

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

AccessAbility

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Number 109

30 Something

by Maria Dibble



2013 marks STIC's 30-year anniversary, and we plan to celebrate it through the year. We'll be revamping our website, and doing several special events, all culminating in a celebration in December. Meanwhile, I will talk about how we got to where we are today, in a series of articles in our newsletter, this obviously being the first.

On June 27, 1983, I embarked on an amazing journey that has taken me to places I'd never dreamed, for that date is the first day of my employment as Director of STIC. My road has been long, often twisting and turning and leading back onto itself, but in the end always looking forward again.

We began with one small grant of \$100,000 through the State Education Department, and the energy and zeal to change the world of disability as we knew it then.

We got our first glimpse of bureaucracy at work when our contract and first check for start-up expenses were delayed almost six months. Little did we know that this was to be close to the norm for many interactions with state agencies.

G.E. was generous enough to donate four desks, and I brought in some folding chairs and a telephone from home. That was it for almost three months as we sought a bank

that would give us a small loan based on a contract that wasn't fully executed yet. By the way, I wasn't getting paid because we didn't have any money. We couldn't even pay the rent or utilities and kept begging those involved to "give us a little more time". Amazingly, they did!

Frank Pennisi was hired in August, also without the promise of a paycheck for a while, and we proceeded to lay some plans for what we needed to do to open as a fully functioning agency.

We finally secured a \$10,000 loan and immediately went out and bought a used copier and some supplies. We already had a couple of typewriters that we brought from home. (Yes, typewriters, not computers, since affordable personal computers were still a thing of the future.)

Where to start? Well, we couldn't open until we had an accessible bathroom, our first renovation project of many to come over the years. It seemed huge at the time, but in comparison to the undertaking that raised \$1.1 million to remodel our current facility, it was a cake walk.

Due to many issues I won't go into here, the bathroom project took four months to get done (lack of money being one major

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factor). On December 16, 1983, we finally opened our doors to the public, holding an open house to introduce our staff and our very unique mission and philosophy. More than 100 people attended, quite a turn-out for a completely unknown agency. One person actually said to me, "I'd love to see where you are in ten or so years, if you are able to stick to your philosophy and make it work." I think we did!

What made our program so different from all others in the community? Well, several important factors:

First our board of directors by law is required to be comprised of at least 51% people with disabilities, so that the policies governing the

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Authorship

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

www.stic-cil.org



agency are made by the people who are affected by them.

Second, we use a "peer approach" (now used by many organizations and programs), whereby people with disabilities are mentoring and serving as role models for others with disabilities, sharing experiences and tactics for dealing with issues and problems of everyday life.

Third, we use a non-medical model. We aren't here to "fix" or "cure" people, but to help them to navigate systems and services to get their needs met as individuals with disabilities. We also don't tell people what they "should do" but rather present them with options and allow them to make their own choices, even if those choices may occasionally be a mistake in the end. We treat people with respect and expect them to succeed instead of to fail. We believe in people's "abilities" and focus on those, rather than on their "deficits" or "limitations", another commonplace idea today that was not common back then.

Fourth, we combine direct services with an ambitious advocacy agenda, working to change "systems"—laws, regulations, policies, and practices to meet the needs of people with disabilities.

Lastly, and most important, we believe in community integration and inclusion. We fight for disability rights, equality and independence. Separate has never been, and will never be, equal.

In essence, we endeavored to change the way services were delivered to people with disabilities and we tried to redefine the issues in our terms, rather than those of "well-meaning professionals". If you've been journeying with us these last 30 years, you can decide whether or not we've succeeded in this effort.

If you have any special memories or reminiscences about STIC you'd like to share, email them to me at mdibble@stic-cil.org, or drop a letter in the mail. We will try to publish some throughout 2013 as space permits.

Let's Go to the DISCO!

Since our last report lots of new information about the People First Waiver(s) has come out of OPWDD, including at least one version of a draft Request for Applications (RFA) for DISCO pilots, reports from the three Targeted Work Teams, and a new Q&A document. The following information is gleaned from those publications.

It is important to note that while lots of good recommendations appear in some of the Work Team reports, it is not clear that OPWDD has accepted many of them. Also, the draft RFA still lacks details that are supposed to be "filled in" by the Teams, but it appears that the Teams stopped meeting after issuing their reports.

DISCO Governance

The Q&A repeats that DISCOs must be separate not-for-profit corporations whose sole purpose is to operate a DISCO. Thus organizations like STIC would have to set up new corporations as part of a DISCO pilot application. The organizations can have some or all of the same board members,

though—or at least it seems they would have to, since the RFA requires that board members have experience in providing services to OPWDD consumers. That means that DISCOs won't be as safe from corrupt self-referral practices as OPWDD claims they will be.

The "Access, Enrollment & Advocacy" (AEA) Targeted Work Team recommended that at least 1/3 of governing board members of DISCOs be people with developmental disabilities, their parents, or advocates. The Work Team also recommended that DISCOs do outreach to enrollees to let them know how they can be involved in DISCO policy-making, and that OPWDD's quality assurance process ensure that enrollees are involved. However, the Draft RFA says that *either* at least 20% of DISCO board members must be people served by the DISCO or "advocates", or that the DISCO must have an "advisory council" that has "direct input to the board".

Since DISCO pilot applicants will have to set up new corporations with new boards anyway, we

BAD WEATHER?

If the weather is bad, call 724-2111 (voice/TTY) to make sure we're open. The answering machine will explain why we're closed. Listen to the entire message since we sometimes ask you to call back to check later in the day. If we're going to be closed, the message will say so by 7:30 am. For Deaf consumers, there will be a generic TTY message saying we're closed. This message is always the same no matter why we're closed.

don't see why they should be allowed to substitute an "advisory council" for a governing board with representation by people with disabilities, and we would prefer that a majority of board members be people with disabilities, and at least 1/3 be DISCO enrollees or potential enrollees.

Quality Assurance

The Targeted Work Teams had a lot to say on this subject, and it appears that OPWDD did adopt at least some of their recommendations. We must point out, though, that they apply only to DISCOs, not to provider agencies. DISCOs would ultimately be responsible for the outcomes of providers' services, but there's no evidence that OPWDD has changed its health/safety/fiscal-governance-oriented provider "Quality Scale" to address these recommendations, and it's hard to see how DISCOs could require good performance from providers using that scale.

The Care Coordination (CC) Work Team recommended that DISCOs be evaluated on such things as the number of people

who achieve a career-related goal and/or self-direct some or all services, whether enrollees received information about self-direction, and the number of people "who identify as not wanting to be in a 24/7 setting that are then being supported in less than 24/7 settings". This last item seems well-meaning, and we applaud the obvious intent to ensure that people get what they want. Still, it seems that some people haven't got the message that intensity of support needs does not have to, and should never, be tied to a physical setting. Any level of support, up to 24/7, can be provided in a person's own home and/or workplace, and the system must make sure that people know that before choosing where they want to live or work.

The AEA Team called for OPWDD to ensure that DISCOs have a statement of enrollee rights. All of the points in the proposed statement are good; we especially like the one that says that enrollees have the right to "lead (not simply 'take part in') decision making about health care and other supports and services".

OPWDD's Q&A says its Division of Quality Improvement (DQI) will create an assessment tool for DISCOs, with measures to "focus on" individual outcomes and consumer satisfaction. DQI will survey and interview consumers and family members, and review their records, to ensure that they got the services described in their Individualized Service Plans, and were told about and encouraged to choose consumer-directed service options. OPWDD also plans to track how

many people aging out of public school get supported work. And they will hire an independent agency to evaluate both the effectiveness of their quality improvement tools and the results thereof.

Independent Advocacy

Throughout the People First Waiver design process, OPWDD has claimed that it can be an effective "independent advocate" for people with disabilities under managed care, and did not say much about other advocates. The agency did not appear to want real independent advocates to have a formal role. However, the AEA Team was very clear that OPWDD cannot be the only advocate. It called for an independent ombudsman program, and also said OPWDD should recognize that other advocacy organizations, including independent living centers like STIC, have a role to play. The Team said DISCOs should provide information about other advocacy organizations to enrollees and include advocacy

organization representatives on internal review boards, and recommended strong state-level oversight, perhaps by the new

Justice Center for People with Special Needs, to ensure that independent advocacy is available and effective.

OPWDD's Q&A says it will have a "third party" ombudsman program to take complaints. This will be in addition to the ombudsman that was moved from OPWDD to the Commission on Quality of Care (and later to the Justice Center) after revelations that complaints to OPWDD's ombudsman weren't kept confidential and whistleblowers were being punished. The AEA Team called for the new ombudsman to have a formal role in resolving grievances (in managed care, if you're denied a type or amount of service that you think you need, you can file a grievance and have it processed within a strict time frame). The AEA Team had many other recommendations for a fair and effective grievance process; we don't know if OPWDD accepted any of them.

We do know that OPWDD is very supportive of a proposal for a generic Medicaid Managed Care Ombudsman Program proposed by Medicaid Matters NY (MMNY) that would be available to people with all types of disabilities who are enrolled in Medicaid Managed Care. This proposed ombudsman would offer education to people with disabilities on how to navigate managed care systems, handle systems advocacy issues, and provide advocates to assist people with filing grievances, among other things. STIC Executive Director Maria Dibble is on the MMNY Steering Committee and had

a role in developing this proposal.

Keeping Your Service Coordinator

OPWDD's Q&A says, "It is likely that many of today's Medicaid Service Coordinators will transition into roles related to care coordination in DISCOs. However, as the DISCOs are formed from existing service providers, it is impossible to know which service providers will become part of which DISCOs. Therefore, while it is possible, it is not likely that individuals will retain their current service coordinator once they enroll in a DISCO."

This isn't good, but we're not sure it's true. As DISCOs take over "care coordination", OPWDD itself will get out of that business. OPWDD thinks a lot of its service coordinators will move to other jobs like doing assessments and alleged "independent advocacy", so you may well lose your state service coordinator if you have one. But some of the not-for-profit agencies that do service coordination may become DISCOs, and many service coordinators whose employers no longer offer the service will probably be hired by DISCOs, so there's a good chance you'll be able to choose a DISCO that employs your current not-for-profit service coordinator.

On the other hand, there is the idea of the care coordinator as a "team", not a person. The CC report envisions teams led by a "Lead Coordinator" who has at least some of the qualifications required for today's service coordinators, but also says the actual care coordination duties would be divided among team members and that DISCOs might have varying ways of doing this. This could be a good thing for overworked service coordinators managing CSS plans. The RFA says each person will have a "primary" care manager, and it appears to view the team as more like a traditional "interdisciplinary team". But DISCOs won't be paid separately for care coordination; it will come from the same capitated rate that pays for direct services. They'll have to organize it in the most efficient way, and highly-personalized service may not be affordable.

Real Person-Centered Planning

Throughout the People First Waiver design process, OPWDD has consistently said it wants "real" person-centered planning, and, just as consistently, has failed to say what that means.

The CC Team had excellent ideas on this topic. They include almost everything that we've called for, especially: People with disabilities should direct their planning and services as much as possible, and should control who else is involved in their planning, and integration in all aspects of

"As DISCOs take over 'care coordination', OPWDD itself will get out of that business."

life should be maximized. The CC Team’s list of quality assurance points, unlike OPWDD’s, correctly prioritizes what is important: It starts with jobs, moves on to integration and self-direction, and ends with health and safety. If OPWDD actually does it this way, we’d be thrilled.

The RFA says DISCOs should “have available” family representatives, including the enrollee’s own family members, to be on care-coordination teams “as needed”. We don’t think this keeps enrollees from controlling who is on their teams but we hope the final RFA makes that clearer.

Strikingly, the RFA requires all DISCOs to promote services in the most integrated settings, paid jobs, and real community relationships. DISCOs must also offer *every* enrollee the option to direct their own services, including having an individual budget and “employer authority”.

Integration and the *Olmstead* Decision

The Q&A explicitly states that DISCOs must comply with the US Supreme Court’s *Olmstead* decision; that is, they must ensure that people with disabilities are served in the most integrated settings appropriate to their needs. The Q&A says that the new system will do a better job of identifying people’s real needs and wishes than the old system does, and that people will get the services they really need. The Q&A also states clearly that DISCOs will have fiscal incentives to avoid using segregated congregate and/or institutional settings whenever possible.

Will DISCO Pilot Applicants Know What They will be Paid before They Apply?

No. OPWDD says it will provide service utilization and cost data, and that care coordination and administrative costs will be covered as part of the capitated rates, but they will not make those rates available before the deadline for applications. It is very hard to see how potential applicants can commit to operating a DISCO without knowing how much they will be paid to do it.

“Partnerships” for Acute Medical Services

The Q&A repeats what OPWDD has said for two years: that managed care for acute medical services will be phased in over time, and is not expected to *begin* until 2015. Before that, DISCOs will only manage “long term care” services—that is, the residential and day services that OPWDD provides now. Beyond that, things get fuzzy. The Q&A mentions “partnerships” between DISCOs and other entities to address acute care services.

At meetings OPWDD officials have implied that these partnerships might completely remove any role in managing acute care from DISCOs aside from entering into an arrangement with, perhaps, a traditional medical managed care organization. Whether that means acute care will be covered by a separate capitated rate, we just don’t know. We don’t think OPWDD knows.

“...they have to figure out where the ‘tipping point’ is...”

That’s how the People First Waiver was shaping up at press time in late November. But don’t just take our word for it. You can read the documents yourself online:

Targeted Work Team reports are at: http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/targeted_work_teams

The Q&A is at: http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/news/new_q_a_now-available

And the latest draft RFA is at: http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/news/draft_rfa

As predicted, OPWDD’s timetable is slipping. “Super-storm” Sandy upset the apple cart. The state now wants Medicaid waiver funds for emergency costs, such as compensating agencies closed by the storm for lost billing, and paying shelter providers who took in people with disabilities. The federal Centers for Medicare and Medicaid Services (CMS) has also been pressing for a resolution of OPWDD’s inflated institutional rate structure, which was to be handled by a separate 1115 Medicaid waiver, before approving the People First Waiver. CMS still has questions about DOH’s MRT waiver amendment (see *AccessAbility* Fall 2012). In fact, NY is preparing so many new waiver proposals and amendments that CMS finally told the state to combine them all and submit them in one package. And there’s a need to re-align fiscal cycles for the new People First Part B and C waivers so there can be one set of reports for both. So now OPWDD plans to submit the People First Waiver proposal in May 2013. The agency claims it can still have an RFA out in March (presumably CMS doesn’t have to approve it), and have pilot DISCO contracts in place by November 1. We don’t think that’s realistic, but time will tell.

Stay tuned!

MAS Transit?

In October STIC sponsored public meetings between DOH representatives, Medical Answering Services (MAS; the private contractor DOH hired

to manage Medicaid transportation in our region) and people with disabilities, service providers and advocates, to iron out ongoing problems with Medicaid Managed Transportation.

The meetings were interesting and potentially productive. Among other things:

Suggestions for making MAS’s website easier to use were offered. MAS adopted some of them. They also explained how the website works, including why you have to get your account set up by phone first, and why information about your providers and routes can’t get on the website until you’ve made some trips. MAS has to verify that each location is legitimate before they can send you there; they don’t have any information from DOH about your doctors, and the website can’t do that automatically. But after you’ve been to a place once, you can schedule more trips yourself on the web.

Monthly bus passes were discussed. The passes must be purchased from BC Lift; before MAS, the BC Department of Social Services bought them. Although BC Lift had said it was going to stop selling passes as a cost-cutting measure, there was so much public outcry about it that the decision was reversed. MAS says it has no problem with providing monthly bus passes; they’ll already send you as many individual trip passes as you need when you schedule appointments. But they have to figure out where the “tipping point” is to decide if it’s more cost-effective to buy a monthly pass instead of several individual passes, so you need to schedule as many appointments in advance as you can. It’s not clear if they include the labor to buy, account for, and mail individual passes in that calculation; they only talked about the fares. But they seemed very reasonable about it.

There was discussion about large numbers of people being jammed into the same cab and having to ride around for hours in order to get to appointments. This turns out not to be an attempt to cut costs, but rather the result of a severe local shortage of cab service. Sadly, the quality of local cab companies is, er, variable; at any given moment one or two of them seem to be thinly veiled criminal enterprises. MAS has to use certified and licensed cab companies, and there aren’t always many of them available. Efforts are being made to recruit new cab service providers.

MAS was told that many of its phone representatives don’t seem to be very well trained; they provide inconsistent or wrong information, and/or claim they will have supervisors call consumers back but those calls don’t happen. MAS officials were reluctant to accept that they have a quality issue with their training; they would only admit

that they have rapidly expanded their organization recently and it takes time for people to learn their jobs.

MAS claimed that various outstanding issues with non-local services and transportation have been resolved to the satisfaction of the parties involved. We have no way of verifying that.

Finally, the after-hours answering machine was discussed. Here's what it boils down to: MAS has specifically contracted with DOH to have humans answer the phone during certain weekday hours. Although its contract also requires it to provide 24-7 service as needed, it does not require humans to answer the phone at all times. When humans don't answer, the message, at least up to early October, said that "providers" could press a number to talk to someone. Neither

MAS nor DOH officials trust that when you call after hours to get medical transportation you are being responsible and only doing so because it's an urgent situation. Therefore they didn't want the answering machine to say, "If this is an urgent or emergency situation, please press x to talk to an operator." This makes no sense, because whether you're being responsible or not, if you can't talk to MAS you're going to call a much more expensive ambulance that DOH will have to pay for. But MAS said they would "consult" with DOH officials (who were at the meeting) on whether and how to change the message. At press time we didn't know if it had been changed.

But if you press the "provider" number you can speak to someone and schedule a trip. You don't have to be a real "provider" to do that.

The MAS website is at www.medanswering.com. You can call them at (800) 850-5340.

Let's Be Frank

This fall disability advocates became increasingly concerned about a proposed federal bill that could limit class action lawsuits to close institutions. This bill has been around for a while without getting out of committee. However, recently its fans have been calling it the "Barney Frank Bill", named after retiring long-term Congressman Barney Frank (known for the weak "Dodd-Frank" legislation that let huge corrupt banking companies off the hook for destroying the economy), who is a principal supporter of the bill.

The bill, HR. 2032, does two things:

1. It creates a new, separate process for letting people with developmental disabilities and/or their "legal representatives" opt out of class-action suits involving people who live in ICFs/MR.

2. In doing so, it allows ICF residents' "legal representatives" who own, operate, or are employed by those ICFs to decide whether their wards can be involved in lawsuits against them.

An ICF/MR is a medical-model segregated congregate residential facility for people with developmental disabilities. Size is not part of the definition; although all developmental centers and "intensive treatment" units in NY are ICFs, the facilities can be as small as 6 beds (many have 12 beds and several have 24 or more). ICFs are owned and operated in NY by OPWDD, and by private not-for-profit corporations.

Current federal law regarding class-action lawsuits already allows affected people to opt out of them. However, the opportunity to do so comes after the suit has been filed and a judge has reviewed the claims of the parties. The judge gets to inform the affected people about their options and must ensure that they make their own decisions.

Barney's bill says that if the federal Department of Justice (DOJ), or a federal Protection & Advocacy service provider, wants to investigate an ICF with a view toward filing a class action suit against the facility, it must first contact every resident and offer them an opportunity to opt out. Many people living in ICFs are not legally competent and don't have involved family members; their "legal representatives" are employees of the facility itself. Can you guess how many residents will opt out if DOJ tries to investigate a 12-bed ICF, all of whose "legal representatives" work for the facility? That's right! 12!

Beyond that, in NY, OPWDD claims that any "active family member" is a "legal representative" of a person with a developmental disability. The person doesn't have to have been formally designated as such, nor does anybody have to decide that the person needs such a representative. This bill could make it federal law that a family member can override the wishes of a competent person with a disability in deciding whether to sue the facility

s/he lives in.

So what Barney wants to do is set up people who live in ICFs as a separate class of citizens who have fewer civil rights than the rest of us. Why would he want to do this?

Because over the last few years disability rights advocates have been successful at getting these facilities closed and requiring states to provide safe, effective personalized integrated support services. This has been viewed as a threat by public employee unions (who fund the notorious "Voice of the Retarded", which claims to represent people with disabilities who want to be segregated), by wealthy facility operators, and by frightened, mostly elderly, family members.

One would think the family members are the most important supporters of this bill, but that may not be true. It's been shown that even those parents who most strongly initially opposed moving their relatives out of segregated facilities have been very happy with the integrated services their loved ones eventually got. And Frank has clearly been in the pocket of wealthy corporations for a long time. So if this bill passes, it will probably be because of the unions and the providers.

And if it passes both houses of Congress and gets to President Obama, he will almost certainly sign it. One of his most important advisors and friends is David Axelrod, an Illinois political consultant whose daughter is famously locked up in Misericordia, a large private institution in Chicago that he loves. Here's what he said about the place in April 2011: "People with developmental disabilities need places like Misericordia to live fulfilled lives, to live happy lives. I've seen it in my own daughter's life, and I want to see that available for many, many others."

Congress members who don't know anything about this stuff may see the bill as reasonable or at worst, harmless, but it's not. And they may vote for it purely because it's being promoted as a retirement "gift" for Barney Frank.

Action will be happening on this before the lame duck Congress goes home in December. We don't know if there will still be opportunities to do something by the time you read this. But if you like what DOJ has been doing to enforce disability rights, if you believe in integration for people with disabilities, if you don't like what happens to people in segregated residential facilities, then you need to get involved in this issue if you still can.



Southern Tier ADAPT Goes to Harrisburg, PA

by Heather and Susan Ruff

Very early (about 3 am or so) on the morning of October 15, seven people left Binghamton for the long drive to Harrisburg, PA. Pennsylvania officials have been cutting Medicaid services that help people live in their own homes. Pennsylvania ADAPT has been trying to meet and talk with these people for over two years and has been turned away. Five of our folks had been to ADAPT rallies but never to a national ADAPT action. Passengers dozed as we traveled south.

When we got to the hotel where members of ADAPT were staying, we were assigned to the purple team and we lined up. People put on ponchos as we headed out in the rain, walking in single file to the state Capitol building. The fountain's water outside the building had been tinted bright pink (Breast Cancer Awareness Month). It took a long time for everyone to get through the security door. Some people went to office areas (governor, legislators) but most gathered around the edge of a very large, five story rotunda. We waited until everyone was in the building.

"We took turns holding signs. Some of us lost our voices!"

Someone gave a signal and all the ADAPTs moved to the center of the floor next to the stairs. Long signs were dropped over the second floor balcony and sign holders were also posted on the marble stairs facing the ADAPT crowd. ADAPT began to chant very loudly and never stopped. While the large group chanted in the central rotunda, the other groups tried to meet with the governor and the chairs of appropriation committees.

Reporters and cameras quickly showed up and leaders and demonstrators were interviewed. Some of us distributed informational fliers to the people coming and going in the rotunda and on the balconies outside the legislative chambers.

We chanted and our leaders spoke. We took turns holding the signs. Some of us lost our voices!

We left at 8 pm because we had a long drive home facing us. We heard the next day that the other ADAPTs had stayed late into the night. The leaders were happy we had come, adding our voices and our presence. We left, though,

very concerned, as we had learned of reports that some demonstrators at legislative offices were roughly treated by police.

Although very tired for a few days, everyone said they were glad they went and they would go again. We want people with disabilities to be able to live in their own homes, not institutions.

Southern Tier ADAPT meets at STIC at 4 PM on the first Tuesday of every month. Join us!

For more on the Harrisburg actions: www.adapt.org/main.harrisburg.harrisburgcapitol
www.adapt.org/main.harrisburg

Southern Tier Independence Center
BLOOD DRIVE
Open to the Public!
Thursday, January 31, 2013
9:00 am to 1:00 pm
Please call Diane Button
(607) 724-2111 (voice/TTY)
To Make Your
Lifesaving Appointment 



Jimmo v Sebelius: No Medicare “Improvement Standard”

For several decades, many Medicare recipients with disabilities have been denied services and treatments that could maintain their ability to function because of the so-called Medicare “improvement standard”.

The “improvement standard” states that Medicare will only pay for services (such as skilled nursing service) or therapies (such as physical or occupational therapy) if they result in an improvement in the patient’s condition.

The problem with this is that disabilities are not curable, but these services can keep people’s conditions from getting worse.

It turns out there is no such standard in Medicare law or regulations, and there never was. Somewhere, sometime, some official just made it up, and added it to a procedure manual that is used to make coverage determinations. The manual is often used by third-party contractors who are hired to make these determinations.

Some clever lawyers at two advocacy organizations in Vermont figured this out and filed a class-action suit against the federal Centers for Medicare and Medicaid Services (CMS). In October 2012 they reached a settlement.

CMS agreed that the “improvement standard” does not exist, and they will revise their manuals to clarify that “services are covered when they are required to maintain a patient’s condition, or prevent or slow further deterioration.”

The settlement doesn’t change the types of services Medicare covers, and it doesn’t change any Medicare coverage limits in terms of number of days or sessions.

As part of the settlement there will be a group of people whose service denials will be reviewed immediately. And it will take a couple of years for the new manuals to be written and distributed.

What’s really important here, though, is that the so-called “improvement standard” does not exist and never did. It has always been illegal for CMS and its contractors to deny Medicare coverage for services that don’t result in “improvement”, and it is illegal to

do so today. So, if you were denied services that would otherwise be covered by Medicare merely because you aren’t “showing improvement”, you should appeal and cite this case. Hopefully the first step appeal will succeed, but if it doesn’t, take it to a Fair Hearing and cite this case. Any administrative law judge would have to overturn the denial.

Johnson v Shah

We reported this class-action suit in our Summer 2011 issue. This was the case where, following the state’s imposition of arbitrary limits on Certified Home Health Aide (CHHA) services, several CHHA providers immediately reduced services without providing advance notice or an opportunity to appeal with aid continuing. As a result, some people were stuck in hospitals or nursing homes.

In late 2011, a temporary settlement was reached under which the CHHAs agreed to provide advance notice before terminating or reducing services. The CHHAs filed a motion to dismiss the case, but the judge set it aside while the parties try to negotiate a permanent settlement.

Strouchler v Shah

This class-action suit about limits on 24-hour homecare in New York City was filed in federal district court in April 2012. The judge granted a preliminary injunction to the plaintiffs in September, ordering the state Health Department to clarify rules regarding this service. The clarification was issued in October.

The details concern the behavior of New York City officials regarding a type of service that is not commonly available in other parts of the state. However, a few points are, or at least should be, relevant to Medicaid-funded homecare anywhere in NY.

The service is called “split-shift”. It’s confusing because it doesn’t mean what you might expect. “Split shift” usually means splitting a single work shift between two separate periods of time. For example, if you work from 7 am to 10 am, and then from 3 pm to 8 pm at the same job on the same day, you work a split shift. But in NYC homecare parlance, “split-shift” means that a person’s care is “split” among multiple full-time shifts worked by different aides, to

achieve 24-hour care.

This is distinct from another form of 24-hour service called “sleep-in” care. Sleep-in care means a single attendant lives with the person and is available to provide care 24-7, except that the attendant must be able to get at least 5 hours of uninterrupted sleep each night. Sleep-in care therefore won’t work for somebody who needs frequent bathroom trips, or needs to be turned frequently to prevent bedsores, at night.

Many of our readers may be surprised that such services even exist. That’s because Broome and several other upstate counties refuse to approve such services except under the most unusual circumstances, if at all. However, as we keep saying, such refusals are illegal under federal Medicaid law, which requires State Plan Medicaid services to be equally available across the entire state—the “statewide” rule. Of course, people who need such levels of homecare are not somehow magically only found in New York City, so these counties are violating the law.

We’re not sure if managed care, which operates under a Medicaid waiver, must follow the statewide rule. But if you are not yet getting attendant services through managed care, and you need 24/7 service and have been denied it, you should appeal and get a fair hearing.

The other relevant points take a bit longer to explain.

This suit arises out of an earlier lawsuit filed by a “whistleblower” who claimed that the city was approving split-shift care without required medical review. After that case was settled, NYC set out to review every person who was getting split-shift service. It cut back the service to “sleep-in” 24/7, or less than 24/7, service for hundreds of people. But 97% of the people who appealed had these cuts reversed.

Legal advocates got involved and eventually filed this suit because people were being needlessly harmed by the stress and effort involved in appealing what were, essentially, serious threats to their health. Investigation revealed evidence that, although the city said it was only doing these case reviews to address the whistleblower’s claims, it was actually intentionally trying to cut costs, under significant pressure

from state health department officials.

The city was using unjustified interpretations of what were, in some cases, unclear or nonsensical state guidelines to cut people off split-shift service. One example should be enough:

The state regulations make a distinction between people who need “some” and those who need “total” assistance with a care task. Only those who need “total” assistance can get split-shift service. The regulations say: “Some assistance shall mean that a specific function or task is performed and completed by the patient with help from another individual. Total assistance shall mean that a specific function or task is performed and completed for the patient.”

One of the plaintiffs was an elderly woman who could not walk or get out of bed herself, and had very little ability to use her hands. She was incontinent and used diapers. However, to prevent skin breakdown and infections, s/he needed her diapers changed at intervals during the night. Because of this she was granted split-shift service.

Following the whistleblower settlement, the state revised its interpretation of “some assistance” to mean “when the task is completed *with the assistance of the patient* so that the patient at least minimally assists with the task.”

This defies the plain language of the regulation, which says the task is completed *by* the patient with some help. The plaintiff could not change her own diaper with some help, but she could hold onto the bed rail to steady herself after being turned on her side by the attendant during the course of changing her diaper, so she was deemed able to “minimally assist” and therefore not in need of split-shift service.

This is obviously bogus, and the judge said so. Even more interesting, though, is plaintiffs’ argument that the entire distinction between “some” and “total” assistance is nonsensical, since it doesn’t matter how much assistance you need, it only matters whether you need *any* assistance more frequently than every 5 hours during the night, in order to preclude “sleep-in” service. In our example, the woman needed her diaper changed more often than every 5 hours to prevent infections, and that could not happen without an aide to do the work. The judge said he didn’t need to consider that point when deciding whether to grant a preliminary injunction, but he implied that he thought it was a good argument.

Here’s why it’s a good argument: Federal Medicaid law says that states must have “reasonable standards ... for determining eligibility for and the extent of medical assistance under the [State Medicaid] plan which ... are consistent

with the objectives” of the homecare program, and services must “be sufficient in amount, duration, and scope to reasonably achieve” the program’s purpose. If you offer discrete services (“split-shift” and “sleep-in”), and have different criteria that qualify you for one or the other and not both, then those criteria have to be reasonable. The state’s regulation using type of assistance (“some” or “total”), rather than how often assistance is needed, to decide if you qualify for “sleep-in” service which requires a maximum frequency of every 5 hours overnight, is not reasonable. It’s also clear that homecare services that are limited beyond a certain point will impair people’s health, and therefore cease to be sufficient to achieve the homecare program’s purpose—which is to keep people healthy in their own homes.

So, to the extent that the state’s inappropriate regulations, or bogus interpretations of them, are being used to deny adequate levels of homecare services to Medicaid recipients anywhere in the state, whether they are in managed care or not, those recipients should appeal.

In response to the judge’s order, the state clarified the rules, and the resulting document is here:

www.health.ny.gov/health_care/medicaid/publications/docs/gis/12ma026.pdf

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Notably, the state agreed that split-shift, as opposed to sleep-in, service may be appropriate for people who need an attendant to do something overnight more often than every 5 hours. The clarification makes a lot of other points that should be eye-openers to upstate county social services departments. If your county doesn't follow these rules, you should pursue it.

The Latest MISCC Takes

As we reported last time, NY's Most Integrated Setting Coordinating Council (MISCC) was allegedly re-invigorated to carry out Governor Cuomo's promise to create a "real" Olmstead Plan.

An "Olmstead plan" is a comprehensive plan to ensure that people with disabilities, when receiving services from the state, are able to get them in the most integrated settings appropriate to their needs. The concept comes from the US Supreme Court's 1999 *Olmstead v LC* decision. This fall the MISCC held public forums and requested oral and written answers to specific questions about what should be in the plan.

In late November we learned that the highly-regarded Chair of the NYS Commission on Quality of Care (CQC), Roger Bearden, will take a position in the Governor's office where he will be the "point man" on the Olmstead Plan. Bearden formerly ran the Disability Law Center of New York Lawyers for the Public Interest; he was appointed to head the CQC by Governor Cuomo after Cuomo fired Jane Lynch in the wake of the OPWDD abuse scandal. The law enacting the new Justice Center for People with Special Needs dismantled the CQC and divided its responsibilities between the Justice Center and a new "independent" protection and advocacy agency.

The next MISCC meeting was scheduled for December 3, and hopefully by then there will be more details on what Bearden will do with the input the MISCC received.

In the meantime, here's a summary of how STIC answered the questions. The MISCC asked the same questions in different ways, so some of our responses are repetitive. This might be a good thing; maybe if they read it over and over and over, they will finally get it:

What are the most important services and supports that individuals with disabilities need in order to live independently in the community?

1. Affordable, accessible, integrated housing that is not linked to services.

2. Access to peers who have successfully transitioned from institutions, and/or who have been successful in maintaining independent living in an integrated community-based setting. Peers function as credible mentors in ways that nondisabled people cannot. Peers: help people with disabilities to assess their own needs and set their own goals, and form and carry out plans to achieve them; teach specific skills in individualized ways that address the unique characteristics and abilities of the person; and assist people with disabilities to meet people who are not paid to serve them, in order to form supportive relationships and enable them to get involved with, and become a part of, the larger community.

3. Accessible affordable transportation, and, if needed, assistance in learning how to use it. People with mental health, intellectual, developmental and/or cognitive disabilities often have difficulty learning how to use public transportation, or how to read a bus schedule, learn routes, etc. Peers can teach these skills, and this will lessen reliance on paratransit services.

4. Access to adequate levels of personal care, homecare or in-home nursing services, including consumer directed personal assistance (CDPA).

5. Reliable, effective assistance to obtain integrated employment.

What should state government do to help individuals with disabilities to be integrated and socially connected to their community?

1. Government is THE actor in this field. People with significant disabilities rely for their health, well-being, and everyday functioning on services and supports that can only be funded by government. State government must implement a comprehensive, consistent policy on community integration that drives all of its disability-related activities. What does this mean?

A. Comprehensive: The policy addresses all aspects of services and supports for people with all disabilities of all ages. This includes, among others, children in public schools; adults whose disabilities do, or do not, affect intellectual functioning or behavior; and elderly people who have physical or cognitive disabilities even though they do not self-identify as people with disabilities.

B. Consistent: Maximum real community integration must be the goal of every disability-related thing that every state agency does or pays for. "Community" means the larger community—the same places—in which typical nondisabled people interact. "Integration" means that in any setting, whether residential, educational (including training), vocational or recreational, the percentage of people with disabilities is no greater than the percentage of people with disabilities in the general population, and people with disabilities are evenly distributed among the larger nondisabled population. Artificial simulations and segregated, congregate residential facilities and programs of any size or type do not meet this definition. This common definition must be adopted by every state-operated and -funded program, without any modification on the basis of diagnosis, funding source or any other criteria.

C. Drives all disability-related activities at all state agencies: The policy must state that the only purpose of any state-operated or -funded disability program is to ensure that people with disabilities are able to live, learn, work and play in the most integrated settings. Every plan and activity of every such program must be specifically oriented toward achieving this goal, and must establish benchmarks describing the current situation, metrics that describe maximum integration goals, and timetables with measurable objectives leading to achievement of those goals. To achieve this, planning must be centralized. Plans directed toward achievement of the goal of maximum integration must be made at a higher level and then provided to state agencies for them to carry out, in order to ensure that all activities and funding are prioritized for that goal, that service gaps are removed, that different agencies do not work at cross purposes or shift responsibility for serving populations among them by modifying eligibility rules, and that rules and regulations are standardized and consistent.

2. The result of the comprehensive policy and planning process described above would be an "Olmstead Plan" that meets the letter and the spirit of that Supreme Court decision. However, there are some issues that require greater illumination.

A. The *Olmstead* decision, and several other federal court decisions following it, have all found that money is fungible despite arbitrary regulations restricting its use. The courts have ruled that: 1) if a state already provides a more integrated service that meets the needs of people with similar characteristics who are being served in less integrated settings, and 2) the

cost of the less integrated service is the same as or greater than that of the more integrated service; then increasing the availability of the more integrated service is not a fundamental alteration of the state's programs, and the cost thereof is not an undue burden. States cannot claim they need new funding to implement the *Olmstead* decision. States can, and must, shift existing funds from segregated to integrated supports and services. NY cannot have an effectively functioning *Olmstead* plan without implementing such a shift of funds. The *Olmstead* Plan must include specifics, including timetables and dollar amounts, indicating how this shift will be made.

B. An effective *Olmstead* plan can't be enacted by Executive fiat. Legislation will be required to modify state laws that prevent consistent policies, definitions, eligibility rules, and quality standards from being applied to programs that serve people with all disabilities of all ages. Such legislation must not, like past laws, merely let state agency heads make such changes as they deem appropriate. This legislation must describe specific changes that will be made, as determined by the *Olmstead* Plan. Legislation will also be needed to authorize the funding shift described above. And finally, legislation will be required to impose consistent policies and procedures on the State Education Department, which is not under the Executive Branch.

C. The development of the *Olmstead* Plan should be carried out under the direction of the people most affected by it: people with disabilities themselves. The MISCC membership should be modified to ensure that it consists of at least 51% people with disabilities, and represents a broad range of disability types and situations, including people who have lived in, or are still living in, institutional settings. The MISCC should have an ongoing oversight role, with authority to modify the plan as needed as well as to correct errors made by officials who implement the plan. Also, the original MISCC law called for the plan to be evaluated by third-party experts to determine its likely effectiveness in achieving the goal of the most integrated settings for people with all disabilities of all ages. The determination of what is a quality plan should not be left to state officials; this third-party role should be maintained.

What are the most important things individuals with disabilities need to successfully transition from institutions to community settings?

1. Outreach to ensure that every person with a disability who is currently in a segregated residential or program setting knows that realistic more-integrated options exist and that s/he has a right to choose integration. The people doing outreach should be peers of people with disabilities or seniors who are not connected with any state agency, and should be representatives of state-of-the-art programs that provide integrated supports and services.

2. Access to peers who have successfully transitioned from institutions, and/or who have been successful in maintaining independent living in an integrated community-based setting.

3. Many people with disabilities, while they may need outreach, information, and advice from peers to understand their options, can make and carry out their own transition plans without formal processes. Others need a true person-centered planning process and a temporary or permanent service coordinator. The meaning of "true person-centered planning" is not widely understood, and qualified practitioners are not widely available. Person-centered planning is not the same thing as "interdisciplinary team planning". Real person-centered planning is controlled by the person or his/her chosen representative, and focuses only on issues that the person deems important, not on the generalized psycho/social/medical preoccupations of medical professionals.

4. A successful transition ends with adequate personalized supports for the person in his/her own home, in employment or other meaningful activities, and in mutually supportive relationships with nondisabled people who are not paid to serve them. Success cannot be achieved unless support services are readily available and easily accessed. These include affordable individual housing, without mandated bundled supports, that is accessible if needed; adequate levels of personal care, homecare, or in-home nursing services; individual integrated habilitation services; respite services; behavioral support services; supported employment services; affordable accessible transportation. Waiting lists for support services must be eliminated.

What are the most important services and supports that individuals with disabilities need in order to stay out of institutions or reduce the amount of time they stay in institutions?

1. Access to peer advocates who can assist with social integration, development of social

skills and daily living skills necessary to succeed. This includes assistance with keeping appointments for medical, benefits and other services, as well as helping people maintain positive self-images and self-esteem.

2. Access to adequate mental health counseling services, with clinicians knowledgeable about a wide variety of physical, cognitive and mental health disabilities.

3. Access to affordable accessible housing and transportation.

What should be done to increase the availability of affordable, accessible and integrated housing for individuals with disabilities?

1. Use savings from managed care to provide very-low-income housing for people with disabilities, not connected to services. 50% of the money saved is non-Medicaid, NY State dollars. These funds do not have to be applied to any type of medical or quasi-medical services. They should be used either to build new housing units (including providing tax credits and other financial incentives to developers), make existing units accessible, or provide housing subsidies to low-income people with disabilities, with priority given to people who are in danger of being placed in a segregated residential facility or who wish to leave such a facility.

2. Forbid use of these "supported living initiative" funds for any form of congregate disability-specific housing complex, including "assisted living" facilities or any other such project, or for the purpose of moving the residents of any single specific institutional facility. Other funds targeted toward downsizing and closure of specific facilities are already available.

3. Significantly increase funding for the Access to Home program.

4. Pass legislation for visitability so that new housing is at least minimally adaptable or accessible for people with disabilities.

5. Pass statewide legislation forbidding discrimination by landlords due to source of income.

What should be done to increase the availability of affordable and accessible transportation for individuals with disabilities?

1. Subsidize public transportation systems in

smaller cities and counties across the state to ensure reliable, frequent, and widespread bus service, and accompanying paratransit service, for reasonable fares. Many of these municipalities are struggling with costs due to the recession, and because typical public-transportation riders have low incomes and little political influence, transportation services have been targeted for deep cuts, including eliminating or decreasing the frequency of routes and substantially increasing fares. These cuts must be stopped and reversed.

2. Require that all new taxis purchased across the state be accessible to people with disabilities.

3. Offer financial incentives to encourage taxi companies to retire old cabs and replace them with accessible vehicles.

4. Enforce the ADA transportation requirements so that all forms of public transportation are accessible.

What should be done to increase integrated employment for individuals with disabilities?

1. Increase the reimbursement rate and availability of funds for supported employment and ensure that programs are assisting people with the most significant disabilities to find jobs. Although federal vocational rehabilitation funds are supposed to be prioritized to serve the people with the most significant disabilities, the trend has been for ACCES-VR to focus on post-secondary education support, and direct placement services, for people with mild levels of disability, while declaring more people with significant disabilities “unemployable”.

How should community supports for individuals with disabilities be better coordinated across state agency systems?

1. As described above, all state agency operations related to disability should be driven by a single Olmstead Plan, focused exclusively on maximizing integration for people with disabilities, and this plan should be created and overseen by a body that resides in the Executive Branch above the level of state agency commissioners, and consists of a majority of people with disabilities. State agencies should not “coordinate services” among themselves; the Executive Branch should accept responsibility for directing and coordinating the activities of state agencies. In the future, the Executive Branch, through the MISCC, should do the planning. State agencies should not plan,

they should follow plans given to them by the Executive Branch.

2. There should be a single point of entry for all disability-related services, with a single application process. Aside from Medicaid and/or other income eligibility requirements, eligibility for services should be based solely on functional need, not diagnosis. The concept of “primary” diagnosis or disability should be dropped. If a person’s functional assessment indicates a need for a service or support, then that service or support must be provided. This will require reorganizing state disability services to remove boundaries related to diagnosis. For example, currently, supported employment is available through ACCES-VR, OPWDD, OMH and CBVH, and each agency has its own application process, as well as rules for documenting services and billing. These agencies have at times unilaterally changed their eligibility rules, resulting in thousands of people being shifted back and forth between them but without funding following them, so that people were denied services or placed on long waiting lists. It is also burdensome for providers. Consolidation would save money and enable more services for more people.

What types of regulatory or policy reforms are needed in order to support community living for individuals with disabilities?

As noted above, all disability policies and regulations: should be developed in a unified process that operates outside of any state disability service agency; should be comprehensive and consistent in addressing all disabilities and all ages; and should fully govern the activities of state agencies, with ongoing monitoring and correction as needed. These principles should be applied:

1. Any NY State Medicaid regulation that is more restrictive than federal Medicaid regulations affecting who is eligible to receive or provide a service, available types of service, or fiscal/programmatic accounting for services, should be dropped. The federal definition of “developmental disability” should be substituted in mental hygiene law and regulation for the state’s current, more narrow, definition.

2. Use of a single comprehensive functional assessment to determine not only need for, but eligibility for, specific supports and services without regard to diagnosis must be maximized across all providers of disability-related services.

3. Self-direction should be an option for people



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/>

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with all disabilities of all ages for any combination of services and supports they receive. Available models of self-direction should include cash and counseling, the current NY CDPA model, and agency with choice. However, people with disabilities should be allowed to mix and match aspects of all of these models to best suit their needs within a single plan of services and supports. No requirement for a “circle of support” should be imposed. For minor children and adults who are not fully capable of self-direction, the option to choose a surrogate should be provided. Flexibility in who can be a service provider needs to be expanded to address ongoing chronic staff shortages as well as severe economic problems in the households of people with disabilities. Especially, any adult family member should be allowed to be a paid provider of services if the consumer chooses.

4. The state must be especially vigilant as it continues to develop and implement managed care. NY must have consistent policies across all MCOs, Health Homes, Behavioral Health Homes, DISCOs, etc. to ensure access to care that is physically and programmatically accessible. This means that not only do doctors’ offices need to be accessible, but that they must have accessible equipment (exam tables, mammogram machines, scales, etc.) and/or available support staff to assist with transfers and positioning of patients as needed.

Choosing segregation for people with disabilities is like choosing to smoke. Both are legal options, and both are harmful and should be discouraged.

5. Choosing segregation for people with disabilities is like choosing to smoke. Both are legal options, and both are harmful and should be discouraged. The Supreme Court’s *Olmstead* decision says that people cannot be forced to leave a segregated setting if they don’t want to. That is a very limited prescription. It should be NY State policy that segregation of people with all types of disabilities at all ages is actively harmful to their physical, mental, and emotional health and development and should be discouraged. Individuals currently in segregated programs (or their parents if they are minors, or their legal guardians only if they are adults who have been adjudicated by a court to be incompetent to make their own decision) should have a person-centered planning process that sets out a realistic and available set of services and supports in more integrated settings and should be offered the

opportunity to choose in a non-coercive environment. If they choose to remain segregated, they should be allowed to do so, but must be offered the option at least annually. Individuals not already in segregated settings should not be permitted to “choose” segregation unless it is objectively proven that a segregated setting is the only one appropriate for their needs. Such determinations must not be made unless and until more integrated options, including consistent provision of all prescribed types, duration and intensity of services over a significant period of time, have been attempted and did not succeed.

What performance measures should be used to track progress in implementing the Olmstead Plan?

1. The following metrics are needed: number of people with disabilities in segregated congregate residential settings (any facility in which four or more unrelated people with disabilities live, including “institutions”, group homes, nursing homes, adult homes, or disability-specific housing complexes); number of people with disabilities in segregated congregate or disability-specific employment or activity programs (including sheltered workshops, “mobile work group” or “enclave” supported employment, “affirmative businesses”, “day training” or “day treatment” programs, facility-based day habilitation, and

disability-specific “clubhouses” or similar programs); number of people with disabilities in integrated living arrangements; number of people with disabilities in integrated competitive employment with or without supports. Comparison of the change in these numbers over time is the single best measure of progress.

2. Consumer satisfaction surveys, conducted in a non-coercive environment that ensures anonymity, are necessary.

3. Longitudinal studies should follow representative groups of people with disabilities over time to see if integration gains are maintained and the factors that contribute to success or failure.

4. Program audit teams should include people with disabilities and disability rights advocates

as well as quality assurance specialists. These teams should personally inspect facilities and interview people with disabilities as well as looking at paper records, to learn whether consumers received information about the risks of segregation and the benefits of integration, and about all available service types and providers; were allowed to make uncoerced choices; and whether services and supports have been accessible to them. These teams should visit not only disability service programs but schools, hospitals, and clinics in order to determine compliance with federal and state law. Assertions by providers that they are in compliance should never be accepted at face value; all such statements should be audited regularly and frequently. NY will have to increase the amount of resources it makes available for onsite program audits.

What is the best way to share information about the Olmstead Plan with the public?

1. Provide extensive and frequent training opportunities to educate nurses, doctors, social workers, teachers, and disability service workers about the benefits of community integration and inclusion, in order to bring about a cultural change that will regard integration as the “norm” and the natural expectation.

2. Conduct a continuous high-profile advertising campaign in electronic (TV, radio, internet), print, and other media (billboards, bus posters) to promote integration and deprecate segregation. Materials supporting integration should demonstrate the abilities of people with disabilities, and show people leading integrated lives in the community.

POTS and Plans for Disaster

Super-storm Sandy wreaked devastation on New Jersey, New York City, and Long Island, among other places. Electricity was off for millions of people for several days, and for hundreds of thousands of people for over two weeks. Cell phone towers were destroyed or lost power. Cell phone service was unavailable in many areas for several days.

People with disabilities were especially hard-hit. Many were stuck in high-rise apartments with no electricity (and therefore, no elevator), no water (because water in high-rises requires electric pumps), attendants unable to reach them, and no way to contact anyone to get help.

But throughout this cataclysm, old-fashioned Plain Old Telephone Service (POTS) lines kept

working, and people who had old-style non-electric telephones were able to communicate.

We've mentioned this before but Sandy has really brought this reality home.

Cell phone service is NOT RELIABLE in a disaster. Cell towers fall down or lose power. Cell phone batteries run down and can't be recharged.

Internet-based phone service is NOT RELIABLE in a disaster. Internet access relies on electricity, so Vonage, Magic Jack, Skype and similar systems won't work.

Cable-based phone service is NOT RELIABLE in a disaster. Cable phone service is digital; it requires electricity.

If you have a significant disability and you need to communicate during a disaster, you NEED a POTS line and a non-electrical phone—one that doesn't have a wireless handset.

You have a CHOICE. Locally Verizon and Frontier both provide this service. And you can still buy a non-electrical phone.

POTS service is CHEAP. We aren't advertising, but you need to know this: Verizon offers a combined local and unlimited long-distance POTS plan for around \$35.00 a month. That's UNLIMITED local AND long-distance service for \$35.00 a month.

Climate change is no joke. In the future there are going to be more of these huge, devastat-

ing weather events. As Governor Cuomo remarked, "It seems like we're having a hundred-year flood every two years."

Stop shaking your head, chuckling, and calling us hopelessly old-fashioned. This is not funny. For many of you, this is life or death.

You have a CHOICE. Cell phones are luxuries. The internet is a luxury. If you can't leave your home under your own power, you NEED POTS. If you don't have it in an emergency, it's on your head.

Electronic Payment Required

Beginning March 1, 2013, the US Treasury will no longer make Social Security or other benefit payments on paper checks. All benefits will be distributed by direct deposit to bank accounts, or through the "Direct Express" card.

Most people have already made the switch, but if you're one of the last holdouts, then it's time for you to face the music.

You can have your check deposited electronically in your own bank or credit union account. Or you can get a Direct Express card, which is essentially a debit card that stores your benefit payments without you needing to have a bank. You'll need your Social Security number or claim number, your 12-digital federal benefit check number and the amount from your most recent federal benefit check. If choosing direct deposit, you'll also need your financial institution's routing transit number (often found on a personal check), account number and account type (checking or saving).

To find out more, or to set up your account, go to www.godirect.org or call (800) 333-1795.

McPharmacy?

(from a NYAPRS press release)

The NYS Department of Health has announced the release of the New York State Medicaid Managed Care and Family Health Plus Pharmacy Benefit Information Website, developed in partnership with the State Uni-

versity of New York at Stony Brook.

The first phase of the website release will provide easy access for members and providers looking for information on the drugs and supplies covered by different Medicaid and Family Health Plus managed care health plans. In the near future, the Department plans to release phase two of the project, which will allow interactive comparison of coverage searches. The Pharmacy Benefit Information Website is at: <http://pbic.nysdoh.suny.edu>.

To use this website, first check your health plan identification card and match it to the one presented on the website. By clicking on the appropriate identification card/logo you will be provided with contact numbers and links to your health plan's website. If you do not have your health plan identification card or do not know what health plan you are enrolled in, call the Medicaid Helpline at (800) 541-2831 from 8 am through 8 pm, Monday through Friday, and from 9 am to 1 pm on Saturday.



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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

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Lebanese Leavening

On November 14, 2012, STIC had a very special visitor: Raif Shwayri, CEO of the Al Kafaat Foundation in Lebanon. Through him, we were able to gain new understanding both of the vast differences and underlying commonalities that confront people with disabilities in very different parts of the world.

Lebanon is a small, embattled country, about the size of Rhode Island, on the shore of the Mediterranean Sea, between Syria and Israel. Once part of the Turkish Ottoman Empire, later a French colony, it gained formal independence in 1943, though in practical terms, it has rarely governed itself. Rather it has been repeatedly fought over and dominated by Israel and Syria, and has experienced multiple civil wars. It is home to a very diverse collection of people who tend to organize themselves on the basis of religion; these include Maronite and other Christian groups, as well as several varieties of

Muslims. Although people's religious identities play a central role in how politics works in Lebanon, the country has a strong tradition of secular government and institutions.

The capital city, Beirut, was once an important center of trade and international finance, but the repeated destruction of war has reduced its wealth and importance over the decades. Still, it contains most of the country's approximately 4.5 million people.

People in Lebanon daily confront serious basic problems including lack of clean water, reliable electricity, and adequate food and shelter. The society is conservative, and traditional views of disability are common.

However, the country is home to a very progressive organization, the Al Kafaat Foundation. Its guiding principle is that people with

disabilities can and should be productive citizens with equal rights and opportunities. Al Kafaat means "the Dream" in Arabic. It seeks no charity or "special" consideration; only the opportunity for people with disabilities to achieve their dream to be educated and employed. The organization's website (www.al-kafaat.org) prominently features the slogan, "Potentials – Not Handicaps". Arising from a sheltered workshop making goods for international trade in the 1950s, today its responsibilities extend to providing a full array of educational and vocational services to people with all types of disabilities, as well as education and training for special education teachers and rehabilitation professionals.

In a country where schools and universities get bombed or can't function due to lack of water or power, Al Kafaat not only assists people with disabilities to attend ordinary schools and colleges, it operates its own schools and university for people with disabilities, to ensure that they will get adequate education. In a country with limited social welfare and where industry struggles for the same reasons, Al Kafaat works tirelessly to convince and assist ordinary employers to hire people with disabilities, but also runs sheltered workshops so that at the very least, people with disabilities will have stable workplaces from which to earn a living. Mr. Shwayri and his foundation believe in true integration for people with disabilities and do what they can to make it happen for individuals, but as he says, they struggle daily with providing the very basics of survival, and integration must sometimes take second place.

An important point that we have in common with Al Kafaat is a belief in education: Not only education for individuals with disabilities and for teachers and professionals, but education for employers and the general public about the abilities of people with disabilities. Mr. Shwayri shares our disappointment with television's failure to offer more education of the latter type, as well as our belief that the power of destructive attitudes can be reduced when people get good information.

STIC deeply thanks Mr. Shwayri for the insights and stimulating conversation he brought us. We also thank Dr. Suronda Gonzalez from Binghamton University, and her colleague in international studies, Rosemary Ortlieb of Nassau Community College, for bringing us together. We already know that this meeting will lead to others, and to more international communication among people interested in disability rights.



STIC Executive Director Maria Dibble, and Raif Shwayri listen to a question from the audience.

Haunted Halls 2012

by Bill Bartlow

STIC's 3rd. annual Halloween fundraiser, held over eight nights this October, goes down in Haunted Halls history as our most successful event yet. Regional organizations, businesses, foundations and individuals, cognizant of STIC's mission to assist people with disabilities in realizing independent living goals, were more supportive than ever before in sponsoring and promoting our project.

Amongst our most outstanding supporters were:

- BAE Corporation and Employees Community Service Fund
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- Clear Channel Radio
- Delta Engineers
- Equinox Broadcasting Corp.
- IBEW
- John Hart Studios
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- Quantum Graphics
- Security Mutual Life Insurance Company
- Spirit Halloween
- The Rozen Foundation
- Tioga State Bank
- United Health Services
- Visions Federal Credit Union
- Warehouse Carpet Outlet
- Wegmans Food & Pharmacy

The incredible dedication and generosity of over 160 volunteers combined to create, populate, produce and administer the event, which drew more than 2,500 visitors. While still tabulating on the balance sheet, it appears that we made an astounding 40% increase over last year's revenues, with net proceeds of \$32,000.

On behalf of all at STIC, and those whom we serve, we offer a huge heartfelt "THANK YOU!" to all involved in contributing to the success of this increasingly popular event. We also are attentive to your feedback and suggestions with the objective of making Haunted Halls of Horror 2013 the premier haunted attraction of the Southern Tier. Follow us on line at www.hhh-stic.com, or on Facebook through our website.

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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!

Southern Tier Independence Center

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 Maria Dibble

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