MAS for Transportation

www.medanswering.com
(800) 850-5340

How to Order

www.medanswering.com/page.taf?ID=27

When ordering transportation, be prepared with the following information:

- Name, address, contact number
- Birth date
- Reason for transportation
- Name of physician that will be seen
- Date, time, location of the appointment
- Preferred transportation company
- Any other special instructions needed for the trip

Is Your Doctor Accessible?

- Can't get in a door?
- Can't get in an examining room?
- Can't get on an exam table?
- No ASL interpreter?
- Parking concerns?

DOH says that they don't get complaints about accessibility at doctors' offices. We know this isn't true, but maybe they just forgot. Help remind them:

Complaint Phone Number
(800) 206-8125

Other issues that came up frequently at the focus groups included: lack of access to dental services (because Medicaid doesn't pay rates high enough for dentists to accept, but see page 12); lack of access to mental health services, especially for children (same rate problem plus the fact that child psychiatry is apparently not a very attractive specialty for MDs); pointless damage to people's credit ratings (although low-income people are not required to pay prescription co-pays that they can't afford, they are still billed for them and as a result are on record as deadbeats); people of color are more likely to be treated brusquely or discourteously by providers.

And Medicaid recipients reported the same kinds of problems that everyone who is unfortunate enough to be stuck in managed care experiences (non-managed private medical insurance plans do still exist for people who have generous employers): Lack of access to specialists (rates again, made worse by the reluctance of many high-quality doctors to live and work in small towns or rural areas); being forced into "step therapy" when they already know most of the "steps" won't work; brief appointments and cookie-cutter treatment rather than doctors who listen to patients.

People First Waiver ABCs

In June OPWDD announced that it had dropped efforts to get federal approval for a Medicaid 1115 Demonstration waiver for its People First project. Instead, the agency will try to combine a new 1915(b) Medicaid Managed Care waiver with a modified version of its current 1915(c) Home and Community Based Services waiver.

OPWDD officials said the Centers for Medicare and Medicaid Services (CMS) had a frosty first response to OPWDD's application. CMS demanded that OPWDD explain how it had let so many people be abused and neglected, and provide a plan to fix those issues, before CMS would even consider a waiver proposal. CMS was also very hostile to OPWDD's plan to keep sheltered workshops indefinitely, which rolled back promises made by former OPWDD Commissioner Ritter. As we've reported (*AccessAbility* Summer 2012), CMS ordered criminally abusive state employees to be fired, which OPWDD refused to do, and required goals and timelines for reducing use of sheltered work, which OPWDD provided,

though they are very modest.

We'd also heard that CMS was dissatisfied generally with the weak efforts of 1115 waiver applicants to ensure that stakeholder input was collected and influenced applications (this is apparently why DOH held a hurried series of "focus group" meetings just before it applied for a "mega-waiver"; see page 12). We had reported to CMS officials that OPWDD was largely ignoring the views of community-integration-oriented advocates in its waiver planning process.

It seems that this combination of events helped lead CMS to informally tell OPWDD that it wasn't going to get an 1115 waiver and suggest they take the 1915(b/c) approach instead.

1915 Waivers vs 1115 Waivers

1915(b) waivers let states mandate enrollment into managed care. Any Medicaid service, acute medical, "institutional" or "community-based", can be included, but 1915(b) funds can't

Value means More!

Put the power of the area's most innovative Credit Union to work for you!

Join VISIONS!

VISIONS Gives Their Members More Value!
Our World Class Service is just the beginning.

Find out more about these and other services at visionsfcu.org



Download our App.
It's Easy!

Express Deposit
Scan & deposit from home or office

VISIONS
Low Loan Rates

Quick and Easy Mortgages
Same Day approvals on-line

**Loans
for Business**



Federally Insured by NCUA.

24 McKinley Avenue, Endicott

VISIONS
FEDERAL CREDIT UNION

be used for people who don't meet Medicaid State Plan eligibility limits. It looks like all of the managed care features that OPWDD wants, including DISCOs with limited networks of providers of both support and acute medical services, are allowed. 1915(b) waivers are often called "Freedom of Choice" waivers, not because they offer choices, but because they limit them; the free choice of providers required for ordinary Medicaid is waived. How important this will be isn't clear; it doesn't have to change what OPWDD has said it wants

(though that may change; see below), as well as outpatient medical services. They can't be used in ICFs, developmental centers, nursing homes or similar places. 1915(c) can serve people who aren't eligible for Medicaid State Plan services; this is how kids with developmental disabilities whose parents have high incomes get OPWDD services. OPWDD will need to modify its present 1915(c) waiver to add the "Individual and Community Supports" service, an allegedly more flexible successor to CSS. We don't know what other modifications OPWDD is planning for this waiver. Current HCBS regulations would seem to rule out OPWDD's proposed services for people in nursing facilities, though they might be fundable under 1915(b). We don't see how OPWDD can include ISS "room-and-board" subsidies in any 1915 waiver at all. HCBS waivers are typically approved for 5 years at a time.

1115 waivers, intended for innovative demonstration projects, are not as restrictive; they can be used for any typical Medicaid service or creative new services and may or may not include managed care. As a result, they have more intensive evaluation requirements than 1915 waivers.

Meanwhile, CMS wants to tighten the definition of "home and community-based" for several 1915 programs. This would make it harder, though not impossible, for OPWDD to use 1915(c) money to support most "IRA" group "homes" as it does now. IRA residents would have free choice

to do, but OPWDD could drop plans to offer people a choice of DISCOs. Officials recently said they realize that the fiscal and experiential qualities needed for DISCOs are uncommon among OPWDD providers. There may only be a handful of organizations that can meet the criteria once they are established. 1915(b) waivers appear to have a sort-of "maintenance of effort" requirement; they can't "negatively impact beneficiary access or the quality of the care services" as compared to how things were before the waiver. They must be re-evaluated and re-approved by CMS every two years.

1915(c) waivers are for "home and community based" services (HCBS), broadly defined: segregated congregate group or adult "homes" or "assisted living" facilities, day programs, and time-limited medical rehab are included

of whether to have roommates and who those roommates are. IRAs couldn't have blanket rules restricting residents; the ability of residents to, for example, lock their doors, have any visitors at any time, come and go as they please, have meals they choose on a schedule of their own, and pursue their own preferred recreational activities, could only be limited on an individual basis for documented safety reasons. Such limits couldn't be imposed unless less-restrictive settings had first been tried and shown to have failed, and the need for them would have to be regularly re-evaluated. Residents would have tenant rights like ordinary renters, including something like a lease and the right not to be evicted except for good cause. Under consideration are rules to let IRA residents choose to get in-home services from providers other than the IRA

operator, and to forbid operators from requiring residents to accept any services as a condition of residence. CMS got over 235 comments on these proposals, with pro- and con- running about 50-50. Many disability advocates feel that the proposal doesn't go far enough.

Although advocates are excited about CMS' proposals, we urge caution. CMS is under enormous pressure from wealthy providers and their lobbyists to water down these requirements, "carve out" exceptions for some facility types such as assisted living, or for certain groups such as seniors, and/or "grandfather in" existing facilities so they'll never have to change. At least one lobbyist's comments strongly implied that CMS would be sued if it adopted the new regulations as-is—a tactic that has been used effectively to intimidate federal regulators in other fields. At the very least, there would likely be a long phase-in period for the new rules. Finally, we don't know enough about the 1915(b) "negative impact" regulations and NY State Plan eligibility rules to be sure, but it seems possible that OPWDD could shift funding for some of its segregated residential and day programs from 1915(c) to 1915(b) to avoid the new regulations.

RFI

The long-awaited OPWDD analysis of the responses to its Request for Information (RFI) on People First waiver issues was published in July. Although for the most part the analysis fairly stated the views of advocates, there were some troublesome points.

Criticisms of OPWDD's proposed Quality Scale, which won't impose real consequences on providers that don't comply with important requirements, such as real person-centered planning, use of most integrated settings, and maximizing consumer choice and control, were downplayed.

Criticisms that OPWDD's plan to let DISCOs provide both care coordination and direct services to the same people, and to have OPWDD staff do needs assessments and "broker" DISCO enrollments, won't really prevent self-referrals or ensure independent advocacy, were mentioned briefly and passed over.

We were rather shocked to see that apparently many people who provided input, including some consumers, do not think consumer satisfaction should be an important measure of quality.

We were sad that many people support heavy

ALS Association Support Group

ALS Association Support Groups provide education, information and support to patients and families living with ALS.

BINGHAMTON

1st Saturday of the Month

1:00 pm – 2:30 pm

Broome County Library

185 Court St., Binghamton

Facilitator: Sara Bush, LMSW,

Spinal Cord Injury Coordinator, VA Medical Center

If the scheduled meeting date falls on a holiday we will reschedule. Please contact us for the new date.

For information on guest speakers, topics, directions or weather cancellations please visit www.alsaupstateny.org or Contact: Kate Cavan (866) 499-7257, kcavan@alsaupstateny.org, or Becky Colville (716) 860-1947 rcolville@alsaupstateny.org

certification and training requirements for direct service workers. **People! This will hugely inflate costs, and it's completely unnecessary.** High-school graduates trained by service recipients themselves or their families already do most of this work for people in the CDPA program, which has an excellent record for safety and consumer satisfaction. If you insist on all this education, credentialing, and formal training for workers, there won't be enough money to pay enough workers to provide the services you want.

Timetable

OPWDD announced a new, more detailed timetable for the waiver development process.

The agency will shift from a monthly to a quarterly public video conference schedule to address waiver issues. The next one is scheduled for October 16, 11:00 am – 1:00 pm.

August 2012

Three Targeted Work Teams were set up to help OPWDD develop its Request for Applications (RFA) for pilot DISCOs and settle details about how DISCOs will operate: Access, Enrollment & Advocacy; Care Coordination; and Modernizing the Fiscal Platform. The members were posted on OPWDD's website. They include people from OPWDD's pet self-advocacy group, the Self Advocacy Association in NYS (SANYS), parents, agency representatives, and OPWDD staff. Two agency representatives, Roger Sibley of the Franziska Racker Centers and John Maltby of the Westchester Institute for Human Development, have good reputations as advocates for integration and consumer direction. However, although people in the Independent Living movement, which advocates for and serves thousands of people with developmental disabilities across the state, asked to be included, none were, nor were any advocates with disabilities who are independent of SANYS/OPWDD. The teams are supposed to meet "frequently" in August and through the fall, and are supposed to use RFI and other "stakeholder input" to guide them.

Insiders said the teams didn't actually appear to be meeting yet, that OPWDD officials were very unsure about how to proceed, and that the more the providers who might be expected to apply to become DISCOs learn about this, the more it looks like a lose-lose proposition for them and for consumers. The draft RFA will be more like a second RFI; responses to it will be used to firm things up. It was supposed to be made public for comment in August but

wasn't available at press time toward the end of that month. It seemed unlikely that this target would be met.

"Assessment Specialists" related to modifying the InterRAI assessment tool will be hired. It's not clear what they will do, though perhaps they will direct the "case studies" (see below).

October 2012

Draft RFA, 1915(b) waiver proposal and 1915(c) waiver amendments go to CMS for approval.

November 2012

Case studies involving the assessment tool will begin.

March 2013

RFA issued. This assumes CMS approves the application, an unknown.

June 2013

DISCO pilot organizations chosen. This is pretty unrealistic, given past state agency management of grant applications. We don't think we've seen a selection process completed in three months for at least a decade. And this one will be more complicated than most.

November 2013

Initial enrollment of people with disabilities into pilot DISCOs begins. Advocates are supposed to get another "bite of the apple" to take part in "implementation teams" during this process.

January 2014

Initial enrollment of (apparently) OPWDD-eligible people into DOH's managed-care-for-dual-eligibles pilot program, the "Fully Integrated Duals Advantage" (FIDA), to begin. This raises lots of questions. All we have on this is that people with developmental disabilities who would be eligible for more than one managed care option are supposed to have a choice of whether to enroll in OPWDD's waiver with DISCOs, a "Health Home", or FIDA.

November 2015

Initial enrollments in non-pilot DISCOs begins.

Final Justice

A law enacting Governor Cuomo's Justice Center for the Protection of People with Special Needs was passed in June. However, at press time in late August, it still hadn't been signed by the Governor, for reasons unknown. The final legislation addressed only a small number of the issues raised by disability rights advocates (see *AccessAbility* Summer 2012). They are:

Independence from State Control?

Two changes were made here:

First, the law explicitly requires creation of an "independent public or private agency" to handle the Commission on Quality of Care (CQC)'s current federally-mandated Protection & Advocacy (P&A) and Client Assistance programs for people with varying disabilities. "To the extent permitted by federal law," this agency will have a governing board whose majority consists of "individuals with disabilities, parents, family members, guardians, advocates, or authorized representatives of individuals with disabilities". The agency appears to have been granted investigatory and reporting powers consistent with those required by federal P&A enabling legislation. It can investigate individual incidents of abuse or neglect that are reported to it.

Second, the law established an "advisory council" for the Justice Center, to be appointed by the Governor with Senate approval. At least half of the council members must be "individuals or parents or relatives of individuals who are or have participated in or are or have been recipients of programs and services within the justice center's jurisdiction". Also, the council "shall include but

not be limited to members of boards of visitors; ... consumer representatives, including current or former service recipients of an applicable facility or provider agency; parents, relatives or

When People with Disabilities Want to Work...

They have lots of questions - like how to apply for Medicaid Buy-In, what is a PASS plan, how do I write a business plan, etc.

Here is a very informative site - through Cornell:

<http://nymakesworkpay.org/m-innovation.cfm>

guardians of such service recipients; providers of services to vulnerable persons; directors of facilities, community services or members of community services boards; current and former consumers of services for individuals with physical disabilities; members of organizations that advocate on behalf of vulnerable persons and individuals with disabilities; and an employee of a facility or provider agency” over which the Justice Center has jurisdiction.

While a step forward, these changes didn’t adequately address advocates’ concerns. It was important for the law to establish the independent P&A agency (Cuomo had promised to do so but it wasn’t in his original bill). This satisfies most of the US Department of Health & Human Services’ complaints about the CQC (see *AccessAbility* Spring 2012). It appears to formally designate the independent agency as the state P&A agency, which gives it standing to file federal lawsuits and fix the problem that led a federal appeals court to overturn *DAI v Paterson* (see *AccessAbility* Summer 2012). But the agency can only issue reports of its investigations; it has no power except lawsuits to compel state agencies or their subcontractors to do anything about them. The law has no criteria for deciding when state agencies will investigate themselves or their subcontractors, when the Justice Center will do so, or when issues will be referred to the independent agency. But it does appear that the Justice Center, most of whose staff will be the same people who mishandled investigations at OPWDD and other state agencies, will have some control over what the “independent” agency investigates. As for the Justice Center’s advisory council: It is no different than any other state agency advisory council. Its unpaid members will meet quarterly to review information provided by the Justice Center and make recommendations for policy or procedures. Justice Center staff can manipulate the information the council gets and ignore its recommendations, as frequently happens with other advisory councils.

Will Abusive State Workers be Fired?

Not likely. The final version includes all of the original language stating that the law does not affect collective bargaining agreements, including those that submit all attempts to fire workers for cause to arbitration, no matter how outrageous or criminal the workers’ actions. The law actually strengthens protections for unionized state workers beyond what was in the original bill, by further limiting the circumstances under which such workers can be charged with serious abuse or neglect and placed on the “do not hire” registry.



Understanding Life with Brain Injury Training

Friday, September 28, 2012 • 10:00 am to 1:00 pm

STIC • 135 East Frederick Street • Binghamton, NY 13904

Offered by:

NYS DOH, Traumatic Brain Injury (TBI) Waiver Program in cooperation with Brain Injury Association of New York State (BIANYS)

Purpose:

To improve the quality of services for people with TBI, discuss causes and results of brain injury, describe the challenges of living with a brain injury, and provide communication tools and promote job satisfaction for direct care staff who work with individuals with TBI.

Training Objectives:

- Providing agencies with a comprehensive training curriculum addressing the issues of traumatic brain injury
- Assisting staff in understanding the experiences of individuals with TBI
- Developing awareness of the daily and life-long challenges for individuals with brain injury
- Assisting providers in addressing issues of TBI with staff members
- Providing tools for effective communication with individuals with brain injury
- Reviewing issues such as personal dignity, privacy, personal choices, and personal rights

Target Audience:

Professionals working with people with brain injury, including TBI Waiver providers; community agencies interested in providing services to people with TBI; community service providers; veterans’ organizations; staff development trainers; emergency room personnel; discharge planners

Trainings are presented in a train-the-trainer format. Each agency attending will receive a complete training curriculum package.

Pre-registration is required to receive a copy of the training curriculum materials and the DVD “Living in the Moment.”

Support for this training and the training curriculum is provided in part by project H25MC00264 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Meanwhile over the summer it emerged that the union representing most “non-professional” state employees, the Civil Service Employees Association (CSEA), was refusing to negotiate the long-awaited “table of penalties” for employee misconduct, abuse and neglect until the Cuomo Administration agreed to some unrelated demands related to health coverage.

Will Nursing Homes be Covered?

No.

Can People Report Crimes to Local Police?

Yes. The original bill had language implying, but not clearly stating, that people can do this in addition to reporting incidents to the new hotline. The final version states that they can

do so more clearly, in several places. However, there is no requirement for local police or prosecutors to investigate complaints or charge people with crimes.

Will Segregated Congregate Settings be the “Last Resort”?

Not any time soon, if ever, but see page 6.

When Does All this Start?

The law gave Cuomo authority to set up the independent agency almost immediately. The rest takes effect on June 30, 2013, but work to get the Justice Center up and running on that date can be done beforehand. At press time nothing had been announced about this.



Bryant v NYS Education Department

This suit was brought by the parents of seven children with disabilities who were in the notorious Judge Rotenberg Center (JRC) in Massachusetts, a residential school that uses electric shock as an aversive “treatment” for unwanted behaviors (see cover). The parents sued in federal district court, alleging that the State Education Department (SED)’s 2006 regulations phasing out the use of aversives in school settings in or paid for by NY violated their children’s rights under the Individuals with Disabilities Education Act (IDEA) and other laws. The district judge ruled against them, so they appealed to the 2nd. Circuit, which, in August, also ruled against them.

The parents claimed that legitimate scientific evidence supports use of electric shock as a “treatment” and that the SED regulations prevent their children from getting truly individualized education plans (IEPs) as required by IDEA.

But the children, who had been at the JRC for several years, could have had the shocks included in their IEPs as late as 2009 to be “grandfathered in” and keep getting the “treatment” after it was phased out for others. In fact, none of them ever had an IEP that called for any form of aversive “treatment”. Such disrespect for legal procedure and children’s civil and human rights has been a JRC hallmark (see *AccessAbility* Fall 2011), and it supports accusations that JRC lawyers, whose interest lay not in these kids’ welfare but in blocking SED’s regulations, were behind the suit.

Beyond this, the judge ruled that prohibiting one specific form of “treatment” does not mean that students can’t get an individualized plan because they still get individual needs assessments, and a broad range of other possible treatments are available to choose from.

Also, while IDEA urges schools to maximize use of positive behavioral supports, it says states can make their own considered decisions as to what education services will be provided as long as they meet IDEA minimum requirements. Having visited the JRC and observed the horrible conditions there, reviewed the scientific literature indicating that aversive “treatments” are dangerous and less effective than properly implemented positive behavioral support plans, and considered the ethical issues involved, SED officials made a reasonable policy decision that they are entitled to have respected by the judiciary.

As the case progressed through the courts,

Massachusetts enacted regulations that will outlaw the use of shocks and some other (but not all) aversive “treatments” in the state. Children receiving the “treatments” at the time of the regulation change will be “grandfathered in” but eventually this form of torture of children with disabilities will cease.

Some parents insist that electric shocks are the only thing that works for their children. But the full story is that their children were mishandled by medical and school professionals who did not competently implement positive behavioral support plans for them, and the JRC, which has long marketed itself as a savior for such suffering families, then stepped in and abused their children into submission. These parents, despite their understandable anguish and feelings of guilt, must accept that their children have been mistreated by all concerned, before and after they went to the JRC, and that, had they *ever* been properly treated, they would not have ended up there.

Douglas v Independent Living Center of Southern California

We reported on this case last fall; it concerned whether people with disabilities can sue states for cutting Medicaid service rates so much that they reduce availability of those services to levels below those for people who have other kinds of insurance (the Medicaid “comparability” clause).

In February the US Supreme Court remanded the case (or, rather, some of the combined cases), back to the Ninth Circuit Court of Appeals.

What happened was that after the Supremes heard oral arguments, the federal Centers for Medicare and Medicaid Services (CMS) made a deal with California to reverse its previous disapprovals of most of the rate increases. This cut the rug out from under most of the lawsuits. Although, as the five-justice Court majority noted, the question of whether people with disabilities can sue the state under the Constitution’s “Supremacy Clause” remains relevant and unresolved, the situation has changed enough that it needs to be reconsidered at lower court levels. There are district court injunctions against the rate increases that need to be re-argued, and the plaintiffs probably should re-file the suit on grounds that CMS may have violated the federal Administrative Procedure Act in approving the increases.

So the issue will eventually return to the Supremes. We’ll keep you posted.

Davis et. al. v Shaw

This case was filed in federal district court in March. Davis and others say that restrictions on Medicaid coverage for prescription footwear and compression stockings enacted in the NY 2012-13 budget violate federal Medicaid law prohibitions against arbitrary limits on medically-necessary services based on diagnosis. In May, the judge issued a preliminary injunction against the state (Nirav Shaw is the Commissioner of the Department of Health), which means he thinks the plaintiffs are likely to succeed at trial.

The argument is that NY pays for these things because they are medically necessary for some people (prescription shoes for people with diabetes, for example, and compression stockings for varicose veins), but not for others for whom they are equally necessary, such as paraplegics, amputees or people with severe arthritis. As a result, people can end up in nursing facilities due to loss of function. Because pressure stockings prevent blood clots, people can die without them.

The judge said the plaintiffs are likely to prevail “since they are being denied coverage of medically-necessary equipment on the basis of their particular illness, without any opportunity to request an exception.” The state doesn’t dispute the facts, but claims that Medicaid recipients don’t have a right to sue the state (the issue that was raised in *Douglas v Independent Living Center*; see above). At press time we had not heard that a date had been set for arguing the case.

If you or someone you know has been denied Medicaid coverage for prescription footwear or pressure stockings, the Empire Justice Center would like to hear about it. Contact Amanda Gallipeau at the Rochester office at (585) 295-5731.

NFIB v Sebelius

This is the “Obamacare” case. There were multiple suits against the Affordable Care Act (ACA) in federal court. After various district and appeals courts produced different decisions, the US Supreme Court consolidated them. NFIB is the National Federation of Independent Business, and Sebelius is Kathleen Sebelius, the US Secretary of Health and Human Services.

As you’ve probably heard, the Supremes upheld the law in part, and struck it down in part.

Briefly: the Court made three decisions: First, making people buy health insurance (the “individual mandate”) requires them to engage in new interstate commerce, which is not the same as regulating existing interstate commerce, so the individual mandate is not allowed under the Interstate Commerce Clause of the Constitution. Second, the Supremes must preserve the laws that Congress enacts if they can “reasonably” do so, and since the individual mandate “looks like a tax” in many ways, and there are few limits on federal taxation powers in the Constitution, the individual mandate is constitutional. (Although people can challenge taxes in federal court after they’ve paid them—which can’t happen with the ACA until 2015—the decision’s language made it pretty clear that the Supremes don’t see much, if anything, that is challengeable about this “tax”.) Third, and scariest: what used to be the feds’ unquestioned right to give states an option to get federal funds for a program, in return for which the states must comply with all of that program’s rules, is no more. Instead, the Court said that tying a state’s ability to continue to get any Medicaid dollars to adopting the ACA’s rules expanding Medicaid eligibility is too much to ask; it’s like “holding a gun to the head” of a state. Because Congress has required states to significantly expand Medicaid several times before without the Supremes uttering a peep, this argument, unlike the others above, is bogus. It’s dangerous because now states can challenge any number of federal Medicaid rules in court without risking their funding.

The most important ACA provisions remain intact: No more limits on lifetime coverage or pre-existing condition exclusions, and children can stay on their parents’ policies until age 26.

By the way, contrary to popular belief, there are no “Medicare cuts” in Obamacare. There are two measures affecting Medicare funding. First, the massive subsidy the feds give to private insurance companies that offer “Medicare Advantage” (managed care) plans will end. These plans were supposed to save money but they actually cost more than “regular” Medicare even though some of them limit access to some services more than “regular” Medicare does. Non-managed Medicare supplement plans will still be available, and the feds will pay rates based on “quality metrics” to Medicare Advantage plans, so they can continue to exist. Second, the law reduces the rate of growth of Medicare fees for providers. Yes, this could affect availability of providers, but since Medicare is a huge economic engine that drives the healthcare industry, it’s not likely that many providers will commit financial suicide by refusing to accept Medicare. Business people often make dire threats to try to get a better deal from the government but they rarely carry them out if they don’t get what they want.

And anti-government types love to say they aren’t cutting government programs, they’re just slowing their rates of growth, so we think it would be nice if they would describe Obamacare in the same terms. They won’t, of course, because this is politics, not policy, but we think it would be nice.

Though the details aren’t clear, the individual mandate “penalty” (“tax”) will be handled along with your income tax. Employers might indicate whether you get health insurance from them on your W-2 form; if you don’t, you might have to submit proof of insurance—perhaps provided by your insurance company—and if you don’t have either of these things, an amount based on your income and family size will be deducted from your return or added to what you owe.

So what does this mean for New Yorkers with disabilities? Not much. The Community First Choice option is intact, if the state ever enacts it. Its only benefits over NY’s existing long-term care services are that it assesses need on a functional rather than diagnostic basis, and it’s a State Plan service, not subject to managed care, which is why officials are dragging their feet on it. It doesn’t provide new services that NY doesn’t already offer. NY has already expanded Medicaid eligibility in most of the ways the ACA calls for, and will likely do the rest because the feds will pay for 100% of the expansion for the first three years, and no less than 90% after six years.

The impact in other states is a bigger deal. Most states’ Medicaid programs aren’t as generous as ours. To date, no Republican governor has said s/he will do the expansion, and no Democrat has said s/he won’t. Given the highly favorable terms the feds are offering, this is clearly just politics and not policy. However, Republican-controlled states are also refusing to set up the ACA-mandated healthcare “exchanges” that are supposed to make affordable coverage available to people who don’t have it, so the feds will set up the exchanges for them. Expanded Medicaid reduces the load private insurance companies will have to bear to achieve the goals of the exchanges. It won’t be long before those companies make those governors change their minds.

All of this, of course, depends on whether the ACA remains a law, and that depends on whether Obama keeps his job. If Romney is President in January, the House will immediately vote to repeal the law, and there are enough right-wing Democrats in the Senate who will support, if not outright repeal, a bill to seriously weaken it. If Obama loses, it is almost certain that the ACA will not survive in recognizable form long enough for most of its provisions to even take effect.



US law says corporations are “people”, with the same civil rights as human beings. The 2010 US Supreme Court *Citizens United* ruling gave corporations free speech rights. It equated money with speech to ensure that rich corporations will always be able to buy elections.

This is why:

- A majority of citizens favor single-payer health care but we can’t get it
- A majority of citizens favor strong anti-pollution laws but we can’t get them
- 60% - 70% of citizens, including super-rich investor Warren Buffett, say taxes should be raised on rich people and corporations to pay our debts but we can’t get that done
- 69% of Americans oppose cutting Medicaid but it’s on the chopping block anyway
- 89% of Americans in a 2010 poll favored raising taxes to ensure that people with disabilities can live in their own homes instead of segregated facilities, but we can’t get Congress to act
- The “Tea Party” is mostly funded by rich corporations, corporate executives, and corporate lobbyists like Fox News, the Koch Brothers, and the US Chamber of Commerce; they want to deregulate corporations and cut taxes for the rich and they are duping good-hearted people into supporting them

We must face facts. The **REAL** people of the United States, including people with disabilities, will never get what they want from government until corporate power is broken.

WHAT CAN YOU DO?

Join the movement to amend the US Constitution to end civil rights for corporations:
<http://movetoamend.org/node/2325>

Take back our government from a small minority of far-right-wing anti-tax fanatics and corporate shills:
<http://rebuildthedream.com/>

Boycott products made by the Koch Brothers: Angel Soft® Brawny® Coronet® Dixie® Mardi Gras® MD Bathroom Tissue Quilted Northern® Soft ‘n Gentle® Sparkle® Vanity Fair® Zee®

Virginia Settlement Weakened

This settlement agreement between the state of Virginia and the federal Justice Department (DOJ) was notable because it said the state can't just accept at face value claims by people with disabilities or their family members that they want to stay in places that aren't the most integrated settings appropriate to their needs. Instead, the state was required to ensure that each such person is fully informed about the relevant issues and offered a plan for integrated services that would address their concerns (see *AccessAbility* Spring 2012).

After the settlement was announced in January, the federal judge in the case heard a lot of complaints from people who objected to being "forced" to integrate their family members.

In response, the judge said he would require changes to the agreement before he would approve it. Although at press time the final consent order wasn't available, the judge said the agreement does not require VA to close any institutions, it only requires a plan to close them, and he said the state government could choose not to follow the plan. He also said the consent order must explicitly say that people can choose to stay in an institutional setting, though they can't choose the site. And he said the order must state that people can't be moved from their settings without "their consent or that of their parents or authorized representatives", according to a news report.

The agreement never said people could be "forced" to move to more integrated settings. It remains to be seen whether it will still include the requirement that people be shown a workable plan for how they could move safely before they make a decision. The above quote is from a news report, not from the judge or the order; it would be problematic only if the actual order lets relatives who are not legal guardians make placement decisions for adults. And we would hope that DOJ would take the state back to court if it chooses not to carry out the closure plan.

DOH Waives Telling the Truth

As part of its Medicaid "redesign", NY has applied for approval from the federal Centers for Medicare and Medicaid Services (CMS) to amend its current Medicaid managed care waivers. The state also asked to "reinvest" \$10 billion in combined state and federal funds that Governor Cuomo claims he's saved with his Medicaid cost cap, 2% "across the board" cuts to providers, and other "reforms", in new programs and services. The plan has been called a "mega-waiver".

In theory reinvestment is a good idea. Advocates have long said that money saved by reducing reliance on segregated congregate Medicaid-funded programs should be used to expand

integrated options and supports. However, in practice there are a lot of problems here.

DOH says its Medicaid Redesign Team (MRT) process has saved millions of dollars without significantly cutting people's services, and so they want to continue and expand the process.

This is a lie. In fact, lots of important services have been cut, including availability of personal care, OT, PT, speech therapy, prescription medications, various types of medical equipment and supplies, access to medical specialists, and medical transportation.

The application in general suffers from "Great Idea" Syndrome. You've heard it before: people with good intentions but no practical experience with people with real, complex problems of disability, poverty, and stigma sit around and come up with wide-eyed proposals: "Wouldn't it be a Great Idea to put doctors into apartment buildings, and then put all the disabled people into those apartments, so they can have access to primary medical care?" "Wouldn't it be a Great Idea to have a special office where people with severe mental health and behavioral disabilities and chronic health conditions can go so they can have better healthcare and nutrition and more stable housing, as long as they behave nicely and comply with all of our rules?" "Wouldn't it be a Great Idea to apply the same model that worked well in the small city of Madison, Wisconsin to all of the big cities, wealthy suburbs, small towns and tiny rural hamlets in New York State?" There's a lot of this sort of nonsense in the mega-waiver application.

CMS has said it's had it up to here with Medicaid 1115 waiver applications that don't take into account real "stakeholder" input. Perhaps CMS learned that the original MRT process, which collected lots of public input on what people thought should be done, and then did what Cuomo and his cronies already planned to do before he took office anyway, was a sham.

So while the "Great Idea" policy wonks had been working on this application for well over a year, just a couple of months ago they suddenly announced another series of public hearings and focus groups. The hearings were scheduled to begin barely a week after they were announced, and people had only two minutes to speak, virtually ensuring that little thoughtful, high-quality input would be provided. An online survey was created to ask how many people supported the new programs that the state wants to start—not what people really think the state should do.

The application grossly overstates interest in "supportive housing" in NY. "Supportive housing" usually means housing "bundled" with services. Often, units are grouped into a single building. Often, people are forced to accept services as a condition of having a place to live. Many, but not all, people with disabilities need some assistance in their homes. Many others need

affordable housing, period, and some need it to be accessible. If and when services are needed at home they can be obtained without "bundling". Integration means that people with disabilities interact with the larger community to get most of their services just like nondisabled people do. "Supportive" housing is, for many people, just a less-intense unnecessarily segregated congregate setting.

People with disabilities have made this point over and over at every opportunity since Cuomo took office almost two years ago, including as members of MRT subcommittees, at public hearings and focus groups, and in written testimony. Yet nowhere does the waiver application say there is a need for affordable, accessible housing not tied to services; instead it created the impression that there is universal support for more "supportive housing". This is another lie.

As DOH Medicaid Director Jason Helgeson told a focus group at STIC (see page 4), it's true that Medicaid can't be used for "room and board" in a narrow sense. And since people in nursing homes get their "housing" paid for with Medicaid dollars, he would like to find a way to use Medicaid to help meet the critical need for integrated housing. This is his stated reason for why "supportive housing" gets pushed. That's fine, but it's not a valid reason for not also reporting to CMS that just plain affordable accessible housing is also needed, and demanded by stakeholders. Since half the money saved by Medicaid reform in NY is 100% state dollars, there is no reason why the "reinvestment" of federal and state funds proposed under the mega-waiver can't include a sizeable transfer of those dollars to affordable accessible housing *without* bundled services.

The waiver application was submitted on August 6. CMS could respond relatively quickly or take several months to make a decision. We'll keep you informed.

Manage Your Smile!

All NY Medicaid managed care plans are now required to cover dental services for their enrollees. Previously, covering such services for ordinary Medicaid recipients was optional. Providing dental coverage for Family Health Plus beneficiaries is still optional, though.

Medicaid managed care enrollees who are currently authorized and receiving dental care on a fee-for-service basis, and who fall under the "interrupted treatment policy", will continue to have those services covered by Medicaid fee-for-service.

Effective October 1, 2012, all NY Medicaid managed care plans will be required to cover orthodontic services for eligible enrollees under age 21. Orthodontic services are currently "carved out" and paid on a fee-for-service basis for Medicaid managed care enrollees.



STIC NEWS

STIC's Honor Roll

STIC's annual awards luncheon returned from a one-year hiatus in June. Once again we honored people who have gone above and beyond the call of duty to improve services and supports for people with disabilities generally, assist individuals with disabilities to have better lives, or have helped STIC achieve its goals.

Thank you all so much for what you have done, and continue to do, in support of disability rights and independent living.

COMMITMENT TO COMMUNITY SERVICE

Professor George Catalano, *Professor of Bioengineering, Binghamton University*
Professor Catalano oversees a program that enables engineering students to develop customized and creative assistive technology devices to meet the needs of people with disabilities. Not only has he helped many individuals to have better

lives, he has inculcated many young engineers with the essential understanding that designers should work with people directly to understand their needs and develop products that work for them.

OUTSTANDING CONSUMER ADVOCACY

Dolores Driscoll

Dolores has a long history of involvement with STIC, and has been a highly effective advocate for personal assistance services and especially for CDDA, enabling people with disabilities to obtain the maximum benefits of these programs.

Joan Henry-Gates, *Service Coordinator, Traumatic Brain Injury Medicaid Waiver*

Over the last several years Joan has been an exemplar of genuinely caring and effective service coordination, moving waiver participants closer to their families and assisting them to access appropriate community services.

OUTSTANDING CONSUMER SUPPORT

Dr. Andrea Chapman, *Psychologist*

Dr. Chapman has provided invaluable service to people with developmental disabilities and their families through high-quality evaluations and eligibility assistance and excellent training and individual consultation for parents.

Stacey Kalechitz & Barbara Travis, *Broome County CASA*

Stacey and Barbara worked heroically during last summer's flood to assist displaced people with disabilities to continue to receive life-sustaining personal assistance services.

Zach Ziemba, *Broome County Council of Churches*

Zach and his team built a ramp for a child with arthrogyposis. The Resource Network paid for almost all of the materials, but we needed experienced labor. Zach led a team

of volunteers one weekend to start the ramp, then spent the next two weeks in the cold and rain finishing it with the child's father, giving his own time and money to make this project happen. Zach went above and beyond his job description and did whatever it took to meet the needs of a very grateful family.

OUTSTANDING COVERAGE OF DISABILITY ISSUES

Danny Hakim, *Albany Bureau Chief, New York Times*

Mary Beth Pfeiffer, *Poughkeepsie Journal*

These journalists each researched and wrote a shocking series of articles detailing abuse and neglect of people in OPWDD-operated or -funded residential facilities, and financial mismanagement, fraud, and corruption by administrators. Prior to their work, New Yorkers with developmental disabilities seeking better, more integrated services were patronized or ignored. The articles led to the firing of OPWDD's Commissioner and CQC's Chairperson and the creation of the new Justice Center. Federal government demands that the problems these journalists exposed be fixed forced OPWDD to propose a new system that emphasizes real person-centered planning and consumer-directed integrated services.

OUTSTANDING LEGISLATIVE SUPPORT

Congressman Maurice Hinchey

Congressman Hinchey will retire at the end of his current term. During his career representing part of our service area, he demonstrated great sensitivity to disability issues and strong support on the important issues that concerned STIC and the people we serve. He will be missed!

OUTSTANDING VOLUNTEER SERVICE

Kelley Braheney

Kelley's skill as a makeup artist was a fantastic resource to our Haunted Halls of Horror fundraiser last year. This year she'll contribute even more as an acting coach for "scare-actors" and a Fire Spinner.

Eric Carpenter

Eric's artistic skill produced the dozens of intricately carved artificial pumpkins that were, and will be, on display in the entrance to our Haunted Halls.

Destiny Salas

Destiny tirelessly comes to STIC every month to do shredding, make copies, assemble charts and any other kind of office work that people need done.

WANT TO JOIN THE FUN?

Binghamton ADAPT
meets on the first Tuesday
of each month from
4 pm to 5 pm at STIC,
135 East Frederick St.

All are welcome

Come One, Come All!
STIC Open House

September 27, 2012
9:00 am – 3:00 pm

Meet our Staff!
Check Out Our Programs and Services!

Special Events:

10:30 am – Opening Address
Maria Dibble, Executive Director

Building Tours on the Hour

**Haunted Halls of Horror
Advance Ticket Sales**

Sign Language Interpreters
Will be Present

For Other Accommodations
Or More Information
Contact: Jennifer Watson
(607) 724-2111 (voice/TTY)



The Haunt History

by Bill Bartlow

In the spring of 2010 Todd Fedyshyn approached Bill Bartlow with an idea. Both were huge fans of Halloween and in years past had set up elaborate displays to celebrate the holiday in their yards. The proposal was to combine all their decorations and create an indoor haunted attraction at STIC as a fundraiser. STIC Executive Director Maria Dibble was convinced that it was a viable proposal and agreed to grant use of the space in our basement for the project. “The Haunted Halls of Horror” was on its way to becoming a reality.

Resources were pooled and a planning committee of interested STIC staff was formed. All work would be on a voluntary basis at no cost to STIC. Over the next months scenes were set and populated with the creatures and props we had available. A synergy of lighting, soundtracks, fog, brainstorming, tickets, posters, publicity and “scare-actors” in makeup and costumes resulted in a surprisingly successful first season. With just over 800 visitors on a “make-do” budget we had created a fun Halloween attraction and raised funds for STIC’s mission.

Well, Happy Halloween, next came 2011. It was time to take what we had learned and expand. Maria agreed. STIC’s Board of Directors approved an operating budget for the fundraiser and we were back to work at the start of the year. This was serious. When a not-for-profit agency invests precious funds in your project you have to come through.

We started by coming through the walls in the basement to lay out a path to our feature attractions that would encompass over 8,000 square feet. STIC volunteers spent their weekends constructing a winding labyrinth more than triple the size of 2010’s haunt. More room meant more scenes and an opportunity to include a greater variety of Halloween themes. Creepy creativity was unleashed and unsuspected talents transformed the halls to a new level of “Haunted”.

The word was out. STIC was getting it out with radio, press, media coverage. Event posters went up all over Binghamton’s East Side. Corporate sponsors partnered with STIC pledging donations, along with private businesses and individuals. STIC staff joined volunteers from the community, Binghamton University and Broome Community College to fill our “scare-actors” roster. The halls were opened with ghosts, goblins, were-wolves, witches, the dead and undead, clowns, and all manner of bone-chilling alter egos. For eight nights we howled as over 2,000 people came through our doors to see what it was in STIC’s basement.

A few came through serene and smiling at the sight. Many more were startled and holding their companions tight. Screaming teenage girls ran down the halls in flight. The terrified curled against the wall or on the floor quivering in fright. And some confessed they wet their pants that night. Must be we were doing something right.

Our second annual Haunted Halls of Horror had not only been a popular success, we had surpassed the board investment to return a significant contribution to fund STIC programs.

The Haunt 2012

“We want all that and more”. That’s the plan (see box on page 3). STIC is hoping to double last year’s 2000 visitors with new attractions beginning outside near the entrance. Did someone say “FIRE?” Well sure people are attracted to it, and they will be engaged by the spectacle of a dancing fire spinner with drumming accompaniment. For the third year we will again be displaying the intricate carved jack-o-lanterns of local artist Eric Carpenter in the reception area. It is also there where we will premier a movie trailer of the Haunted Halls followed by our animatronic rocking talking skeleton, “Buckey”, with instructions and warnings for our visitors. Buckey is only the first of a number of animatronic additions to this year’s cast of characters.

“Are they static displays or will they come after us?” We will leave those brave enough to take the trip through the Haunted Halls to wonder: “Dead or Undead?”. Many volunteer scare-actors will be lurking, stalking and then suddenly making their presence known. Perhaps you’ll meet them in the village or in the corn maze. See if they make any sense in the dungeon, or Dr. Dementia’s Head Shed. The bloody butcher will try to interest you in

ECDC

by Sue Lozinak and Laurie Wightman

Mid-South Early Childhood Direction Center, located at STIC, is pleased to offer information regarding early childhood development and behavior in children from ages birth through five.

Our services are free and confidential to parents and professionals. We offer workshops on such topics as: Early Childhood Development, Your Rights as Parents/Caregivers, Special Education Laws and Regulations, Special Education Terminology, Inclusion, and Transition from Early Intervention to Preschool and School-Age Services. Other topics include Sensory Integration, Challenging Behavior and “Red Flag” Scenarios, Effective Home and School Communication and Collaboration, Social-Emotional Skills, Specific Disabilities, Literacy and additional topics tailored to your needs.

We serve twelve counties throughout NY, including Allegany, Broome, Chemung, Chenango, Delaware, Greene, Madison, Otsego, Schoharie, Schuyler, Steuben, and Tioga. We are affiliated with and funded by the NYS Education Department.

Our phone number is (607) 724-2111 (voice/TTY) and our email address is ecdc@stic-cil.org.

We offer useful information and activities for parents and professionals on our Facebook page. Be sure to search for us and LIKE us at Mid-South ECDC.

the special of the day. For those who didn't make it there's the medical examiner, the morgue, the crematorium and the funeral parlor. Then it's time to plant your feet and perhaps the rest of you inside the cemetery gates. Don't be too shocked to find that not all are resting in peace. So now what? Not the end? Descend that long, dark cave to the netherworld where the master and his minions will warmly welcome you. Bet you wish you had something to drink. Don't despair; perhaps the witches in the woods before you will brew up a cup from their cauldron that will quench your thirst forever. Then again, they may roast you in their oven. Demoralized and depressed, time for some cheering up? Come one, come all, step right this way to Barker Bob's Psycho Circus. Spin the wheel and take your chances to discover if all the clowns are creepy. Let's see what they think is funny. The end is near. The end has happened as you enter the postapocalyptic toxic wasteland, the zombie zone. Hope you can leave and with all your parts intact.

You're nearing the restrooms so if you haven't already, you may go now... back to the reception area for some refreshments. Please be sure when you drive away that there are no added passengers in your vehicles. Our creatures love a wild ride.

Equipment Needed!

Do you have used durable medical equipment in good working order? Help us help others by donating it to STIC. We receive numerous requests and appreciate opportunities to find new owners for used equipment. We currently have a high demand for wheelchairs, commodes, raised toilet seats, shower chairs, and tub benches. You can drop those items off to STIC during our regular business hours.

And if you have borrowed this equipment from us: Please remember that this was a **loan**, NOT a give-away. You are required either to return the equipment at the end of the loan period, or contact us to request an extension.

Contact Andy at (607) 724-2111 (voice/TTY) if you have any questions. Thanks!

RAFTSMEN

Mobility Systems



570 Hance Rd. Binghamton NY 13903



Ramps, lifts and Elevators



Auto Accessibility



Bath & Bed lifts

Experience for YOUR benefit...

For over 20 years, Craftsmen Mobility Systems has been serving mobility needs in greater Binghamton & surrounding areas. From vehicle to home modifications, whatever your need, Craftsmen Mobility will work hard to get you up and mobile again.

- Home Modifications

- Vehicle Modifications

- Specialty Modifications
(Tractor Trailers, RV's , Farm implements)



1-800-498-7087



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

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

135 E. Frederick St.
 Binghamton, NY 13904
 (607) 724-2111 (voice/TTY)
 Toll Free (877) 722-9150

email: stic@stic-cil.org

Free Access Is Not Free

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

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

<input type="checkbox"/> Individual	\$5	<input type="checkbox"/> Contributing	\$100
<input type="checkbox"/> Supporting	\$25	<input type="checkbox"/> Complimentary	\$ _____
<input type="checkbox"/> Patron	\$50	<input type="checkbox"/> Newsletter Subscription	\$10/year
		<input type="checkbox"/> Make Me A Member	

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

Name _____
 Address _____
 City _____ State _____ Zip _____
 Phone _____

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

THANK YOU!

Southern Tier Independence Center

EXECUTIVE DIRECTOR
 Maria Dibble

PROGRAM SERVICES COORDINATOR
 Frank Pennisi

PROGRAMS & SERVICES

- | | |
|---|---|
| ACCESSIBILITY SERVICES
Cheri Robinson | SYSTEMS ADVOCACY
Susan Ruff |
| ADA SERVICES
Frank Pennisi | DEAF SERVICES
Jonathan Dollhopf |
| BEHAVIORAL CONSULTING
Rachel Schwartz | SERVICE COORDINATION
Jo Anne Novicky Marci Germond
Jessica Arnold Stacey Engel
Thea Arnold Chad Eldred
Jessica Hinton Christine Klein
Aimee DePue Cynthia Meredith
Sann Dee Walter Jeff Rogers
Kathy Sas Shannon Smith
Emily Neville Andrea Hanover
Laura DiRenzo Marcy Donahue
Angela VanDeWeert Gayle Barton |
| COMMUNITY INTEGRATION
Brianna Spak Robert Deemie
Darlene Dickinson Lucretia Hesco
Tammy Virgil | PSYCHOTHERAPY
Charlie Kramer
Jane Long |
| DEVELOPMENT
Bill Bartlow | TECHNOLOGY SERVICES
Cheri Robinson
Andy Sedor |
| ECDC
Sue Lozinak
Laurie Wightman | MONEY FOLLOWS THE PERSON
Robin Carroll Peg Schadt |
| EDUCATION SERVICES
Casey Calvey Beth Kurkoski | PEER COUNSELING
Susan Link Jane Long
Danny Cullen Robert Deemie |
| INTERPRETER SERVICES
Stacy Seachrist | PERSONAL ASSISTANCE SERVICES
Joy Earthdancer Susan Hoyt
Danielle Amorese
Wendy Hitchcock
Diana Salvemini |
| MONEY FOLLOWS THE PERSON
Robin Carroll Peg Schadt | SUPPORTED EMPLOYMENT
Amber Salerno Kandi Stevens |
| PEER COUNSELING
Susan Link Jane Long
Danny Cullen Robert Deemie | TBI RESOURCE CENTER
Anita Ferris
Todd Fedyshyn
Jamie Haywood
John Roy
Belinda Turck
Betsy Giannicchi
Margaret Hulbert |
| PERSONAL ASSISTANCE SERVICES
Joy Earthdancer Susan Hoyt
Danielle Amorese
Wendy Hitchcock
Diana Salvemini | NHTD RESOURCE CENTER
Daena Scharfenstein
Anita Ferris Kara Burden
Danette Matteo
Laura O'Hara |