

AccessAbility

Spring 2013
Number 110



This is the second installment of STIC's 30-Year Anniversary series that will run throughout 2013 in this newsletter.

During our history, we have always been advocates and agents of change, seeing an issue that needed addressing and taking a leadership role in making things happen. Change is at the core of what we do, not for its own sake, but for the sake of human rights, independence and quality of life.

One such issue became apparent in the mid 1980s. As an Independent Living Center, we serve people with all types of disabilities. However, we began to notice that STIC was virtually the only agency that worked with people with traumatic brain injuries (TBI). As we delved into the whys of this, we learned that almost no one knew about or understood the disability very well, including STIC. So we set out to remedy the situation.

We contacted the local head injury association, gathered information, conducted research, etc. (and research wasn't as simple as "Googling it" back then).

We decided to hold a conference to educate the community and shortly after, we hired a person to focus solely on TBI-related issues. The person we hired was Pat Green, just the right combination of persistent advocate, patient friend and savvy leader.

With her skills we were able to pull a task force together, comprised of consumers, family members, and medical and other

professionals. There were so many issues to tackle, it was hard to know where to begin. The task force decided that one of the first and most prominent needs was to have outpatient services available to people with TBI, so they wouldn't have to travel out of the area for rehabilitation and all of the therapies that involves.

Additionally, there was much concern about the unemployment rate among people with disabilities, and the lack of understanding in particular about TBI. The District Office of ACCES-VR (then OVR) didn't have a poor track record on this issue, it had no record at all. To be fair, however, neither did anyone else, so they were in good company. Again, through our advocacy and education efforts both locally and with Albany officials, this began to change and they began to assist people with TBI in supported employment.

As the pieces started to fall into place, Pat, ever the visionary, decided that we needed a statewide program to address the issues. After a great deal of research, we came to realize that many people with TBI were being warehoused in nursing homes, and to add insult to injury, those facilities were outside of NY. This meant they couldn't get visits from family members and were quite effectively locked away from the outside world. Additionally, this was being done at an exorbitant cost to NY taxpayers.

While there were many other crucial issues, our strategy was that if we could propose something that would save the state money, public officials might listen. And they did,

INSIDE

State Budget: New Tunes and Moldy Oldies.....	pg 2
OPWDD DISCO News:Ain't Dancin' Yet but It's Time to Choose Partners.....	pg 5
Are We Really SAFE Now?...	pg 6
Fraudulent Federal Fraud Findings.....	pg 7
SAGE and Time on Our Side...pg	9
The Cabinet of Dr. Cuomo...pg	10
Justice Center Ramps Up... pg	10
Long Term Care over the Cliff.....pg	11
NYAIL 2013 Disability Rights Agenda.....pg	11
Canning Spam.....pg	14

starting with Senator Tom Libous, who took a leadership role in making things happen.

After a bit, with Pat's patience and persistence, legislation was proposed that eventually led to what are now the Regional Resource Development Centers (RRDCs), which have very successfully helped to move people out of nursing homes into the community, as well as helping many to avoid nursing home placement. The model was so successful that it eventually resulted in the Nursing Home Transition and Diversion Waiver and its RRDCs.

STIC also received the J.M. Foundation's Award for Excellence, for all the work we did on behalf of, and jointly with, people with TBI. It is one of our proudest achievements.

AccessAbility

March 2013

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



We had one casualty of these efforts. When the Department of Health was given the task of implementing the TBI program statewide, under the direction of Bruce Rosen, they hired Pat Green to take a leadership role in the program. STIC's loss was NY's gain, because she did an outstanding job. She never lost sight of who she was really working for, the consumer. No matter how bureaucratic things became, which of course they inevitably did, she stayed true to her roots, which were planted at STIC, and to her own passionate belief in our philosophy, combined with her unwavering optimism. She never faltered or gave up. Pat was always fond of

saying, "The universe will provide," and when Pat was involved, it did!

So if ever there is a time when you think that one person or one committee can't make a difference, can't create change, can't improve the lives of your friends and neighbors, remember this story. One idea led to STIC hiring Pat, which over the course of several years resulted in a great deal of systemic change that improved the lives of thousands of New Yorkers with traumatic brain injuries and other disabilities as well.

Keep the change, it has paid off!



The proposed New York State budget for fiscal year 2013-14 may be the most "technical" budget we've ever had to analyze. There are many complexities that we don't fully understand. There seems to be a lot of administrative trickery being used to arrive at a "balanced" budget, something Governor Cuomo took office claiming he would end. Oh well. Here it is:

Oldies but Baddies

As usual, Cuomo re-introduced some ideas that the state Legislature shot down last year. Many are, no doubt, red herrings: "negotiating points" that the Governor expects the Legislature to make deals with him to remove. These things make advocates devote scarce time and resources to fight them, making it harder to pro-actively push for real reform.

- "Prescriber Prevails" rule: NY has a preferred drug list for Medicaid recipients. Doctors are only supposed to prescribe drugs on the list, but sometimes a medication not on the list works better. "Prescriber prevails" means the doctor gets the last word. For years governors have tried to end this, and it's been cut back quite a bit. When the dust settled last year, "prescriber prevails" remained in effect for anti-psychotic

medications. This year Cuomo wants to create a "gold card" program that will give only psychiatrists "prescriber prevails" rights for these drugs. He says too many primary care doctors prescribe them inappropriately. Maybe so (see page 10). But these drugs have uses for mental health issues short of serious psychoses, and psychiatrists are in short supply in some areas, so this could delay appropriate treatment for some people.

- Spousal Refusal: Under some circumstances, federal Medicaid law, and NY Medicaid regulations, let the spouse of a person who needs Medicaid long-term care services "refuse" to financially support the spouse who needs services. In other cases, the income of the spouse who doesn't need services can be ignored when deciding if the person who needs services is eligible for Medicaid, so that the couple won't be "impoverished". In the end, these rules amount to the same thing, sort of. The amount of income and assets to be disregarded differs, as do some eligibility rules. What's clear is that without these options, many married couples who don't have much money, or tangible assets, to start with would be forced into real poverty in order to get the services needed. These services are *only* permanently available from Medicaid,

not from Medicare or private insurance, and there's *only* one way to qualify for Medicaid: be deemed poor. It's rarely a question of somebody "hiding assets" to get Medicaid; it's a question of being able to keep your home, your car, and a reasonable standard of living, or not, when your husband or wife needs long-term care. Cuomo wants, once again, to end "spousal refusal", but this time he wants to expand "spousal impoverishment" to people in Medicaid managed long-term care.

- **Early Intervention Services:** Cuomo once again wants to convert the Early Intervention (EI) Program, which serves very young children with disabilities, to managed care. He also wants to prevent conflicts of interest by not letting the same provider both evaluate the needs of, and provide services to, the same person. STIC generally supports such rules. We've certainly seen lots of self-dealing in developmental disabilities services. But sometimes there is only one provider of a service who has expertise with a particular type of disability within a reasonable distance from a family, and that provider is also the only qualified local evaluator. Provider shortages are already getting worse due to rate cuts and more complex billing requirements imposed in recent years. And while the Cuomo Administration will explicitly permit such conflicts in its new OPWDD DISCOs, it seems obsessed with blocking them in the EI system. The Legislature rejected it last year, so Cuomo enacted the rules by Executive Order. A State Supreme Court judge granted an injunction against that, so Cuomo went back to the Legislature. If service providers can also be evaluators in the DD system (which serves many of the same kids who get EI services), then why not in EI? Even worse is the revived plan to give managed care insurance company representatives a seat at service planning meetings. This is unheard of anywhere else in the disability service system. It's unconscionable.

Latest Hits

Fun from the Feds

Before mid-February, the above list was about the worst that could be said for Cuomo's budget. Then he released his "30-day amendments".

After making a deal with the federal Centers for Medicare and Medicaid Services (CMS)

to address claims of Medicaid overpayments to NYS (see below), at least for the next fiscal year, Cuomo announced that NY's Medicaid reimbursement from the feds will be cut by \$500 million, meaning that about \$1 billion needs to be recouped from NY Medicaid spending (because the state has to match federal Medicaid money dollar for dollar).

He floated several ideas. The worst is to take \$120 million out of OPWDD "community-based services" through a 6% "across the board" rate cut for OPWDD-funded services provided by not-for-profits (costing STIC over \$150,000). It's unfair; OPWDD's much larger state-operations budget will only lose about \$5 million. Once again, the system bends over backwards to preserve mostly segregated day and residential programs operated by the state and its unionized workers, while gutting more integrated personalized services. Most of the remaining losses will be magically

NY's Medicaid reimbursement from the feds will be cut by \$500 million, meaning that about \$1 billion needs to be recouped from NY Medicaid spending.

"disappeared" by dodges like resubmitting claims that were denied by the feds in hopes that they'll be paid, and making guesses about how much Medicaid money will

be saved by people moving to Obamacare "exchanges". Some program startups will also be delayed.

The feds are still planning to audit NY's Medicaid program and apparently require repayment. State officials said that any repayment demands will be fought in court because CMS approved the state's rate-setting methodology.

Meanwhile, in his 30-day amendments Governor Cuomo also made a positive change of a sort. His original proposal would have extended the 2% "across the board" Medicaid cuts enacted 2 years ago through the end of fiscal year 2014-15. He now says, though, that those cuts "could be" ended as early as January 2014 if expected Obamacare savings are achieved.

Special Protection for Nursing Facilities?

New provisions would be added to public health law to require nursing facilities to pay adequate wages. This can be read in different ways. A union representing nursing facility workers is very happy about it. Some disability rights advocates called it an unfair benefit for segregated programs. However, the proposed language appears merely to force

nursing facilities to use state funds to meet special minimum wage requirements for staff members (as opposed to, say, executive salaries and perks or profit-taking). The language doesn't specifically require the state to pay nursing facilities extra money to cover these costs, it only says that nursing facilities that fail to pay these wages will be "sanctioned". Still, state officials have said the money will be there. This may be moot anyway, because among the 30-day amendments is one labeled "delay nursing home quality initiative", which may refer to this item.

New Chart Climbers

A couple of measures in the budget bill could be good news for disability advocates:

Psych Center Closures?

There is a proposal for new "regional centers of excellence" in psychiatric programs. Cuomo said it will save \$20 million in FY 2013-14 and \$40 million the following year. This could mean closing some state psychiatric centers and consolidating their services in these regional locations; it's hard to see how it can save money otherwise. However, no specific closures were announced. Instead, information will be gathered from "all constituents" to decide how to proceed, and the Cuomo Administration said it's too early to know what effect it will have on psych centers. Every time the state tries to close one of these places the local politicians start screaming about job losses and letting dangerous people loose on the streets; it's quite possible that Cuomo just wants to keep the real plan out of the papers for a while.

Housing Initiatives

Cuomo appears to have stepped up to the plate on affordable housing—sort of. Not "supported housing", not necessarily accessible housing, but just plain affordable housing—depending on how you define "affordable". The new "House NY" program provides about \$1 billion over 5 years to preserve and create 14,300 affordable housing units statewide. Almost 75% of it, though, would go to fix up crumbling publicly-financed apartments for people with "moderate" or "middle" incomes in New York City. Most of the rest would repair existing units elsewhere, with some new ones created. None of it is really low-income housing of the sort that most people with disabilities can afford. Cuomo also wants to increase the Year 2 allocation for the Medicaid Redesign Team (MRT) housing initiative by about \$12.5 million. This would be good if

they don't use the money for handouts to nursing facilities that want to build segregated congregate "assisted living" centers, or for housing bundled with mandatory services, like they did last year. Advocates again called for the funds to be used for housing subsidies for people with disabilities to obtain accessible, affordable scattered-site housing that is not tied to services. They also asked for support for housing for people with very low incomes. So far Cuomo has ignored all of these requests regarding MRT housing. And the 30-day amendments include "delays" for some "MRT reinvestments", so now we don't really know what, if any, new housing will come from this.

Managed Care Ombuds Program

In an initial resounding victory for disability rights, Cuomo agreed to create a statewide ombuds program for people in Medicaid managed care. The program would assist individuals to resolve complaints and help with appeals, and collect data and work to fix systemic problems. It was largely designed by disability advocates at Medicaid Matters NY (whose board STIC Executive Director Maria Dibble currently chairs), with support from other advocacy groups. It was to get \$3 million this year, but the 30-day amendments delayed start-up until next year.

A Golden Oldie

Level Funding for CILs

Once again, the Governor didn't try to cut funding for Centers for Independent Living (CILs) like STIC. This means there was no initial proposal to reduce the amount of NY State IL money that is administered by ACCESS-VR (formerly VESID). There was no guarantee it wouldn't be on the chopping block during budget negotiations later on. Many CILs rely heavily on this money to survive; for others, it's a small portion of a very diverse budget. In any case, it has not increased in many years, but Cuomo can't decree that inflation, especially in employee medical insurance costs, must stop. So CILs will lose money in real terms again this year. Still, given the overall state of the economy and fiscal climate, we're probably lucky to have this much.

Cuomo's Personal Faves

Several proposals known as "Governor's Program Bills" always come out with the

budget proposal, and their costs are addressed in the budget, but in common sense terms they aren't budget measures so we're describing them separately.

Managed Care Threats

As NY continues to force managed care on more Medicaid recipients, it has tried to limit their rights. It already claims it can arbitrarily cut availability of some services, in violation of federal Medicaid law, because that law provides no effective redress for people (see *AccessAbility*

Fall 2012). Now it's clear that Medicaid managed care may seriously weaken your right to appeal care decisions. The new system will make people undergo long and, perhaps, poorly-monitored internal appeals processes within managed care organizations (MCOs) before they can get a fair hearing before an impartial judge. Even worse, the state is imposing severe limits on "aid continuing". "Aid continuing" means that if your services are cut or ended, you can opt to have them continue while you appeal. There's a risk; if you lose the appeal you must pay back the cost of those services. But people win a lot of these cases, and without "aid continuing" they could be forced into institutions or have their health damaged. Cuomo wants to permit "aid continuing" only during the 60 days when you first transition into managed long-term care. Once you're in an MCO's hands, it can cut your services and force you into a nursing facility until, after months of appeals and, perhaps, losing your home, you win your case. Assemblyman Gottfried introduced a bill to stop this unacceptable plan (A. 4996) that's getting widespread support from advocates.

OPWDD to Close Taconic and Monroe Developmental Centers

OPWDD is on a fast track to close its large institutions (the latest euphemism is "campus-based facilities"). CMS is pressuring the agency, pointing out that many states have no such facilities so it's really hard to justify keeping even one. OPWDD now says it will only continue to keep about 150 people in such places (down from 300 in its original People First Waiver proposal), and only on a time-limited basis. So Taconic and Monroe are on the FY 13-14 closure schedule.

Sole Sourcing DISCOs

Once again Cuomo proposed to dispense with

open bidding for OPWDD's new "DISCO" managed care organizations. He tried this last year and the Legislature shot him down. OPWDD insists it's going ahead with its open "Request for Applications" process as planned (now hopefully set to begin "this spring", instead of "in March"). Certainly the requirements for establishing a DISCO are staggering in financial, regulatory, and organizational terms. The number of potential qualified applicants is very small. We only know of four across the entire state. We're sure it would be an easier process if the state could just pick a few favorites and be done with it. However, one of the goals of the People First Waiver is to offer people as much choice and variety as possible. We think Cuomo's proposal suggests bad faith.

Moving OPWDD and OMH Rate-Setting to DOH

This one initially hit disability advocates like a bombshell. People seemed to think it meant OPWDD would cease to exist. We're tempted to say, "no such luck." That won't even happen if the rest of the SAGE Commission's recommendations are ever implemented (see page 9).

The proposal means exactly what it says: the Medicaid rate-setting machinery housed in these agencies would move to DOH. Why? Two reasons: First, it's a show of taking responsibility by the Cuomo Administration in the wake of the OPWDD rate scandal and blistering Congressional report on NY's Medicaid system (see page 7). DOH has always been the state authority on Medicaid rates; it always signed off on whatever OPWDD and OMH did. Now though, it will look more like the process is actually under central control. Second, it enables "efficiencies". In reality, the people at DOH don't have a clue how to design rates for DD or mental health programs, so it will be the same people who did this at OPWDD and OMH now working (perhaps) in a different building for different supervisors but doing what they always did.

Still on the Charts?

Owing to our late start with this newsletter, Cuomo's eerie penchant for getting budgets passed on time, and the Easter recess before the end of March, the final budget may be passed by the time you read this. If we had to bet, we'd wager that the Legislature won't approve anything it didn't approve last year, and everything else we've described will go through mostly unchanged. But we'll have to get back to you on that this summer.

Once you're in an MCO's hands, it can cut your services and force you into a nursing facility



Ain't Dancin' Yet but It's Time to Choose Partners

The big Medicaid news recently in NY has been the Congressional report and federal demands for rate cuts and repayment (see page 7). This, along with Super-Storm Sandy recovery issues, appeared to dominate the Cuomo Administration's activities over the winter.

Cuomo insisted that the OPWDD rate scandal, and his efforts to get the new "mega waiver" and OPWDD People First

waivers approved, are separate things. But insiders told a different story. Approvals were clearly held up until Cuomo accepted a \$500 million cut in federal Medicaid funds for NY for FY 2013-14, and that may not be the end of it. The feds are still demanding repayment and may still be using the waiver approvals as blackmail... er... "leverage".

We were also told that the demand by the federal Centers for Medicare and Medicaid Services (CMS) to package up all of the new waiver applications into one proposal had been dropped and that separate applications would again go forward.

Here's what we can tell you:

1. OPWDD's "March" deadline for release of the final Request for Applications for the DISCO pilot program has now been changed to "sometime this spring".

2. OPWDD continued to provide a completely inadequate response to concerns about conflicts of interest when DISCOs evaluate needs, plan services, provide services, and allocate funds for services, for the same person. Everyone knows that the "separate not-for-profit corporation" is a legal fiction; if a DISCO is established by a service provider, most or even all of the same board members and administrators from the provider agency can run the DISCO, with plentiful opportunities for self-dealing. And there will also be internal pressure to understate needs in order to cut costs. OPWDD claims that this isn't a problem because it will do the initial needs assessments. However, it expects

DISCOs to do subsequent (probably annual) assessments. Neither OPWDD nor DISCOs are impartial; needs assessments should be done solely by independent entities that neither provide direct services nor control funding for them.

3. Some people remained concerned about independent advocacy. We don't think any formal advocacy role will work, whether it's called "independent"

or not. Like "independent" advocates assigned by OPWDD or "parent" advocates assigned by school districts, any officially designated advocates will be controlled by whoever recruits, assigns, or pays them. We think real advocacy under managed care has to work like real advocacy does now: If you need help getting your rights protected and your needs met, you go out yourself and pick someone you trust to advocate for you. Independent Living Centers are good at that but there are other options, including forward-thinking family members or friends, or Protection & Advocacy lawyers.

4. The formal appeals process is another problem. OPWDD has expressed support for the Medicaid Matters NY statewide managed care ombuds program that Cuomo has apparently adopted. However it has not provided details of how DISCO managed care would interact with that program. NY's approach to managed care appeals processes is suspect. There is emphasis on using internal appeals controlled by the managed care company first, with an impartial Fair Hearing the last option, and Cuomo wants to restrict "aid continuing" (see page 4).

Announcing iCircle

But time marches on and these changes are coming.

Over the past few months STIC conducted an exhaustive investigation into the nuts and bolts of starting and running a DISCO. In the end, we found that the up-front costs and ongoing financial risks are just too expensive for an agency of our size. We can't do it folks, and we're sorry.

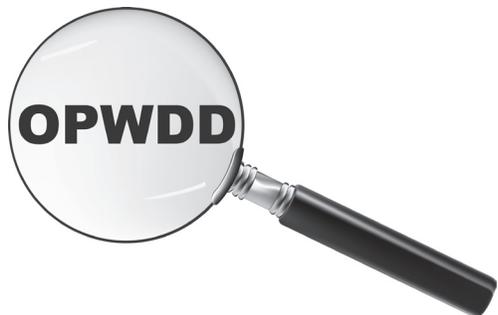
But we have good news. STIC has joined a network of over 40 developmental disabilities and mental health service providers serving the Finger Lakes and Southern Tier regions called iCircle. iCircle will be applying to OPWDD to form a DISCO. As a founding member, STIC has a permanent seat on the iCircle governing board and executive committee, and will have a great deal of influence over its management and policy decisions. The original and principal partner in iCircle is CDS Monarch, located in Webster, NY, near Rochester. They are a very large, progressively-oriented full-service DD agency with an excellent reputation for supporting consumer choice and integration.

iCircle's governing board will have at least 20% of members who are its own service recipients. It will also have advisory boards that involve people with developmental disabilities, family members and advocates in policy development, quality monitoring, and service design. Some of you will have an opportunity to participate.

STIC will serve as the iCircle "point" agency for the Southern Tier region. That means we will be the primary source of information and point of entry in Broome and surrounding counties.

The details are still being firmed up. Our hope and expectation is that STIC will provide care coordination for people living in our region who choose the iCircle DISCO, while continuing to offer habilitation and other DD services, and some new types of integrated personalized residential support services as well. We hope this means that all of our current Service Coordinators and other staff will be able to stay with us, though it is not clear what specific type of work they will be doing in a

STIC has joined a network of over 40 developmental disabilities and mental health service providers serving the Finger Lakes and Southern Tier regions called iCircle



DISCO care coordination environment.

We emphasize that iCircle is applying in an open competition to be a pilot DISCO. There is no guarantee that the application will be successful, though it is shaping up to be very impressive.

Being part of iCircle does not have to limit our availability only to people who choose that DISCO, if it is established. STIC remains ready and willing to enter into partnerships with other DISCO applicants that may serve our region.

We will provide more information as it becomes available, and are hoping to hold public meetings in the near future to spread the word and answer questions.

Are We Really SAFE Now?

In the wake of the Sandy Hook shooting, Governor Cuomo quickly pushed the SAFE gun control bill through a horrified legislature and signed it into law.

The SAFE (the Secure Ammunition and Firearms Enforcement) Act contains, in addition to generic gun-control provisions, several important new requirements related to people with mental health disabilities. The civil rights issues involved are delicate and complex.

First, it extends “Kendra’s Law”, the Assisted Outpatient Treatment Act, for another two years. The law enables various medical and social service professionals to initiate a court proceeding to decide if a person with a mental health disability who is a significant risk for harm to self or others can be mandated to accept outpatient mental health treatment, including medication, therapy, and supervision. Advocates have understandably objected to the law on several points:

- It stigmatizes people with mental health disabilities as violent and dangerous when the truth is that such people are much more likely to be *victims* of violent crime than perpetrators, and people with mental illness as a group are somewhat less violent than the population as a whole.
- It violates a fundamental right of adults to refuse medical treatment.
- In its application it appears to have targeted people of color, though perhaps in reality it targets poor people, who are disproportionately non-white in New York State.

- If the community mental health system were adequately funded and managed, people could get treatment voluntarily. After all, the law was named for a person who was killed by a man with mental illness who had asked for treatment several times but was turned away.

NY’s mental health services are woefully limited. Most people with mental illness know they need help, even if they can’t say exactly what it might be, and try to get it. But it is very difficult for a person with a significant mental illness to get anything beyond an occasional 15-minute appointment with a psychiatrist to prescribe drugs. Most of these drugs don’t work as well as Big Pharma advertising would like us to believe, and a lot of them have horrible side effects. Simply prescribing drugs is not an adequate treatment strategy for people with serious and persistent mental illness. People with these disabilities need ongoing support services to maintain stable and productive lives in the community. The thing is, Kendra’s Law actually provides this. It’s been very effective for many of the people whom it has touched. It’s not good because it forces people into treatment, it’s good because it forces the state to *provide* treatment.

The SAFE Act made other changes to Kendra’s Law that are likely to benefit most people: It extends the initial treatment order from 6 to 12 months; requires a review 30 days before the order expires to determine if it needs to be extended again; requires such a review before discharging a person from the state’s only “forensic” (criminal) psychiatric hospital; requires the order to cross county lines so if the person moves the treatment can follow him/her.

Then there are the gun-control provisions for people with mental health disabilities:

A NY State database will collect information about people who have been involuntarily committed to inpatient psychiatric care from the national gun background-check system.

Specific mental health professionals (physician, psychologist, registered nurse, licensed clinical social worker) will be required to report to the local “director of community services” (a county Mental

Health or, sometimes, Developmental Disabilities, services director) any person who, in their professional judgment, they think is likely to seriously harm him/herself or others, “with a goal of removing their guns and gun licenses”. The part about the guns is the only really new thing here; mandated reporters have always had an obligation to report dangerous people to the authorities, and even those who aren’t mandated have an ethical duty to do so. The community services director will decide if the report is credible and, if so, pass it on to the State Division of Criminal Justice Services, which will then make the final decision on whether to send out law enforcement to revoke the license(s) and pick up the gun(s).

We are well aware of the horrible effects of stigmatizing people with mental health disabilities as a group. They are, overwhelmingly, non-violent people who know they need help and try their best to get it and cooperate with appropriate treatment. The stigma is made worse by NY State’s leaders, who consistently refuse to design and fund an adequate community mental health system that can respond quickly and effectively to requests for help.

But we’d be lying if we said that’s all there is to the story. We at STIC know that there are people with serious mental health disabilities who are clearly dangerous and have access to guns, and there isn’t always an effective response. We do believe that more must be done to keep guns out of the hands of individuals who can be identified as likely to do harm, and we think the SAFE Act is pretty reasonable. It’s not enough. We need a well-funded and managed community mental health system, and it may take a federal lawsuit to get one, as it has in other states. But we can’t find much to criticize in the SAFE Act itself.



Fraudulent Federal Fraud Findings

The latest fallout from OPWDD's Medicaid rate-setting scandal arrived in early February with a US House of Representatives Committee on Oversight and Government Reform report called *Billions of Tax Dollars Wasted Annually by New York's Medicaid Program*. The report followed inflammatory public hearings, and got lots of media attention, all of which painted NY as a near-criminal enterprise designed to systematically defraud the blameless US Government.

No big surprise from a group of 22 Republicans (15 from southern or rocky-mountain states) and 16 Democrats (only 6 from the northeast), and just one New Yorker (who objected to the report). This political hatchet-job harps on the usual right-wing anti-Medicaid, anti-NY themes:

1. NY's spousal refusal rules

The report claims that droves of NY millionaires are being allowed to fraudulently hide assets in order to qualify for Medicaid.

There are always a few crooks in any sizeable collection of millionaires, of course. But the truth is that most rich people simply privately pay either for luxurious top-of-the line nursing facilities, or for aides, out-of-pocket. They don't mess around trying to get Medicaid; it's beneath them.

"Spousal refusal" is perfectly legal under federal Medicaid law. It lets married couples with moderate incomes avoid spending almost all of their income and assets, to the point where they would lose their homes, vehicles, and savings, in order to qualify for Medicaid long-term care services. Medicaid is the only reliable source of funding for long-term care. The key words are "long-term": Medicare and private medical insurance only pay for these services on a very short-term basis. Private long-term care insurance is extremely costly, even for younger people—several hundred dollars a month. Couples with moderate incomes can't afford that, and anyway, it also is time-limited; you're lucky to get 2 or 3 years of coverage out of it.

Sure, "spousal refusal" sounds dicey: you "refuse to support" your disabled spouse, in apparent defiance of all expectations of a marriage. But the only other option to keep a decent standard of living is to get a divorce.

Would the right-wingers in Oklahoma like that better?

If they really want to end this practice, they should make Medicaid long-term care available to everyone. People with incomes over the current top-level Medicaid threshold could pay sliding scale premiums for coverage. Simple, eh? Not for people who are determined to "prove" that government can't do anything right by keeping the government from doing the right thing.

2. NYC's bogus "whistle-blower" suit

A few years ago a New York City employee filed a "whistle-blower" suit claiming that the city routinely re-approved homecare services for people with disabilities without requiring a medical review. In response, the city began reviewing every homecare case, and disallowed many of them (see *AccessAbility* Winter 2012-13). The committee report applauded this and claimed it saved lots of Medicaid dollars.

Wrong. In fact, in almost every case where someone appealed a review decision, s/he won and services were restored. This was because the city systematically violated Medicaid law and regulations. Eventually a federal class-action lawsuit stopped the city's practices. In the end, there were only a tiny handful of real cases of improperly approved service.

3. Insane OMIG behavior

"OMIG", the Office of Medicaid Inspector General, is a department of NY State government. Its job is to investigate questionable Medicaid expenditures and recover misspent funds. OMIG has been around for a while but became a bigger player when NY entered into a 5-year Medicaid waiver agreement with the feds called "F-SHRP", which promised additional federal Medicaid dollars to the state if it met ever-growing targets for Medicaid "fraud" recovery.

Medicaid fraud does exist. A few crooked

medical providers do deliberately bill, and get paid, for excessive or undelivered services, for people who don't need them or, perhaps, are dead.

But Medicaid billing documentation and process requirements are fiendishly complex. It's very easy to make errors, by providing proper services but transposing digits, or omitting a signature or date somewhere on the reams of required forms, and such honest mistakes account for the vast bulk of funds OMIG recovers. Actually, most providers find the mistakes themselves and repay the money before OMIG even gets involved. Still, every time OMIG makes a big score, officials make sure the media hear about how NY is heroically combatting "Medicaid fraud".

As the final years of the F-SHRP agreement approached, it got harder and harder for OMIG

Private long-term care insurance is extremely costly, even for younger people—several hundred dollars a month. Couples with moderate incomes can't afford that...

to meet the now-draconian "fraud" recovery targets, because they were based on wildly inflated estimates of the amount of actual fraud that occurs. So OMIG resorted to practices that, if they weren't explicitly legal, most people would call robbery. For example, it

declared that if it detected more than a tiny number of errors in a tiny "representative sample" of audited bills, the provider must pay back a comparable percentage of its total Medicaid receipts for the audited period. So, if OMIG looked at ten bills at random and found an error in two of them, it would make the provider pay back 20% of everything it got from Medicaid. This could amount to millions of dollars in "recoveries" for only a few hundred dollars of proven mistakes.

Eventually providers had enough and complained. Cuomo responded by firing OMIG head James Sheehan and replacing him with James Cox. Almost immediately there was a hue and cry from OMIG bean counters; their publicly heroic but privately obsessive nit-picking had been stopped, they were furious about it, and they made outrageous claims that the new Inspector General was allowing unchecked fraud. The reliability and stability

of these people was shown by a news story that described someone smearing feces on the walls of OMIG restrooms. What actually happened was that OMIG began taking a more reasonable approach to billing errors.

But the noise from disgruntled OMIG employees was pleasing to the ears of Congressional Republicans, and so they made a big deal out of it in the report.

4. Demanding return of payments CMS approved

The report cites the Poughkeepsie *Journal* articles that told how OPWDD charges daily rates for people in developmental centers that are ten times higher than the actual cost of serving them. OPWDD claimed the extra money was used for its other more integrated programs and services. Later reports showed that nobody really knew where all the money went, but some went to OMH and OASAS to serve people not eligible for OPWDD services, and some went into the state's General Fund for stuff completely unrelated to disability.

Without a doubt, this was a very bad thing. However, it was a very bad thing that the federal government had (at least mostly)

approved. The rate-setting methodology was developed to create an incentive for moving people out of large institutions into smaller facilities such as group homes. The state was allowed to keep most of what it received for a person in a developmental center after the person moved out, to support "community based" services.

This is a vague explanation, and the state did not provide more details until it was repeatedly and aggressively pushed by the people who are currently running the federal Centers for Medicare and Medicaid Services (CMS). We don't think all the money was ever completely accounted for.

This may be the only serious charge of fraud against the state that sticks. If some of this money was actually used for purposes not allowable for Medicaid, that's fraud, and it should be repaid. And the people who did it should go to jail. (Though no one has proposed that. In NY, only flunkies go to jail; high officials are allowed to retire, resign or, at worst, get probation.)

But, the people who ran CMS throughout the 1980s, 90s, and 2000s approved this rate-setting methodology year after year, knowing that the rates charged for individuals in

developmental centers were much higher than the actual cost of the service. Their wounded cries of moral outrage today are not credible. But they are music to the ears of Congressional Republicans.

NY has agreed to a rate cut but vowed to fight any demand for repayment (see page 3). A big repayment bill would hit the developmental disability service system very hard. That system does truly waste a lot of money on segregated congregate settings when integrated personalized services would be cheaper and provide a better quality of life for people. That's undeniable. But the state should not be forced to repay billions of dollars that CMS said it could have.

A more fitting punishment would be to force OPWDD to produce a strict timetable for closing not only its large institutions, but every state-operated or -funded ICF, group home larger than 4 beds, and segregated congregate day program and sheltered workshop, by the end of this decade, with a requirement to use all of the resulting extra funds for integrated personalized supports and services for people on waiting lists. But, of course, that would be government doing the right thing, and the right wing wants none of that.

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



Federally Insured by NCUA.

24 McKinley Avenue, Endicott

VISIONS
FEDERAL CREDIT UNION



SAGE and Time on Our Side

In February, Governor Cuomo’s Spending and Government Efficiency (SAGE) Commission released its final report on ways to consolidate and streamline NY State government. It includes some things that are in Cuomo’s 2013-14 budget proposals, like moving Medicaid rate-setting functions from OPWDD and OMH to DOH. And it contains some interesting ideas that echo proposals that we at STIC have made.

STIC has long called for all disability services and supports to be consolidated within a single agency that serves people with all disabilities of all ages, determines need for services based on a uniform functional assessment without regard to diagnosis, and focuses on personalized supports and services in the most integrated settings. People keep telling us this is unrealistic. We don’t agree. We just think it will take a lot of careful planning and a long time to phase in.

NY has moved a lot closer to a uniform functional needs assessment than people thought possible a few years ago. The SAGE report endorses closing segregated programs and increased use of integrated settings. If all of its recommendations are adopted, we could be almost home. Here’s what’s in there:

1. Merge OMH and OASAS

There are so many overlapping responsibilities between these two agencies (OMH: Office of Mental Health; OASAS: Office of Alcohol and Substance Abuse Services) that this is a no-brainer. 40% of people with significant disabilities labeled “mental health” also have substance abuse issues. People with mental health disabilities have a very difficult time getting ongoing support and treatment and many “self-medicate” with whatever drugs they can get their hands on as a result. Many of the modalities of support and treatment are very similar for both groups.

2. Division of Central Services for Health and Disability

There has been talk for a couple of years about merging “back office” services for the so-called “mental hygiene” agencies: OPWDD, OMH, and OASAS. This idea goes beyond that, though. This new office would encompass many of the activities of not only OPWDD, OMH and OASAS, but also DOH and the Office for the Aging (OFA).

Those activities would include “facilities management, communication and legal services, and human resources”. Also, staff at the different agencies involved in “certification, licensure, credentialing, and surveillance of health and disabilities programs” could be moved to the new office. The Commission says, “Much of the staff in these functions could formally remain under the auspice of their existing agencies, but would be coordinated by the Division of Central Services within a shared services model.” “Formally”, in this sense means, “in name only”.

3. Re-aligning Agency Field Offices and Co-Locating Services

Different state agencies have

different regions encompassing different counties and often have service offices widely separated from each other. The report notes that this makes it harder for people who need services from more than one agency to get them, and calls for the regions to be standardized across agencies and offices co-located whenever possible.

Now consider what all this would mean:

Many people who pooh-pooh agency consolidation do so out of an inability to imagine how all of the complex variations could be combined. The SAGE report makes this a lot easier by breaking it down into separate steps. But if these suggestions are adopted (and the report says it’s not happening right now mostly because the state wants to finish the Medicaid Redesign process first), then for the first time, the actual people who do the same (or virtually the same) things at the different agencies will all be together in one place. They will be forced to see that they really are doing the same things. They will be forced to experience how hard it is to get stuff done when the person next to you has to work with you to accomplish the same task while following different rules. They will finally see that the different rules have to be abolished.

After the new Division of Central Services for Health and Disability has been running for a few years, almost all of the organizational and procedural complexity involved in agency consolidation will have been resolved. The people working there will themselves be asking for all remaining distinctions to be removed so they can get on with their jobs.

And what distinctions will remain? Only political ones, involving constituencies divided by age and diagnosis. With all of the practical problems solved, it will be obvious to everyone that the rest is just divisive politics that benefits no one and harms everyone. At that point, it may be politically possible to take the rest of the steps to fully consolidate all disability services into a single agency that operates equitably and effectively without regard to age or diagnosis:

The Division of Central Services for Health

*Southern Tier
Independence Center*



BLOOD DRIVE

Open to the Public!

Thursday, May 16, 2013

9:00 am to 2:00 pm

Please call Diane Button
(607) 724-2111 (voice/TTY)

To Make Your
Lifesaving Appointment

and Disability would become the Division of Disability Services. Vocational and Independent Living services could be moved from the State Education Department to the Division. The Commission for the Blind and Visually Handicapped and ACCES-VR could be merged there. Office of Family and Children's Services programs that largely serve children who have behavior issues due to developmental, mental health, or learning disabilities could be moved out of that agency. Long-term care services and supports could be moved out of DOH. OPWDD, OMH, and OFA, all of their day-to-day administration already in the Division, would become policy and quality improvement directorates under it.

It won't happen quickly and there will be problems along the way. One of the biggest problems is how to deal with people who call for change but get cold feet when change actually starts to happen. The disability rights community needs to provide better leadership in that area.

But we think that if this new Division is created soon, we could begin to see the final steps taking place by the end of this decade. Wouldn't that be worth waiting for, and working for?

The Cabinet of Dr. Cuomo

In December Governor Cuomo surprised the disability community by announcing an "Olmstead Plan Development and Implementation Cabinet". As we've reported, Roger Bearden, respected disability rights lawyer and then Chair of the NYS Commission on Quality of Care, was named as Cuomo's "Special Counsel for Olmstead". There hasn't been much information released about Bearden's duties or powers but it appears that he'll have a leadership role in the Cabinet.



The Executive Order describing the Cabinet's responsibilities contains some good things: It will make recommendations to the Governor on what should be in an Olmstead Plan, including "measurable goals for providing supports and accommodations necessary for successful community living; statutory and regulatory changes to implement the Plan;" and "coordination strategy for the work of state agencies and authorities to implement the Plan, including specific and reasonable timeframes for implementation". These are all things that have been missing from the alleged plan produced by the state's Most Integrated Setting Coordinating Council (MISCC), which has been supposed to be designing an Olmstead Plan for over a decade.

However, unlike the MISCC, which had been moving to broaden its membership to include more people with disabilities and advocates, the Cabinet consists of the usual state agency heads and Cuomo staffers. It has no members who are people with disabilities who use state services, and no decision-making role for them. The Cabinet is supposed to "seek the guidance and expertise of stakeholders, including, but not limited to, organizations that advocate on behalf of people with disabilities, providers of services to people with disabilities, associations concerned with housing and employment for people with disabilities, academic institutions and local governments, and shall solicit input from the public." After Cuomo's attempt to identify Syracuse University as an organization that adequately represents people with disabilities (see below), we are troubled by this language. It doesn't say "people with disabilities" themselves, or "organizations controlled by people with disabilities".

Despite the presence of Bearden, who is universally well-thought-of, many disability advocates were very concerned that this was a Cuomo attempt to prevent actual people with disabilities from gaining controlling influence over Olmstead planning. That remains to be seen. Since the December announcement there has been no significant news on this front. Stay tuned.

Justice Center Ramps Up

As the June deadline approached for establishment of the new Justice Center for the Protection of People with Special Needs, the Cuomo Administration was busy getting things moving. After a long struggle with advocates, in February Governor Cuomo

formally designated Disability Advocates, Inc. (DAI) as the independent Protection & Advocacy, and Client Assistance Program, agency for NY.

DAI has a strong reputation in the disability community for filing several lawsuits to defend the rights of people with disabilities and pursue integration. When the Justice Center was announced, DAI applied to be the "independent agency" described in the enabling legislation, and agreed to change its governance to a board of directors controlled by people with disabilities. Advocates virtually unanimously supported DAI's application. However, Cuomo indicated that he didn't think DAI had sufficient experience or expertise to carry out all of the duties required of the agency. He floated the idea of having a think tank within Syracuse University, the Burton Blatt Institute, take on the job, possibly with DAI as a junior partner. People with disabilities would not have had a controlling interest, and Cuomo would have appointed 1/3 of the board members. Syracuse University would have had the majority share, and the chair of the SU Board was a former pharmaceutical industry executive and current healthcare industry lobbyist.

Advocates, led by the Center for Disability Rights in Rochester, made it clear that they were unalterably opposed to Cuomo's plan. They also pointed out that Cuomo appointing board members might not sit well with the federal Justice Department, which had strongly suggested that the agency be independent of state government. The advocates got their point across.

One thing that still won't be happening is moving oversight of nursing facilities from DOH to the Justice Center. This despite the fact that DOH has, according to a news report, done a poor job of monitoring and correcting improper over-use of drugs in the facilities.

In February, the Gotham Gazette website reported its investigation of misuse of anti-psychotic drugs in nursing facilities in New York City. The reporter reviewed data from the federal Centers for Medicare and Medicaid Services showing that in 2011, about 25% of NYC facility residents were prescribed anti-psychotic medications, while no more than 6% of residents, on average, have serious psychiatric conditions. The facilities with the highest use of anti-psychotics did not report a higher-than-average number of inmates with psychiatric diagnoses.

Family members of inmates as well as some facility employees and experts on geriatric services all agreed that these drugs are being used as “chemical restraints” on people whose behavior can be difficult to deal with due to dementia. However, medical research indicates that anti-psychotic medications are not appropriate for dementia and can worsen that condition.

New York’s Department of Health (DOH) has first-line responsibility for monitoring nursing facilities. Despite this very high rate of misuse of drugs by these facilities, documented by CMS inspectors, DOH inspection reports contain almost no mention of the problem. As advocates pointed out during the debate over the Justice Center, DOH nursing facility inspectors tend to give facility administrators the benefit of the doubt and downplay complaints by inmates or their families. Perhaps somebody should have listened to the advocates even more closely.

Long Term Care over the Cliff



The “fiscal cliff” deal made in Washington this past winter repealed the “CLASS Act” part of the Affordable Care Act (“Obamacare”). The CLASS Act provided a new kind of

long-term care insurance for people who can afford it; although it could have benefited some aging middle class folks, it wasn’t going to help typical low-income people with disabilities.

As a substitute, a new “Long-Term Care Commission” was set up to consider policy ideas to address the growing need for affordable long-term care services. Both houses of Congress and President Obama were to appoint members to the commission. Advocates bombarded these worthies with requests to ensure that people with disabilities themselves were represented. At press time in March, both houses had made their appointments: 12 people, mostly health care and nursing home industry representatives, and not one person with a disability or disability rights advocate. Obama’s appointments were not yet announced, and advocates were bombarding him. We didn’t know who he’d appoint but we had this sinking feeling...

NYAIL 2013 Disability Rights Agenda

(abridged)



The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs are disability-led, cross-disability, local not-for-profit organizations that provide community-based services and supports, and individual and systems advocacy, that empower people with disabilities to live independent, fully integrated lives in their communities. NYAIL priority proposals for legislative and administrative action include:

INDEPENDENT LIVING CENTERS

- **Invest in funding for ILCs, which serve as the safety net to ensure people with disabilities have services and supports to live independently in their communities. Savings from reducing Medicaid costs for institutional care should be reinvested in ILCs.**

The State has an unprecedented opportunity to use ILCs to help implement *Olmstead* and the Medicaid Redesign Team reforms, including the transition to managed long-term care. Data from ACCES-VR show that ILCs’ work to transition and divert people with disabilities from costly institutional placements **saved NY more than \$1.2 billion since 2001. These activities save the State more than \$9 for every state dollar invested.** ILCs are well placed to support *Olmstead* by helping people get the services and supports they need to live integrated lives.

NYAIL is grateful for Governor Cuomo’s budget proposal to level-fund ILCs in FY 2013-14 at \$12.361 million. The demand for ILC services continues to increase despite years of flat funding. ILCs served 80,177 people with disabilities, family members, and others in 2007-08. In 2011-12, ILCs served 90,985 people, a nearly 14% increase in just 5 years. As NY continues to implement major reforms to the state’s Medicaid system that drastically change how health care is delivered to New Yorkers with disabilities, this number will

continue to increase.

HEALTH/MEDICAID

- **NYAIL strongly supports funding for a managed long-term care ombuds program for people with disabilities and older adults.**

We applaud Governor Cuomo for proposing to support Medicaid Matters NY’s proposal to provide individual and systems advocacy for people with disabilities and older New Yorkers in managed care. We urge the Legislature to approve \$3 million for the program. It will help managed care enrollees resolve disputes with managed care entities; monitor, document, and investigate systemic problems such as inadequate accommodations for people with mobility impairments; offer information, guidance, and support; and provide direct representation in grievances, Fair Hearings, and appeals. With the roll-out of mandatory managed long-term care already underway, we support starting this program as soon as possible.

- **NYAIL supports the State’s implementation of the Balancing Incentive Program.**

The 2013-14 budget includes \$10 million for the Balancing Incentive Program (BIP), an option offered to states by the federal Affordable Care Act. BIP would provide an enhanced 2% federal Medicaid match until NY’s long-term care spending shifts to more than 50% for community-based services, or until the program ends in 2015. NYAIL urges NY to use the increased funds to promote home and community-based services across all disability service systems.

BIP requires the State to establish a “no wrong door” system for long-term services and supports. NY’s extensive network of ILCs should be part of this system to provide information on services to older adults and people with disabilities. ILCs assist people with all types of disabilities of all ages to navigate complex service systems. ILCs understand the complexity of Medic-



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®

aid services, as well as all other available community-based services for older New Yorkers and people with disabilities, and are experts in nursing facility and other institutional transitions and diversions.

• **NYAIL strongly supports increased funding for the Medicaid Redesign Team (MRT) “Supportive Housing Development Program.”**

The 2012-13 budget adopted the MRT Affordable Housing workgroup recommendation to reinvest Medicaid savings in a “supportive” housing program for New Yorkers with high needs who will be enrolled in a care coordination model, including managed long-term care, health homes, and behavioral health organizations. That budget funded the program at \$75 million for 3 years and included reinvesting Medicaid savings from hospital and nursing home closures or bed de-certifications to expand supportive housing and related services. This year’s proposal includes the expected \$75 million, and an additional \$12.5 million plus \$4 million from bed closures. We strongly support the additional funding for this program to increase housing options for people who are leaving or diverting from institutions. NYAIL urges adopting the following strategies to increase affordable, accessible and integrated housing through reinvestment of Medicaid savings:

1. Increase access to rental subsidies for people with disabilities who are institutionalized or at risk of institutionalization due to lack of affordable, accessible, integrated housing.
2. Increase funding for the Access to Home program, a successful State program administered by NYS Homes and Community Renewal (HCR), that pays for home modifications to allow people with disabilities and older New Yorkers to stay in their homes.

NYAIL urges that any reinvestment ensure full community integration and independence, as required by *Olmstead*. The following principles must guide the development of affordable, accessible and integrated housing for New Yorkers with disabilities:

1. All people with disabilities can live in their own home with supports. They should have the opportunity to make informed choices, with full and accurate information about their options, including what services and financial supports are available in integrated settings.
2. Everyone should have access to housing integrated in the community, with control of a lease or ownership. They should be assured full independence, including deciding where and with whom to live, when and what to eat, who visits and when, etc.
3. Housing should not be conditioned on compliance with treatment or with a service plan.

• **NYAIL opposes prohibiting the Medicaid “spousal refusal” option.**

Eliminating “spousal refusal” does not harm wealthy New Yorkers; it harms low-income couples or parents of young children with disabilities. NY’s spousal refusal provision eliminates the huge inequity that forces low-income couples to institutionalize a spouse who requires long-term care services. The rules let the “community spouse” of an institutionalized spouse keep enough of the couple’s income and resources to

Eliminating “spousal refusal” does not harm wealthy New Yorkers; it harms low-income couples or parents of young children with disabilities.

realistically meet living expenses. However, the same spouse who seeks Medicaid homecare for his/her spouse at home must become impoverished, living on income and asset levels that in many parts of the

state are insufficient. This puts pressure on the “well spouse” to institutionalize the disabled spouse as a purely financial decision. The only alternative is divorce. Spousal refusal also helps families of children with disabilities, whose parents would be forced to impoverish themselves to qualify their child for Medicaid.

• **NYAIL supports the proposal to extend “spousal impoverishment” protections to married couples living in the community, where one spouse receives home care.**

If approved by the federal government, this

would extend a key feature of the long-term home health care program Medicaid waiver to managed long-term care recipients. This provision lets spouses with disabilities stay at home, rather than be forced into a nursing facility for economic reasons. It's important to realize that couples that benefit from this change are different from those helped by "spousal refusal," and that spousal refusal rights must be protected.

HEALTH

This panel advises DOH on issues related to Medicaid managed care. With the expansion of managed care to previously exempted or excluded people and creation of the Health Benefit Exchange, which must integrate public program enrollment, the panel membership should be expanded to include people with expertise in access issues for people with disabilities. The panel's work should be expanded to include evaluation of service denials, effectiveness of grievance and appeal mechanisms, evaluation of data collection and reporting on health disparities, evaluation of implementation of consumer protections.

HOUSING

- **Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law. S.168 (Squadron)**

Landlords often reject tenants with rental

subsidies, such as Section 8 and subsidies tied to the NHTD and TBI Medicaid Waivers. Many people with disabilities rely on subsidies and other assistance programs to live in the community. Discrimination based on source of income is illegal in New York City. NYAIL has advocated to make such discrimination illegal throughout New York State for several years. **We support Governor Cuomo's 2013 State of the State commitment to make discrimination based on a tenant's source of income illegal in NY.**

Most housing was not built to meet the needs of people with disabilities, including disabilities acquired as one ages. Housing built with basic accessibility features—known as "inclusive home design" or "visitability"—would meet the needs of people throughout the lifespan and allow homes to be visited by friends and family members with disabilities. Renovating homes is much more expensive than including accessibility features at the start, when the home is built.

CIVIL RIGHTS

- **Incorporate Title II of ADA into NYS Human Rights Law. A.2070 (Paulin)**
- **Waive NY's sovereign immunity to claims under the ADA and Section 504. A.828 (Lifton)**

The ADA and Section 504 of the federal Rehabilitation Act provide comprehensive protection for the civil rights of people with disabilities. Under the 1999 US Supreme Court *Olmstead* decision, people with disabilities are entitled to receive services and supports in the community and avoid unwanted placement in nursing facilities and other institutions. ADA Title II protects against discrimination due to disability in services provided by public entities, including state and local governments. The NY legislature passed bills to incorporate Title II into state law in 2009 and 2010, but they

were vetoed. The bill would clarify the scope of protections against discrimination by public entities in the provision of services, programs and activities. Public entities would be required to make reasonable accommodations and people with disabilities would gain critical access to enforcement by the NY Division of Human Rights. More than 30 states have added Title II to state law; none have reported increased costs as a result.

EMPLOYMENT

- **Create a small business tax credit for employing people with disabilities. A.570 (Cusick) & S.1907 (Addabbo)**

Working age people with disabilities in NY have a 34.5% employment rate, resulting in an employment gap between them and nondisabled people of 40.9% (*Disability Matters*, Center for Independence of the Disabled, NY, 2011). The poverty rate for people with disabilities in NY is 17% higher than for nondisabled New Yorkers. The proposed tax credit would be an incentive for small businesses to hire people with disabilities, increasing opportunities for self-sufficiency.

TRANSPORTATION

- **Cap paratransit fares at levels no higher than public transit base fares for non-disabled adults. A. 943 (Kellner) & S. 510 (Espallat)**
- **Require appointment of riders, including seniors and riders with disabilities,**

STIC is on the Web



www.stic-cil.org

**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

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

to Transit Authority boards of directors.

- **Require taxi and limousine services to buy accessible vehicles.**

The shortage of accessible transportation is a major barrier faced by people with disabilities across NY, often leading to unemployment, inability to get medical care or to voting sites, and isolation from friends, family, and full community participation. Many people with disabilities rely heavily on paratransit services, but public transit budget woes have led to increased fares. Paratransit fares should be capped because fares for people with disabilities that are higher than those for nondisabled citizens are discriminatory. Involving riders with disabilities with Transit Authority boards ensures that local public transit and paratransit decisions address their needs. Greater availability of accessible transportation will bring considerable Medicaid savings as the cost of using ambulettes to transport wheelchair users to medical appointments will decrease. The need for accessible taxis, being debated in New York City, should be addressed statewide.

- **Visor communication card for people with hearing disabilities. A.1320 (Zebrowski)**

This bill would provide all deaf or hard-of-hearing drivers with a visor communication card from the Department of Motor Vehicles, after paying the standard car registration fee, which details the appropriate procedures for assisting a deaf or hard-of-hearing driver during a traffic stop.

EDUCATION

- **Include the history of people with disabilities as required curriculum in all elementary and secondary schools. A.2006 (Cusick) & S.1703 (Grisanti)**

In order to fully integrate people with disabilities into the community, our society's attitudes toward people with disabilities must change. Education on civil rights of people with disabilities is the foundation for ensuring these rights are protected. This bill would adopt a statewide curriculum to promote greater awareness and understanding of people with disabilities.

Self Help Issues & Answers

Canning Spam



In recent months STIC's email boxes have been flooded with hundreds of spam messages, and a growing number of viruses, every day. Why should you care?

Email spam isn't somebody else's problem. It's yours. The internet is an untidy, unmanaged, and risky place. Personal responsibility requires using the internet in a way that protects not only yourself, but other people you deal with. Responsible internet consumers use safe email.

ALL free email accounts have serious problems, but Yahoo is the worst. They are constantly being hacked. It is likely that hacked Yahoo email accounts are responsible for much of the recent increase in spam and virus email that STIC has seen.

But hacking is only one way that these accounts are used to send spam and viruses. Data-mining is another, much more common way. All free email providers use software to comb through your email address book and messages to harvest information about you and your associates. They use it to display ads on the email website and on other websites that they know you visit. They also sell information and email addresses to other people who send out spam.

It is likely that when you use a free email account to communicate with someone, you directly cause some spam to be sent to that person. And if the email company isn't very strict about whom it sells information to, this can also cause viruses to be sent to that person.

So we strongly recommend that you not use **any** free email service, and especially **don't use Yahoo email**. Here's what we suggest instead:

1. If you're a professional at an organization that has an internet domain (like "stic-cil.org"), then most likely the company that hosts the domain also provides email. Organizations

should provide their employees with email accounts from their own domain instead of requiring, or expecting, them to use their own accounts. You don't have to host the domain or email on your own server; you can purchase that service. Come on, it just isn't that expensive for a small organization!

2. If you're a professional working for yourself, consider that along with all the other reasons for not using free email for your work, free email addresses are widely regarded as amateurish. You can purchase a domain and email service as a business expense for very little cost. Health-related professionals need to know that free email subject to data-mining is **not HIPAA-compliant** and should never be used to transmit anyone's identifying or health information.

3. If you have internet service, then email almost certainly comes with it for no extra cost. Time-Warner/Roadrunner, Verizon, Frontier, Pro-Net all do this. It includes "web mail" available from mobile devices as well as from software installed on a computer. Most big cell phone providers also offer email. If your internet or cell provider offers email you should use it. It's much safer.

4. If you don't have internet or cell service that offers email, Gmail is probably the best option to prevent hacking. Unfortunately, it's also the worst for data-mining. Hotmail is another option.

If you must use a free email service, **PLEASE, WE BEG YOU:**

Don't use it to send email to STIC addresses, STIC staff at other addresses, or to other people you know who interact with STIC. But if you really can't do that, then at least:

PLEASE don't store STIC email addresses in your address book, or any messages containing such addresses, or the names of any STIC staff,

in email folders. As soon as you send them, delete them, and empty the trash folder.

If STIC staff send you something, **read it and delete it, and empty the trash**. This will reduce the chance that if your account gets hacked, it can be used to flood STIC with spam and viruses.

5. Email passwords should be hard to guess, but they don't have to be all nonsense characters. You can combine 3 or 4 unrelated words that no one would expect you to use. For example:

VillagePorkrindClownLawnmower

Then make up a story about the words: "I went to the village square to buy pork rinds when suddenly I was surrounded by laughing clowns all riding power lawnmowers." You'll remember the story, and the password, but nobody will be able to guess it. (DON'T use this example.)

Internet Hygiene Tips

1. Don't run your computer under an administrator account. Computers come with accounts you don't have to log into and can do anything with. That's very convenient, but also very dangerous. You should create an ordinary user account with no administrative rights on the computer, with a password. Use that account for day-to-day stuff. Only log into the administrator account to do software installations, updates, or removals, and to run periodic virus and malware scans.

2. Don't post your "intact" email address on Facebook, other social media sites, blogs, or similar places. Spammers "screen scrape" these addresses and use them. If you want to put your email address on such a site, do it in a way that it doesn't look like an email address. For example: "Want to email me? My email address is my first name and last initial at Verizon dot net."

3. It is not "normal" for a new computer to slow down after only a year or two of use. If your computer was fast when you first got it, but a year or two later it's slow as molasses, then it's infested with malware, some of which is probably spewing spam or viruses around the internet. You need to get it cleaned up.

4. There are hundreds of fake "anti-malware" programs on the internet. They install crud on your computer, then make you pay to have it removed—but it's never removed completely. There is only a handful of legitimate free anti-virus and anti-malware products. I can't list them here. If you want help, contact Ken Dibble. My email address is that first name plus last initial, and it's at STIC hyphen CIL dot org.



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

COMMUNITY INTEGRATION
 Brianna Spak Robert Deemie
 Darlene Dickinson Lucretia Hesco
 Tammy Virgil

Jessica Arnold Stacey Engel
 Thea Arnold Chad Eldred
 Jessica Hinton Christine Klein
 Aimee DePue Cynthia Meredith
 Sann Dee Walter Jeff Rogers

DEVELOPMENT
 Bill Bartlow

Kathy Sas Shannon Smith
 Emily Neville Andrea Hanover
 Laura DiRenzo Marcy Donahue
 Angela VanDeWeert Gayle Barton

ECDC
 Sue Lozinak Laurie Wightman

PSYCHOTHERAPY
 Charlie Kramer
 Jane Long

EDUCATION SERVICES
 Casey Calvey Beth Kurkoski

INTERPRETER SERVICES
 Stacy Seachrist

TECHNOLOGY SERVICES
 Cheri Robinson
 Andy Sedor

MONEY FOLLOWS THE PERSON
 Robin Carroll Peg Schadt
 Leslie Hadden

NHTD RESOURCE CENTER
 Daena Scharfenstein
 Anita Ferris Lori Wilmot
 Danette Matteo
 Laura O'Hara

PEER COUNSELING
 Susan Link Jane Long
 Danny Cullen Robert Deemie

PERSONAL ASSISTANCE SERVICES
 Joy Earthdancer Susan Hoyt
 Danielle Amorese
 Wendy Hitchcock

TBI RESOURCE CENTER
 Anita Ferris
 Todd Fedyshyn
 Jamie Haywood
 John Roy
 Belinda Turck
 Betsy Giannicchi
 Margaret Hulbert

SUPPORTED EMPLOYMENT
 Amber Salerno Kandi Stevens