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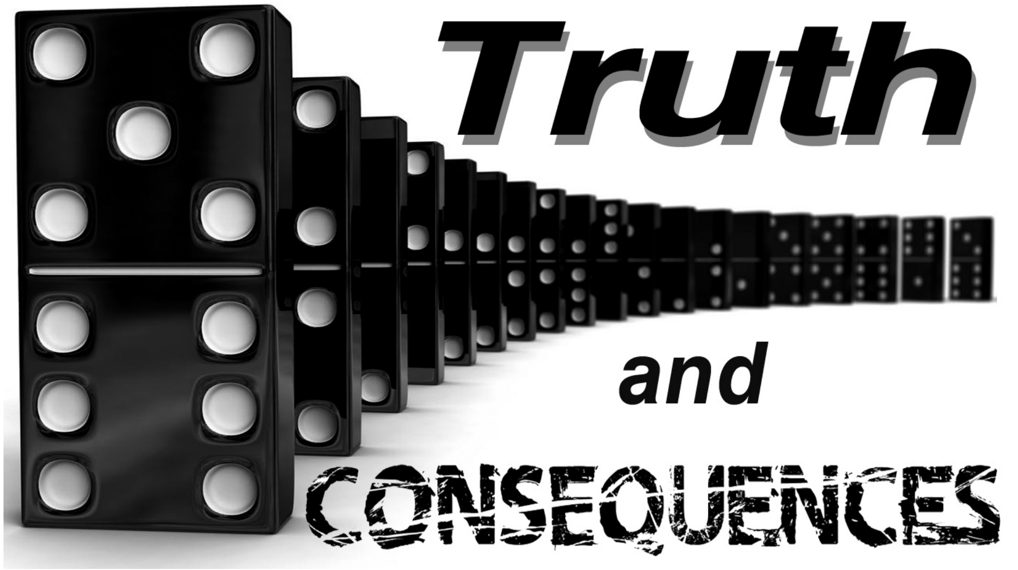
# AccessAbility

Summer 2014
Number 115

## INSIDE



# Truth and Consequences

### by Maria Dibble

Two months ago, one or more Broome Developmental Center employees released confidential information about a consumer, including much that was untrue. The employee(s) alleged that the consumer was a convicted sex offender and had molested both children and adult women; or had committed sex offenses but wasn't convicted; or had committed sex offenses but was court-ordered to BDC because he/she was incompetent to stand trial. All of these scenarios were circulated, including varying degrees of what the person did, with whom and with how many.

The Facebook posts went viral, and more and more speculation occurred. The only accurate information that was actually shared was the person's name, address and a picture of the place where he/she was residing. The rest was fiction.

The person was evicted, had to move, got a volunteer position and had that sabotaged by people in the community, and essentially has been subject to tremendous injustices all in the name of "keeping our kids safe".

I stayed silent except for a "Guest Viewpoint" I had published in the newspaper, because I couldn't discuss confidential information to which I had access that disproved the allegations.

However, recently I saw a post that finally has moved me to write. I will not put the person's name here, because I don't go in for that sort of thing if I can avoid it, but the person wrote, "She must not have ever known anyone who has been abused by a 'mentally incompetent' person..." I've seem similar posts saying that if I'd been subjected to abuse I wouldn't be an advocate for sex offenders, etc.

I'm writing this to answer those posts. First, not only have I known many people who have been abused, I've done everything in my power, and the power of STIC, to assist them. Second, I too am a survivor of sexual abuse as a child.

That last sentence caused me more emotional stress than I can describe to write and reread, but it had to be said. I can no longer keep quiet.

I understand the anger and rage, I've felt it. I understand the guilt and shame, I've felt it. I understand the deep grief, I've felt it. I understand the fear, I've felt it, and I understand the intense abiding pain. I've felt that too. I understand all of these things as only a survivor of abuse can.

However, I understand and have felt one other very crucial thing: the relief and release and freedom that come from forgiveness. Yes, I mean forgiving the priest who abused me, and moving on with my

AccessAbility
June 2014

EDITOR IN CHIEF: MARIA DIBBLE
MANAGING EDITOR: KEN DIBBLE
EDITOR: ELIZABETH SIGNOROTTI
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

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

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life. Taking my life and my power back, and saying no to fear.

Forgiveness doesn't mean that the perpetrator is off the hook for his crime or that he isn't responsible for the consequences. It simply means that I let go of the anger and other emotions that would give him power over me, and that would block my ability to see the truth or reason clearly about this very sensitive topic.

Why do I write all of this? Certainly not to gain your pity, or out of a burning desire to share this very personal information, because I don't feel those needs; but rather to show that I'm right there with everyone who abhors the crime of sexual abuse, rape, or molestation of any kind against children or adults.

I have not, nor would I ever, knowingly put someone whom I believe to be dangerous in proximity with others without appropriate supervision.

I tell you now, though some will choose not to believe me or even give my explanation consideration, the truth: The individual in question did none of the things of which he/she was accused. I'm not speaking about convictions vs accusations vs court-ordered confinement. I mean the person did not commit those acts.

Some of you have suggested that STIC is trying to "dupe the community" into accepting sex offenders in our midst. Sadly, it is not the community, but only certain people, who have been duped into poisoning the atmosphere of this community for people with developmental disabilities.

Any one of you could someday make an enemy and have false information spread about you—by an angry spouse, significant other, or even a child. Once that information is out, you can't get it back. It is out there forever. I am asking you to think about that when you go to "like" a post or send it on to "friends". Once the damage is done, it can't be undone, and in a way, you're committing your own kind of rape.

## *News & Analysis*

# Inconvenient Truths (for Some People)

For several months now, irresponsible employees of Broome Developmental Services, aided and abetted by elected officials, have unleashed a firestorm of controversy in their stop-at-nothing efforts to prevent that facility from being closed. STIC Executive Director Maria Dibble's editorial in this issue summarizes the situation well.

In April she published a "Guest Viewpoint" in the Binghamton *Press & Sun-Bulletin* in which she castigated those officials as well as public employee unions for their behavior, and raised the question of whether our society treats people accused of sexual offenses fairly, especially when they have disabilities. The paper published more "Viewpoints" in opposition to ours, and there has been an ongoing conversation on Facebook about the issue. All of these later publications have been filled with falsehoods, some deliberately spread by people who know better, others simply repeated by people who are ignorant of the facts.

In the Winter 2013-14 issue of *AccessAbility*, we addressed the falsehoods in two articles. It's time to do so again.

**1. Did Broome Developmental Services release a violent serial child rapist into the community?**

No.

EVERYTHING that has been published on Facebook, circulated elsewhere, and repeated by former and current Broome County officials about a particular person is FALSE. There is NO TRUTH in ANY of the claims made about this person.

One or more employees of Broome Developmental Center (BDC) illegally published identifying and location information, as well as vicious lies about the history, of a person who was released from the Broome Local Intensive Treatment Unit (LIT). It is likely that this information was spread by LIT employees in retaliation for an act of courage and responsibility that this person performed before being released.

*Did Broome Developmental Services release a violent serial child rapist into the community? No.*

Local public employee union representatives, who know the facts about this, have refused to condemn these actions, and have encouraged BDC employees to keep spreading false rumors about people being released from the facility to bolster their efforts to keep it open.

State legislators representing our community, who know the truth, have refused to condemn these actions or help the community understand that this is a deliberate attempt to destroy the life of an innocent person with completely false claims of criminal behavior. They see this as an opportunity to get publicity in an election year for uncritically supporting the public employee unions that pay for their campaigns.

We repeat: ALL of the claims being circulated about a specific person released from BDC are COMPLETELY FALSE. We hope that our readers will help spread the truth.

### 2. Are any people who have committed serious sex offenses being released directly into our community without monitoring by OPWDD?

In his April 18, 2014 "Guest Viewpoint" responding to Dibble, Roger L. Shaller said, "I have no problem with individuals with developmental disabilities being released back into the community. I have a big problem with those who have been institutionalized for more than a decade for molesting children and adults being released directly into our community without first spending time in a group home setting where they can be monitored."

Shaller is describing a thing that does not happen in New York State.

NY has strict laws regarding what serious sex offenders can do, and where they can go, after being released from confinement. These laws apply to serious sex offenders whether they have disabilities or not, and whether they are in prison or disability-related institutions. Serious sex offenders cannot be released into the community without the community being informed of where they live. There are restrictions on where they can live and what they can do, and there are monitoring requirements for them. OPWDD in general, and BDC specifically, fully comply with these laws and restrictions.

Furthermore, no person who is remanded by a judge to BDC, either because s/he was convicted of a crime, or because s/he was charged with a crime and determined incompetent to stand trial, can be released from the facility except by order of a judge.

NY law does not sentence people convicted of minor sex-related offenses to terms of "more than a decade" in jail or prison. A few months is more typical for nondisabled offenders, while remands of people with disabilities for the same minor offense are open-ended and can last years. That's unfair and discriminatory, but it's the truth. (And again, the specific person discussed above ***did not*** commit any sex-related offense, ***was not*** prosecuted for any sex-related offense, and ***was not*** under remand to the LIT.)

NY does not require that people convicted of minor sex-related offenses be "registered" or monitored, or that information about them be released to the public.

Once again:

A. OPWDD is NOT going to release ***all*** of the people who live in the LIT to ANY "community setting." OPWDD will continue to maintain two secure institutional facilities, including one in Norwich, to house people who need to be in such places.

B. OPWDD and BDC do not release ANYONE who has been mandated by a court to be there, whether to a group home or their own home, unless a court mandates their release.

C. OPWDD and BDC comply with all applicable laws regarding releases of registered sex offenders.

D. A group home is NOT required to securely monitor a person who has committed a minor offense. Completely adequate monitoring can be done in ordinary homes, including frequent in-person checkups and the continuous use of "ankle monitors" or similar devices. The community considers this adequate for nondisabled people who require monitoring. We're sure public employee unions don't like it because it doesn't require a lot of unionized employees to be hired to do the monitoring. But the only bases for arguing that people with disabilities should be treated differently than nondisabled people in this situation are bigotry, self-interest, or both.

### 3. Do the public employee unions protect OPWDD employees who abuse or neglect people with disabilities from being fired?

In her April 6, 2014 "Guest Viewpoint" Dibble said, "Closing these facilities will mean a loss of union jobs. Not a net loss; the people being released need lots of support services, and new jobs will be created to provide them. But the unions that are still preventing OPWDD from firing workers who abuse people in state facilities will lose jobs."

To which Dave Jenkins, the President of the public employee union CSEA's Local 449, replied on May 10: "These remarks are inaccurate, as are her claims that unions are preventing abusers from being fired. If an employee accused of abuse receives no reprimand or worse, that fault lies with a lack of evidence or, lately, the bureaucratic behemoth that is the Justice Center."

In fact, NY State's contracts with public employee unions, including CSEA, prohibit state agencies from simply firing employees for doing something wrong, no matter how bad the act or how obvious the guilt.

*The answer to the question "Do the public employee unions protect OPWDD employees who abuse or neglect people with disabilities from being fired?" is clearly YES.*

At OPWDD, if an employee is accused of doing something wrong, an internal investigation takes place. The employee has a union representative assisting him or her during the investigation. If the investigation results in a recommendation of termination, sometimes OPWDD administrators will negotiate a lesser penalty with the union instead of sending the case to binding arbitration. If not, the case goes to an arbitrator, who may find that the person did nothing wrong, may issue a lesser penalty, or may agree that the person should be fired.

Early in 2011, The New York *Times* reported that OPWDD succeeds in firing only 23% of people for whom firing was recommended after an internal investigation. This number does ***not*** include people who were later determined by an arbitrator to have done nothing wrong, or in Jenkins' terms, it does ***not*** include people for whom there is a "lack of evidence." In August 2013, the *Times* reported that another examination of new cases decided since 2012 showed the number had not changed. (See *AccessAbility*, Fall 2013.) The Justice Center did not begin operations until July 2013 and has nothing to do with OPWDD's failure, over the past five years, to fire 77% of the employees justly recommended for termination.

As a response to the OPWDD abuse scandal that emerged in 2010, the Cuomo Administration announced it was attempting to negotiate a "table of penalties" arbitrators would have to use to decide whether people should be fired. Cuomo claimed this would result in certain dismissal for employees who commit abuse or serious neglect. He said he reached agreement with CSEA on this point, but the "table" was never adopted.

Binding arbitration means the arbitrator's decision is final. "Arbitration" comes from the word "arbitrary," meaning that the decision is not based on rules and can be anything ranging from complete exoneration to immediate firing. You can't give rules to arbitrators, and if you do, they are free to ignore them. But if you did give clear, hard-and-fast rules to arbitrators about cause for termination, then there is no point in going to arbitration, is there? So why not skip that step and just fire the people?

States cannot legally override provisions of an existing union contract. States ***can*** control what they will agree to in ***new*** union contracts. We recommended to state legislators and the Governor that the state pass a law that says, in all negotiations for new union contracts, the state will not accept provisions that allow arbitration of dismissals of people who have committed abuse or neglect. That recommendation was ignored. Neither Cuomo nor the overwhelming majority of the members of the state legislature are willing to cross the public employee unions on this issue, and that includes all of the state legislators who represent our region.

Meanwhile, also in August 2013, the *Times* reported that it had obtained a CSEA "draft union proposal" that indicated that "the union wants to continue to give arbitrators wide leverage, and would not require firing even many of those found to have committed inappropriate sexual conduct or physical abuse." A CSEA spokesperson said, "With regard to the issue of arbitrators having discretion on disciplinary penalties, it is a practical reality for resolving cases. Most cases have nuance."

There you have it. CSEA is publicly on record as believing that even when a public employee has sexually abused an OPWDD consumer, s/he should not necessarily be fired because "most cases have nuance."

We are not surprised that union officials who publicize false claims that OPWDD releases dangerous sex criminals into the community also believe that sex criminals who work for OPWDD should not be fired. As Dibble said in her "Viewpoint," this is not about sex crimes or protecting the public. It's about protecting union jobs, union leaders' influence with state government, and union money funneled to elected officials.

The answer to the question "Do the public employee unions protect OPWDD employees who abuse or neglect people with disabilities from being fired?" is clearly YES. And our elected officials protect the unions.

**4. Do people who don't really need to be in institutions have a right to stay in them if they want to?**

The short answer is, "No." The long answer is, "almost always no."

CSEA Local President Jenkins also

claimed there is a “misconception that the Olmstead Act mandates the closure of institutions, which OPWDD officials and the governor use to justify the current plan. The truth is that the Supreme Court stated in a brief in the *Olmstead* decision: ‘We emphasize that nothing in the [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. ... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.’”

The full truth is that the Supreme Court also said that only impartial experts carrying out objective evaluations of an individual can determine whether that individual is able to “handle or benefit from community settings.” That does not include the person him/herself, his/her family members, or public employees who think that releasing people from institutions will threaten their livelihoods. None of those people are impartial.

Jenkins is right that there is no ***federal*** requirement that community-based treatment be imposed on patients who do not desire it. However, the *Olmstead* decision doesn’t prevent ***states*** from creating such requirements.

A very conservative federal judge in Virginia recently ruled that people with developmental disabilities can’t be compelled, by the ADA, to leave institutional settings if they don’t want to, but he did say that they don’t get to choose which institutional setting they then end up in, and Virginia can close all of its institutions but one, and downsize the remaining one to meet actual need, without violating any federal law. Which is what OPWDD is planning to do—only it’s leaving two institutions open, not one. Several states have NO institutions for people with developmental disabilities, and they are not violating any laws.

So: If a person with a developmental disability has an objective needs assessment, done by impartial third parties who are experts in the field, and if that assessment shows that the person needs to be in an institutional setting because it is completely impossible to set up a more integrated setting that will meet her needs, then the person can stay in an institutional setting. If not, then the person has no right to stay in such a setting, even if she, her parents, the staff who work with her, or anybody else, such as grandstanding politicians, wants her to. Nor does she have the right to choose which particular institutional setting she will be in.

The primary reason these facilities are being closed has nothing to do with the *Olmstead* decision. The main reason for the closures is that OPWDD has repeatedly and consistently violated federal Medicaid law that governs those facilities as well as other programs that it operates. That includes failing to follow service planning regulations, failing to protect facility residents from abuse and neglect, and massive mismanagement of Medicaid funds. The agency has been ordered by the federal government either to close most of its institutional programs, or lose most of the Medicaid money the agency uses to run its programs. That is not a matter of interpretation of a court decision. It is not a matter of anyone’s “choice.” That is a cut-and-dried federal ultimatum to New York State. There is nothing that any state official can do about it.

**5. Does STIC have a financial interest in the closure of Broome Developmental Center?**

BDC and the LIT are residential facilities. STIC, as an independent living center organized under NY law, cannot operate residential facilities. And STIC follows the Independent Living model, which means we cannot accept custodial responsibility for any person with a disability.

The people leaving those facilities will need a lot of residential supports, and STIC will not be the agency that provides them. Other community agencies will, and they will receive the bulk of the funds that are transferred from those facilities to the community.

We already provide a lot of other OPWDD-funded services to a lot of people, including over 500 recipients of service coordination, about 300 recipients of habilitation services, and many others. We currently have waiting lists for most of those programs. People are beating down our doors to get us to serve them, and we literally cannot hire new people fast enough for them. We do not need any OPWDD facilities to close to ensure that our budget continues to grow. Our budget grows because hundreds of people like what we do and how we do it, and they are telling their friends and neighbors about it.

## OPWDD’s Latest Plans

This spring OPWDD released a wealth of new information on its plans for system reform, and they asked for public comments. Unfortunately, by the time most of you read this, the comment deadlines will have passed. But here’s a summary of what we said.

### New Home and Community Based Settings Rules

We've covered this before, in great detail (most recently, see "We Found Our Way Home" in the Spring 2014 issue of *AccessAbility*).

To summarize: OPWDD has a Medicaid Home and Community Based Services (HCBS) waiver that lets it offer specialized services and supports to people with developmental disabilities in places that are not institutions. It is how most people with developmental disabilities get OPWDD services today. But the definition of "home and community based" was not very strict, and it has been abused to allow a lot of unnecessary segregation of people with disabilities. So the federal Centers for Medicare and Medicaid Services (CMS) wrote a new definition, with regulations to better define "person centered planning," another misused term. The new regulations took effect in March 2014.

OPWDD now must negotiate a plan with CMS to ensure that its HCBS programs comply with the new regulations, and may be given up to 5 years to achieve that compliance. One of the things OPWDD wanted to hear about from us was, how should they do that?

The agency released a brief "administrative memorandum" draft late last year, before it knew exactly what would be in the final regulations. But even then a lot of the new requirements were known, and OPWDD officials have been saying for a while that they think their system is already pretty much in compliance.

We had to tell them, in clear and detailed terms, that it's not. It took over 15 pages, and we can't do that here, but essentially:

● As we've reported, the person-centered planning rules will no longer let most agencies (including STIC, ACHIEVE, and others) provide both service coordination and direct services to the same individuals. They won't even let the same people run two separate agencies to do that. Across the state, 60% of OPWDD consumers get service coordination and direct services from the same agency. This is a very big change, and it's one that neither STIC nor OPWDD expected. OPWDD is definitely not ready for this. Neither are we. What we can tell you is this: It doesn't prohibit a single agency (or a group of people having an interest in multiple agencies) from offering both service coordination and direct services. It just prohibits them from doing both things for the same people. And it means that people served by agencies that have refused to tell them about all of the available service providers and service options will now have better information and much more freedom to choose.

● You must control your service planning process as much as you can. Even if you have a guardian or other legal representative, you are still to make as many of your own decisions as possible. You decide who comes to your planning meetings—every person, every meeting—and who doesn't. Your service coordinator and everybody else must respect that. You must also be offered the choice to "self direct" your services. That means you can choose the people who work with you and tell them how and when you want things done, or you can decide how the money used to serve you is spent, or both of those things. Your service plan must say if, and how, any unpaid family or friends will help you, but your family and friends can't be forced to help you.

● Every person who gets HCB services must be offered the opportunity to live in your own home, or in a home operated by a provider where you can live alone if you wish. The number of hours of support you need doesn't matter. If you choose to live in a place where you must have a roommate, you must be allowed to choose who your roommate is. This means that OPWDD has to make sure that these options are available to you if you choose them. And "available" means now—not after years on a waiting list. Services in your own home or in private apartments managed by provider agencies, even at high intensity levels, are not unusual in New York State. But they are unusual around here. OPWDD has to change how it hands out money to encourage new and existing agencies to offer those kinds of options.

● If you live in a group home, then you have to get a lot of things currently not offered to you now. That includes things like a lease; a lockable bedroom and the key to that lock; the right to talk to anybody on the phone at any time, and to unrestricted internet access; to have any visitors you choose at any time, including overnight; to eat what you want when you want it; to do what you want, inside or outside the home; to have actual people to take you to the places you choose and help you do those things—even if everybody in the house wants to do something different at the same time. Very few group homes do this now, and OPWDD will have a huge task to get them to change.

● Sometimes it makes sense not to let certain people do certain things, like locking their bedroom or eating as much as they want when they want. But it can't be a "house rule" for everybody, and it can't just be some staff person's opinion. Any restrictions must be in your service plan, which you can accept or reject. Restrictions cannot be placed on you unless people have first tried, and failed, to help you with your issues without restricting your freedom. And if restrictions are put in place, your plan must have a schedule to regularly review them to see if your full freedom can be restored. This is another big retraining task for OPWDD; restrictive "house rules" are common, and so are personal opinions about people's abilities, and fears about their inabilities, being treated as facts.

● By the way, if the place where you live doesn't meet the new HCBS requirements, then you can't get ANY HCB services, anywhere, e***ven if you don't get or need them at home***. Not habilitation, not respite, not supported employment, not anything. Any and all HCB services are for people who live integrated lives the community—period. We think that's going to be a big stunner for OPWDD once it starts thinking about it.

● This isn't just about OPWDD waiver services. These rules will also apply to the new Home and Community Based services that will come out of OMH (known as HARPs), and the new Community First Choice program. But it's OPWDD that will face the massive problem of changing what it already does.

## Closing ICFs

An ICF is an "Intermediate Care Facility." It's a specific kind of medical-model residential facility. Size doesn't matter; big developmental centers, medium-sized intensive treatment units, and relatively small "community ICFs" are all ICFs.

Because OPWDD mismanaged federal Medicaid dollars, and because it did not protect people living in facilities that it runs or funds from abuse and neglect, and because OPWDD has consistently violated federal regulations regarding discharge planning for people who live in ICFs, CMS has told OPWDD that it must close almost all of its ICFs and help people to live in more integrated personalized settings.

OPWDD's plan to close the big ICFs is well known and has generated much controversy.

More recently, the agency released a plan to close nearly all of the smaller "community ICFs." Today over 6000 people live in those places. By October 1, 2018, there will be no state-operated community ICFs, and only about 400 people will be in community ICFs operated by not-for-profit agencies. OPWDD expects something less than a thousand ICF residents to move to individualized integrated settings (their own homes or those of family members). The rest are expected to be in the kinds of group homes that are now called IRAs.

> *CMS has told OPWDD that it must close almost all of its ICFs and help people to live in more integrated personalized settings.*

We like this idea. It has always been illegal for OPWDD to treat ICFs as permanent homes. They are supposed to be temporary intensive transition programs to help people with the greatest needs get ready for real community living. Only a tiny fraction of the people living in them really need that kind of program. We have been calling for these facilities to be closed for years.

But OPWDD's plan is just a chart. It doesn't contain any text explaining how this is going to get done. We have to guess that it will mostly be done by converting existing ICFs to IRAs. The people living there won't move anywhere but the money that pays for, and the rules governing, those places will change.

The new rules will be the same new HCBS Settings rules we described above. As we said, OPWDD will face enormous challenges bringing existing IRAs into compliance with those rules. And the ICF closure plan will increase the number of people in non-compliant IRAs by about 15%. Everybody will have to watch carefully to make sure OPWDD doesn't do what it did in the early 90s—simply change the names of those facilities without changing anything about the lives of the people in them.

## The People First Waiver

Most people think of this as the "DISCO waiver." This is OPWDD's plan to bring managed care to its services. Some interesting new things have been published about it.

### *DISCOs will be Voluntary...Forever?*

OPWDD has always said, up to now, that at first its new managed-care organizations—DISCOs—will be a trial project, and people will not be required to use them. Only people who volunteer to try them out will be included. But later, DISCOs were to become mandatory managed care for all OPWDD consumers. This was all to be part of a new Medicaid waiver being sought from CMS.

However, OPWDD's recent announcement seeking public comment simply says that participation in the new DISCO waiver will be voluntary. There is no mention of trial projects or mandatory managed care. We aren't sure if this was intentional or not. CMS may no longer be willing to consider both "demonstration" and mandatory managed care in a single waiver approval process; it may have decided that it's going to wait and see what happens with the voluntary program before it commits to anything else.

We still don't see why anyone would volunteer for this program, because so far NY State's roll-out of managed Medicaid long-term care has been very discouraging. In recent years, the state has tried very hard to limit the rights of Medicaid long-term care recipients to appeal decisions made about their care; it has badly damaged the public transportation system in smaller communities by mandating statewide managed Medicaid transportation; it has allowed managed care providers to police themselves, resulting in two major Medicaid fraud scandals; and it has cynically challenged advocates to prove in court that limitations it has tried to put on access to medical supplies and Early Intervention services are illegal—which the advocates promptly did. We are beginning to believe that the people running the state are not really acting in good faith, and so even though we are involved with an organization that is seeking to become a DISCO, we are not going to encourage anybody to take part right now.

### *CSS Reform*

One of OPWDD's current waiver services is called Consolidated Supports and Services (CSS). This is the so-called "Self Determination" program. It was, until recently, the only way people with disabilities could do "self direction" of their budgets and services. It's a good program—if you have involved friends and family members with lots of time to put into it. Since most people don't have that, it's not used by many people.

We have always asked OPWDD to make the program simpler, but the latest information they've published doesn't include any simplifications. In fact, it's just a bunch of PowerPoint slides that OPWDD officials haven't been able to explain. CMS is demanding better accountability for how OPWDD spends Medicaid dollars, and that's fine with us. But it appears that OPWDD may be handling that demand by destroying the flexibility that makes CSS attractive. They are changing the billing rules in a way that may make it more difficult, or impossible, for CSS users to "mix and match" habilitation, respite, and other services to enable people to have flexible schedules, do things on the spur of the moment, and use more or fewer hours of service as needs change. The CSS complexities are already a problem, and if they make it even less flexible, nobody will want to use it.

OPWDD also has been required by CMS to offer "self direction" (see above) to people using Community Habilitation services. Unlike in CSS, which provides both "budget authority" and "employer authority," the new "Self Directed Community Habilitation" service only gives you the ability to choose, train, schedule, and fire your habilitation workers; you can't control the budget. On the other hand, it's much easier for people to use than CSS. We don't know if, down the road, OPWDD plans to keep that simpler form of self-direction for habilitation services, or force everybody who wants self-direction into CSS.

### *Better Services for People with Dual Diagnoses*

People who have both developmental and mental health disabilities are poorly served today. Neither OPWDD nor OMH wants to take responsibility for meeting their needs. This is an especially bad problem in Broome County, where the county Department of Mental Health refuses to cooperate with the local OPWDD office, and mental health programs funded by the county often refuse to serve people if they also have a developmental disability.

With the new Medicaid waiver, OPWDD wants to make available a new program to address this. It's called "START" (Systematic Therapeutic Assessment, Respite and Treatment). The program will, if properly funded, put a lot more "boots on the ground" to provide rapid response and ongoing assistance to address the behavioral issues of dually-diagnosed OPWDD consumers. Right now OPWDD is test-piloting the program in the Finger Lakes and Hudson Valley. Because Broome County's attitude toward people with dual diagnoses is so bad, we urged OPWDD to expand the pilot to our region.

### *Employment Services*

OPWDD got its plan to improve employment for people with developmental disabilities approved by CMS. We had previously reported (*AccessAbility* Winter 2013-14) that the plan relied too heavily on ACCES-VR making changes to its procedures and policies. ACCES-VR is under the State Education Department, which is under the Board of Regents and not controlled by the Governor, so the Governor cannot force ACCES-VR to cooperate with OPWDD.

In recent years ACCES-VR has been "dumping" people with significant developmental disabilities back into the OPWDD system, claiming they are not "employable." They are typically more expensive to serve, and it takes longer to find them jobs; this messes up ACCES-VR's budget and success rate.

The final plan more clearly states OPWDD's commitment to serve people whom ACCES-VR rejects. We still believe that all employment services for people with disabilities should be in one place, and not broken up into "silos" based on diagnosis. Nor should ACCES-VR be excused for its practice of "creaming" (only working with people who are easiest to place in jobs). But something is better than nothing.

The plan emphasizes OPWDD's new "Pathways to Employment" program, which it says will begin rolling out this summer. This is a year-long program designed to help people with developmental disabilities decide what kind of work they want to do and then prepare to do it. It combines aspects of "pre-vocational" services with "job shadowing." It's a good idea.

The plan describes a segregated employment setting (for "data collection purposes") as a setting where a person with a disability exclusively interacts with, or works along side of, other people with disabilities. That is what "enclave" and "mobile work group" supported employment models are. Although the plan doesn't forbid those models, we hope that this step will lead to that eventually.

The final plan also removed references to "affirmative businesses" as an alternative for sheltered workshops that must be closed. We consider any employment setting that exists primarily for the purpose of employing people with disabilities to be segregated employment, so we object to "affirmative businesses." People with disabilities can, and should be expected to, successfully compete in the open job marketplace with everyone else. "Special" employment settings strip people with disabilities of their dignity. The plan talks about "community businesses" instead, which may mean the same thing. Sheltered workshops should either become ordinary businesses that are not intended to, and do not, primarily employ people with disabilities, or they should cease to exist.

The final plan says that people who are not working full-time will be able to get habilitation services to help them take part in community activities when they are not working. However, OPWDD did not address our concern that service planning takes a long time and that the agency needs to ensure that people have immediate access to supervision and support as soon as they need it (for example, when aging out of school), and not have to wait for several weeks while the needs assessment and service planning process moseys along.

We'll let you know how OPWDD responded to these comments as soon as we know.

# courts watch

***Amanda D. v Hassan*** **Settled**

We first reported on this class action suit as "*Lynn E. v Lynch*" in *AccessAbility* Spring 2012. It's also known as *United States v New Hampshire*.

The case, filed in February 2012, concerned NH's failure to provide adequate levels of integrated community-based services to people with mental health disabilities; instead the state continued to keep people in a large psychiatric hospital or a large nursing facility. The case was interesting because NH had investigated its own mental health system and called it "failing" and "broken"—but then refused to fix it, mostly because it didn't want to spend the money to do so. The feds ordered the state to fix it, and entered into negotiations with state officials to come up with a plan. But negotiations broke down, so the US Department of Justice intervened in the suit on behalf of the plaintiffs.

In February 2014 a federal court approved a settlement agreement. It requires the state, within four years, to provide greatly expanded Assertive Community Treatment and mobile crisis response programs, scattered-site integrated housing, supported employment, and transition planning for people leaving segregated facilities for the community.

These are the same sorts of services that the Cuomo Administration has recently promised to beef up here, through funds reallocated by the OMH Centers for Excellence plan, the Medicaid Redesign plan, and OPWDD's proposed START program. This settlement shows that federal courts will enforce such promises if they are not fulfilled.

***US v Rhode Island*** **Consent Decree**

This is the first-ever case in which a state was required by a federal court to take specific steps to downsize and close sheltered workshops and maximize successful integrated supported employment job placements.

The US Department of Justice filed a complaint that the state of Rhode Island violated the ADA by unnecessarily segregating thousands of people with intellectual or developmental disabilities by sending them to sheltered workshops or congregate facility-based day programs. Approximately 80% of people with developmental disabilities in Rhode Island end up in segregated day activities instead of real jobs.

In April 2014, a consent decree was signed by the feds and the state. It imposes some remarkable requirements on RI, and is a great template for what NY should commit to achieving:

- It requires specific annual minimum successful supported employment job ***placement*** targets, not just provision of services to some number of people. These targets stretch across ten years.
- Like NY's Transformation Agreement with CMS, the consent decree requires RI to stop new referrals to sheltered workshops and to find ways to downsize and close those programs. While it does not specifically require stopping referrals to segregated congregate day programs, it does require the state to gradually reduce its use of those programs, and it mandates specific annual minimum placement targets for "integrated day services" for people not in real jobs.
- It specifically rules out enclave and mobile work group supported employment models, except if an individual who has completed at least one trial work experience in a truly integrated setting requests a "variance." Any approved variance must be reviewed every 180 days and the person must be offered another chance to get a truly integrated job.
- It specifically requires the state to pay for integrated day services for working-age adults for up to 40 hours per week, as needed by people who are not working full-time in paid integrated jobs. Integrated day services "must include an adequate mix of leisure, employment-related, and daily life activities that are comparable to those activities engaged in by working-age non-disabled peers"—which means that, while some of the time people will be involved in community activities, they will not be frog-marched into doing "constructive" things the whole time and should be able to just sit home and watch TV or take a nap if they want to.
- It requires the state to achieve an average integrated employment workweek for people with intellectual disabilities of at least 20 hours by May 2018.
- People of working age can choose up to 40 hours a week of day services instead of employment without undergoing vocational assessment or trial work, but must have the option revisited every 180 days.
- Specific school-to-work transition services are required, and must include opportunities to gain work experience, not just "planning."
- It requires the state to set up a sheltered workshop conversion trust fund to help workshops pay up-front start-up costs for conversion to integrated services.
- It requires interagency agreements among state agencies that allow "blending and braiding" of funds from different sources to remove service gaps and ensure uninterrupted integrated employment.
- It requires the state to reallocate money from workshops to integrated employment so money follows the person, and to adequately fund all of the services in the decree.

OPWDD has an employment plan containing many of these things. But the consent decree beats OPWDD in its specific numeric commitments. OPWDD, for example, says it will provide "support for community activities" for people unable to get full-time real jobs, but has not committed to 40 hours a week of coverage. OPWDD's plan mentions "collaboration" with ACCES-VR, the state's vocational rehabilitation organization, but it doesn't commit to specific results such as ensuring uninterrupted services. The consent decree should help educate NY officials about what can be aimed for and achieved, and what a court may compel them to do if they don't do it voluntarily.

### *Forziano v Burke* at a Loss

This is the case of the married couple with developmental disabilities that wanted to live together in a group home. As we've reported, the couple found another agency that offered them a supported apartment setting within a group home. But they (really, their parents) continued the suit.

In March 2014, a federal district court judge dismissed all of their claims.

We said previously (*AccessAbility* Summer and Fall 2013) that regulations for Medicaid-funded group homes require them to provide services to meet the specific needs of the residents, and that certainly could include helping with issues related to a marital relationship. But we also said that no group home operator could be forced to move residents around between facilities, or physically modify those facilities, to provide large-enough living quarters for a married couple if they didn't already have such quarters available. And we mentioned that state law requires people in the "custody" of OPWDD or an organization funded by that agency to pass a test of their ability to consent to sexual activity in order to be allowed to cohabit, and it didn't seem likely that this suit would override that law. The group home provider housing the woman, Hava Samuels, a Catholic religious organization called Maryhaven, had reportedly said they didn't think Samuels had the capacity to consent to sex.

Beyond that, media reports had not included many of the legal details of the case. For the first time, we can now see court documents and the issues the judge's decision raises.

The judge's decision indicated that neither Samuels nor Paul Forziano, her husband, had ever been offered any sort of training regarding sexual relationships by the facility operators. Samuels had been through two sexual-consent capacity assessments conducted by Maryhaven, but the "validity of the results were disputed." Forziano had never been assessed. During the litigation, Forziano's group home provider, Independent Group Home Living Program, Inc. (IGHL) conducted an assessment and failed him. So the families did some research and found out about an assessment tool and package of training materials offered by the Young Adult Institute (YAI), a group-home operator in New York City. They got the materials, spent some time teaching Forziano and Samuels, and then put them through the YAI Sexuality Consent Assessment. Both passed. But both Maryhaven and IGHL refused to accept the results as valid.

The couple's parents sued under almost every applicable federal and state law, including the Americans with Disabilities Act (ADA), Section 504 of the federal Rehabilitation Act, the non-discrimination provisions of the federal Fair Housing Act (FHA), federal Medicaid law, the 14th Amendment of the US Constitution, and "state laws" that were not listed in the judge's decision.

The decision shows that the plaintiffs wanted money damages for past discrimination and a permanent injunction against future discrimination. Their new provider gave them an upstairs apartment in a group home, but the couple's parents alleged that, as the couple ages, if one of them can no longer climb stairs they might have to leave that setting, so they wanted the judge to issue a permanent injunction to prevent the defendants, including OPWDD and any other provider, from denying them future services.

The judge said the issue of accessibility of their current apartment is not "ripe for review" because legal precedent says people can only sue over some "actual or imminent, not 'conjectural' or 'hypothetical'" injury. He dismissed the claim for a permanent injunction.

Depending on the law being considered, the US Constitution's Eleventh Amendment "sovereign immunity" concept comes into play. Sovereign immunity prevents states from being sued for money damages unless they agree to be sued. Because of previous court cases, states are considered to have implicitly waived sovereign immunity when they accept some types of federal funds. The judge found that claims for damages under the FHA, and "Section 1983," a federal law that lets people sue state governments for using state laws to violate their civil rights, are covered by sovereign immunity. He did say that Section 504 of the Rehabilitation Act carries an implicit waiver of immunity.

That law contains the same language as the ADA on forbidding discrimination by governments on the basis of disability, but applies only to government programs receiving federal funds. The FHA has similar language, so the judge cited a precedent that let him "interpret them in tandem."

Then he dismissed the claim that the couple was discriminated against under these laws. He pointed out that the FHA applies only to "buyers or renters" of housing, neither of which the couple was. And he said that the discrimination wasn't due to disability but to marital status.

Did the defendants violate state laws? A federal judge can't consider that once the Section 1983 challenge is gone.

The couple's parents have already filed papers to appeal this decision to the Second Circuit. It will be interesting to see what issues they raise.

The case already raises plenty of interesting points.

If Forziano or Samuels had identified needs for training or counseling on sex or relationships in their service plans, then somebody would have clearly been required, under Medicaid law, to provide it to them. The decision doesn't say whether the couple had these needs in their plans and didn't get the services, or those needs simply had not been formally identified. Folks, it's really important to get ALL of your specific service needs in writing in your plans. Some agencies try to avoid documenting needs that they can't or don't want to meet. That's illegal. Call them on it.

The case provides a great example of the flaws in OPWDD's inconsistent approach to so-called "capacity assessments": A group home operator is apparently allowed to disregard a capacity assessment—even one conducted via a standardized test that is recognized by New York State and used by many providers—if it is not performed by that operator. This also underscores the importance of having these evaluations conducted by impartial third parties. Of ***course*** these group homes “disputed” or “failed” the couple’s capacity assessments. They didn’t want to help or allow them to cohabit. State law says that certified residential facility staff who let people who can’t consent have sex are committing sexual abuse. OPWDD’s policy that any family member of a person with a developmental disability can be considered the person’s “legal representative” means that some angry prudish relative can challenge a capacity assessment in court, and if s/he wins, people can go to jail. So there are understandable, even if completely unfair, reasons why group home operators don’t want to let residents have sex lives.

But we have to say that anyone who is able to understand what it means to be married, even in a simple way, is not a person who needs to be in a segregated congregate setting like a group home. Perhaps the couple’s parents don’t understand or accept that, or maybe nobody in any of the provider agencies involved told them they could get adequate services in their own apartment. OPWDD and its contractors are very inconsistent in what services they promote.

And finally, we have to say this: We as a society have a huge problem with irrational fear of the sexuality of people with intellectual disabilities. The same emotional response that decries everybody released from Broome Developmental Center as a “sex offender” also assumes that people with intellectual disabilities are unable to consent to sex unless they prove otherwise—and, as we have seen, sometimes not even then.

So again, we say, if you want to have sex, you should choose not to live in a group home, or other certified setting. You can still get the services you need in your own apartment or house, where your sex life will be nobody’s business but your own. Under the new HCBS regulations, OPWDD ***<u>MUST</u>*** offer you that choice, and make sure you get it.

# PRACTICE MAKES IMPERFECT

Last time, we told you that Governor Cuomo had proposed language to amend the state’s Nurse Practice Act (NPA) to allow people other than nurses to administer medication to people with disabilities, and to allow creation of a new “advanced home health aide” service. This service would be available for people to be served under the new federal Community First Choice Medicaid program who cannot self-direct their services (CDPA would be available to those who can). A nurse would evaluate each individual case and delegate highly-trained aides to carry out tasks that a nurse would otherwise have to do. Cuomo’s original proposal wasn’t as flexible as it needed to be, but with input from advocates, he improved it.

Then the legislation stalled, largely due to opposition by State Assemblymember Deborah Glick. It was at first portrayed that Glick was responding to concerns expressed by the New York State Nurses Association (NYSNA), a union that said it was worried about the safety of people with disabilities. So ADAPT camped out in the NYSNA office for several days—and nights—and got the organization to agree to language that would, or at least could, accomplish the disability community’s goals. All parties fully assured ADAPT that the language agreed on with NYSNA would be passed into law after the budget was dealt with.

So the budget passed, the legislative session continued, and ADAPT activists actually got to see the language being considered by the Assembly. Although it included medication administration provisions, it was not even close to what had been agreed on, and the bottleneck was still Glick, who chairs the Assembly Higher Education Committee. That committee oversees professional credentialing issues, which includes determining what nurses and other healthcare workers can or can’t do. Glick was reminded that the nurses were no longer objecting to anything. She was also told that CDPA workers, who aren’t even professionally trained aides of any sort, had been performing the exact same kinds of tasks for decades without any significant safety issues. Glick refused to budge; she simply said she still had “concerns.”

At press time, although the influential Glick was clearly a problem, it remained true that this legislation was part of Cuomo’s agenda, and he was doing nothing to fight for it. Cuomo has gotten gay marriage and major gun control legislation, as well as a number of other things, passed despite strong opposition over the last few years. If he really wanted a NPA amendment passed, he could get one. Advocates, however, chose to focus on Glick's committee. Glick's office indicated it was willing to "listen", new bill language was being floated, and various strategies were under discussion near the end of May.

This is a fast-moving story, so stay tuned.

## State Budget Final: Loosening Our Belts a Notch

Here's the roundup on the outcome of the annual State Budget bust-up:

**Lift your caps!**

The Governor's proposal to lift the 2% "across the board" cap on Medicaid spending was adopted, and will be rolled out in various ways over time.

**Have a COLA on us!**

One of those ways, and one that surprised us, is a 2% cost of living adjustment (COLA) that takes effect in January 2015 for direct-care workers such as OPWDD habilitation workers and, perhaps, CDPA attendants. Later, the COLA will be extended to "clinical" workers such as service coordinators. These people have been denied raises for several years since the economy tanked in 2008. This is long overdue.

**Aid Continuing continued**

As we've reported (*AccessAbility* Spring 2013), the Cuomo Administration's approach to managed long-term care has included an aggressive effort to make it harder for you to appeal decisions about your care. Although Medicaid still requires that you have access to an impartial Fair Hearing, Cuomo has ordered that you must go through your managed care insurance company's internal appeals process first. That will take a long time, and it will most likely result in your appeal being denied. That is still going to happen.

Cuomo also wanted to limit your access to "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 wanted to permit "aid continuing" only during the 60 days when you first transition into managed long-term care. Once you got into an MCO's hands, it could cut your services and force you into a nursing facility until, after months of appeals and perhaps losing your home, you win your case. Thanks to Assemblyman Gottfried this was stopped, and aid continuing will be available throughout the full appeals process.

**Provider Prevails prevails**

"Provider prevails" means that if your doctor prescribes a medication for you, and it's not on NY State Medicaid's approved list, you still get the medication. The state has gone back and forth on this in recent years. Last year the provision, which had been limited to a small number of drugs, was greatly expanded and applied to Medicaid managed care drug plans as well as State Plan Medicaid. The Governor tried to kill the provision again this year, and lost—again.

**Spousal Refusal refusal refused**

Cuomo's annual attempt to disallow "spousal refusal" for Medicaid community-based long-term care recipients was again rejected by the legislature. People with incomes just above the poverty line will still be able to use this provision to get services for their loved ones without divorcing their spouses or disowning their children.

**Reinvestment restated**

Cuomo and his Office of Mental Health (OMH) floated vague plans to close state psychiatric hospitals and "reinvest" the resulting funds in community-based services for people with mental health disabilities. The closure plan got socked in the jaw, with the result that the Greater Binghamton Health Center will remain open with most of its beds intact. As part of that deal, 60 new "community-based" residential "slots" are to be provided for people with mental illness in our region, and support services are supposed to be beefed up, including providing a new mobile crisis service.

We still haven't seen precise numbers on this. Cuomo's original proposal included $25 million for "front-loaded" community service expansion (before facilities are closed), and we understand that's what was finally approved, even though the number of closures was reduced by nearly a third. Cuomo had also proposed another $120 million in what were called "reinvestments" but are now called simply "investments" in services for people with mental health disabilities. $110 million was approved, including $30 million to get the new HARPs plans started. This program would make available HCBS waiver-like services, including habilitation, supported employment, and peer support available. The program will require the feds to approve another Medicaid waiver proposal, and we don't know if Cuomo plans to hold off spending this money until approval is received or not. Also usually mentioned in the same breath with this $110 million is more supported housing services. However, Administration officials have been quite frank about the fact that very little of the housing money will make it to our region; it's almost all going to the New York City area. There are also provisions requiring the state to publish more information about service quality.

# STIC NEWS

## Accessibility Advocacy Committee says Thank You!

by Jessica Hinton

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

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

- Lowes on Upper Front Street in Binghamton for correcting and re-striping their parking lot.

- UE High School for their efforts to be accessible to the public at events and announcing that accessibility in their flyers, making the public aware.

- Hillcrest Heights Plaza for correcting and re-striping their parking lot.

- The DMV in Binghamton for their quick response on snow removal this last winter when informed that snow piles were blocking the handicapped parking area.

We applaud your efforts and would like to point you out as an example to other businesses in the area. Thank you on behalf of people of all abilities.

## There's a New Regional TRAID Director at STIC

by Kevin Jackowski

The Technology Related Assistance for Individuals with Disabilities (TRAID) program at STIC has a new regional director. My name is Kevin Jackowski and I will more than happy to help you with your assistive technology (AT) needs.

I run the TRAID loan closet, a closet filled with equipment that is used to increase, maintain or improve the capabilities of someone with a disability. If there's an AT device you are looking for, feel free to contact me. If we have one available you can borrow it from our loan closet to see if it will fit your needs.

TRAID serves individuals of all ages with disabilities, their family members, service providers, employers, educators and others who are interested in assistive technology and disability issues. The regional TRAID center at STIC serves Broome, Chenango, Delaware, Otsego and Tioga counties. If you live outside these counties feel free to call and I will get you information on the TRAID center nearest you.

Kevin Jackowski

Regional TRAID Director

traid@stic-cil.org

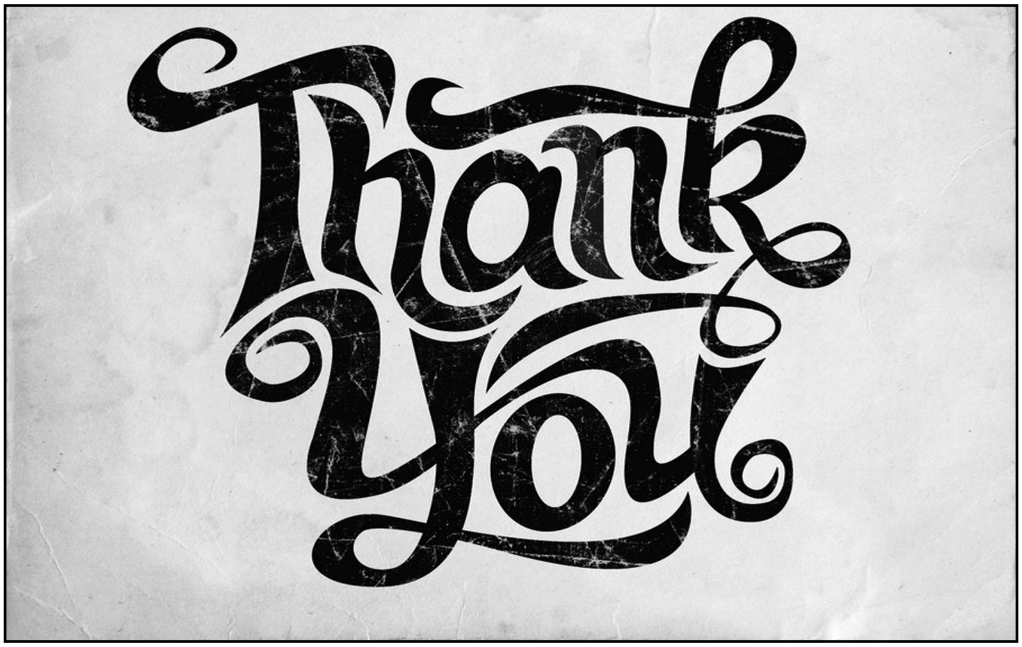
(607) 724-2111 (voice/TTY) x214

## On the Campaign Trail

by Bill Bartlow

STIC's 2014 Annual Campaign launched early this May with over 7000 letters sent to supporters of our mission. With appropriated governmental funding dwindling and the needs of those we assist increasing, this appeal becomes even more critical to maintaining STIC's standards of service in our region.

If you haven't returned your tax-deductible contribution yet, there's still time. Please use the form and return envelope we provided, and be sure to let us know if we can publish your name.



Our profound gratitude is extended to those who have already responded and to those who will invest their funds and confidence in the work of our not-for-profit organization. Our staff is here to serve you, should you need us, and your sustaining gifts allow us to continue to offer support to our friends and neighbors in need.

***Thank you*** for making it all possible:

**Gordon Allen**

**Ronald Bailey**

*in name of Rebecca Bailey*

**Victoria Dattoli**

*in name of Elliyana Dattoli*

**Peter and Mary Beth Gamba**

**Nellie Hickok**

*in memory of Donald Hickok*

**Barry Kinney**

**Al Klossner**

**Jenny Lee**

**Michael and Rachel Leonard**

**Sam J. Liberto, Jr.**

**Dale and Terena Loomis**

*in name of our son with TBI, Brian Brow*

**Rita A. Mattucci**

*in memory of John Mattucci*

**Carla Moore**

**Michael and Debbie Rigo**

**Stephen C. and Martha Thompson**

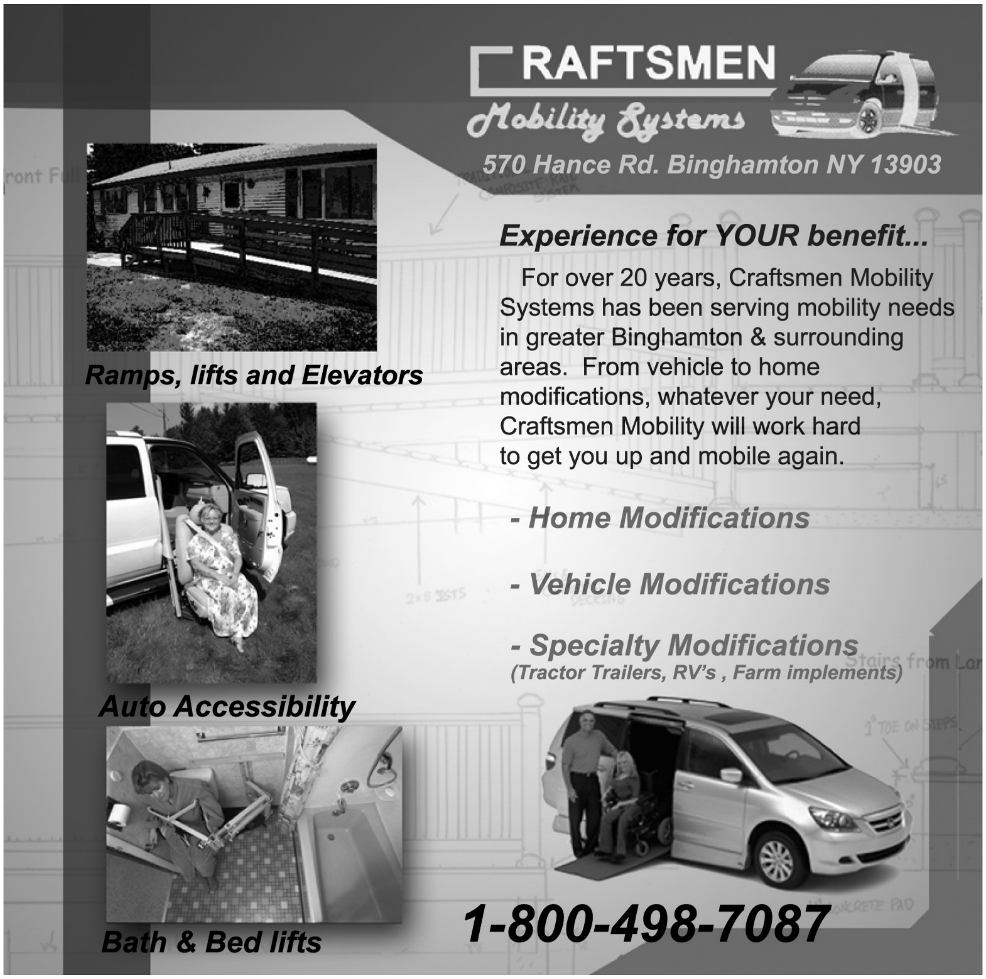
**John P. Turner**

*in memory of Barb Turner*

**Jean VanBuskirk**

**James and Pamela Vincens**

**Robert D. and Dawn Watson**



**STIC**

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

**THANK YOU!**

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