

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

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To the Victor Go the Spoils

by Maria Dibble

“What must be remembered is that this is not a game, these are stakes that are attached to many, many lives of highly vulnerable people and their loyal support systems. We all know the expression, ‘to the victor go the spoils’, but not many know the origin ... during a congressional debate in 1831, Senator William Marcy from NY made that statement in reference to the fact that every time a new political party took office, thousands of public employees lost their jobs. Much like transitioning to a new system of care may threaten thousands of people losing their current services. The ‘spoils’ here are living, breathing human beings who are in this fight to hold on to those very lifeline programs and services. They deserve our support not abandonment.”

This quote came from a message written by Lois Tannenbaum, a person with a traumatic brain injury, regarding the transition of the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) waivers into Managed Long Term

Care plans (MLTC). Both waivers serve people with significant disabilities who would be living in nursing facilities without the services they provide. The waivers offer support to people with brain injuries, dementia, and many other disabilities, whose needs often increase with age.

Who are the victors in that quote? New York State and its Department of Health (DOH), which is overseeing the transition. What are the spoils? A few weeks ago I’d have said the millions of Medicaid dollars that the state was claiming would be saved. That is, until DOH Director of Long Term Care Mark Kissinger spoke at a hearing convened in October by Assembly Committee on Health Chair Richard Gottfried, along with the Standing Committee on Mental Health and the Assembly Task Force on Developmental Disabilities. Kissinger said that actually, no savings would be achieved.

Kissinger’s statement was misleading, if not outright mendacious, for reasons you

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can read elsewhere in this and past newsletters (page 7, for example).

DOH promises that nobody will lose services, but it’s already happened for other New Yorkers who have gone from fee-for-service Medicaid to an MLTC. Hours get cut, services are eliminated and people do not get the quality they are used to. Furthermore, MLTCs frequently refer people with complex needs over to the TBI or NHTD waivers, either because the person’s needs are too expensive, or the MLTC doesn’t understand how to serve them.

The MLTCs are not the enemy here. They are simply not equipped or trained on the types of disabilities that the waivers cover; they are used to a strictly medical-model approach to services. And at least some of them aren’t getting enough money from DOH to provide these services.

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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.

The waivers, on the other hand, while required to keep costs down just like managed care, have expertise in serving these populations and they use a human services model to do it. They are trained to provide Service Coordination, a vital service for those who cannot always understand or navigate the various systems, and people come to rely on that support to help keep them living in the community. Service coordinators dedicate the time necessary to assist people to develop plans for their services, help them fill out applications, apply for supports that the people being served may have not known existed, and in general, keep their lives on an even keel. The service coordinator is a vital component of the waiver process, providing many hours of support to each of the up to 20 people they serve. They are the unsung heroes of the waivers.

DOH says the MLTCs will have service coordinators as well, but I'll bet a week's salary that their caseloads will be at least four times larger than those of the waivers. Waiver caseloads are limited because the needs are complex and most of the people don't have the cognitive ability to manage their services and troubleshoot day-to-day problems on their own. More people assigned to a service coordinator means less and lower-quality service provided to each, which will result in neglect, less-than-optimum health and productivity, and, in some cases, placement in nursing facilities.

My mom is on the NHTD waiver, and the service coordinator is critical to helping me keep her in her own home, where she wants to be. As the Executive Director of STIC, I'm aware of the services and supports in the community, and STIC op-

erates Regional Resource Development Centers that oversee the waivers, but my brother and I rely heavily on the service coordinator to maintain my mother's independence and quality of life.

On both a personal and professional note then, I dread the thought of transitioning these waivers to managed care, because no matter what DOH promises,

their words haven't matched their deeds. The record is full of cases of people with other kinds of disabilities who were well-served before managed care, and who lost vital services and are still fighting to get them back. When DOH was forced to open its waiver transition

process to the public, it was revealed that, despite claims to the contrary, the agency had no intention of continuing most of the specialized waiver services under managed care. Under scrutiny, DOH changed their tune and said those services would transition with the waivers. But how long will they be available? MLTCs can, and do, cut or eliminate services after the minimum "transition" period of 90 days. DOH has made no commitments to ensure these service changes are not arbitrary or harmful. DOH is currently violating federal Medicaid law, which requires MLTCs to follow a person-centered planning process to create or modify service plans. DOH has been repeatedly chastised by federal authorities for flagrantly violating requirements to involve stakeholders, including people with disabilities, their families, and their advocates, in the planning process.

So why should we believe DOH when they say people won't be harmed by the transition of the waivers to MLTC? Well, I don't, and neither should you.

**I dread the thought of
transitioning these
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Lane v Brown: Common Sense Prevails

This is the “*Olmstead* of sheltered workshops” case that we first reported in Spring 2012, when it was “*Lane v Kitzhaber*,” before Oregon got a new Governor. It was a class-action suit in federal district court alleging that Oregon violated the Americans with Disabilities Act (ADA) and Section 504 of the federal Rehabilitation Act (now “WIIA,” the Work Incentives Improvement Act) by relying on sheltered workshops as the primary employment service for people with developmental disabilities. Plaintiffs alleged that OR had retreated from its renowned program of closing workshops and providing supported employment services since the 1990s. Especially egregious, the state’s public school transition programs for teenagers with disabilities operated on the assumption that they would naturally go to workshops after graduation, and even provided “mock workshops” on school grounds to prepare them for this.

Around the same time as the suit was filed, the federal Department of Justice (DOJ) investigated OR’s employment programs for people with disabilities and found them out of compliance with the ADA’s integration mandate. There followed lengthy negotiations with the state on a plan of correction. In the end, DOJ concluded that the state was not going to act in good faith to resolve the issues, and DOJ intervened in the lawsuit to support the plaintiffs.

Seeing the writing on the wall, OR officials suddenly got serious. The governor issued an executive order in 2013 (updated in February 2015) requiring the state to beef up its supported employment programs, end new admissions to workshops, and close mock workshops in the schools.

Slowly did the wheels of justice grind on, with the state reducing the population of its workshops by nearly 30%. Then in September of this year, the parties came to an agreement that essentially restates the terms of the executive orders. At press time, it hadn’t been formally approved by the judge in the case.

Although the proposed settlement isn’t as progressive as the Rhode Island consent decree that we reported on in Summer 2014, it contains some interesting points.

Under the terms of the settlement, OR does not admit to violating any law. Like the Rhode Island decree, the settlement only applies to people with developmental disabilities. Unlike that decree, the OR settlement does not require the state to take specific affirmative steps to downsize and close sheltered workshops. Also, while the RI decree requires the state to achieve specific job *placement* targets over ten years, the OR settlement only commits the state to provide supported employment *services* to targeted numbers of individuals. The RI decree requires the state to provide 40 hours of daytime support services to individuals leaving sheltered workshops, with supported employment the preferred activity but also with integrated non-work activities, which may include both training and non-goal-oriented leisure. The OR settlement contains nothing of this kind. However, like the RI decree, the OR settlement requires the state to offer actual supported employment experiences to transition-aged teenagers while they are still in school.

OR did agree to further reduce the number of people with developmental disabilities in workshops by a bit under 20% by June 30, 2017 and to reduce the hours worked by people with those disabilities in workshops by a bit over 33% by that date. In addition, the executive orders incorporated in the settlement require the state to provide supported employment services to a total of at least 7000 people by July 1, 2022.

Enforcement is weak. The state doesn’t really have to achieve any of the targets so long as it can demonstrate that it is continuing to “improve Oregon’s delivery of employment services, with the goal of achieving competitive integrated employment for individuals with intellectual and developmental disabilities, consistent with their abilities and choices.” Only if the state achieves fewer than 50% of the goals in two consecutive years can the plaintiffs bring them back to court.

The settlement does contain some common-sense definitions of terms that are of interest to advocates in NY, who have been battling to keep OPWDD from “wordsmithing” its definitions to allow sheltered workshops to continue doing what they have always done under other names:

Competitive Integrated Employment “is at a location where the employee interacts with other persons who are not individuals

with disabilities (not including supervisory personnel or individuals who are providing services to such employee) to the same extent that individuals [without disabilities] and who are in comparable positions interact with other persons.”

That’s almost identical to a definition we proposed to OPWDD in our comments on the agency’s proposed new regulations for supported employment services. Those comments were ignored.

“A ‘Sheltered Workshop’ is a facility in which individuals with I/DD are congregated for the purpose of receiving employment services and performing work tasks for pay at the facility. [It] primarily employs individuals with I/DD and other disabilities, with the exception of service support staff. [It] is a fixed site that is owned, operated, or controlled by a provider, where an individual has few or no opportunities to interact with non-disabled individuals, except paid support staff. A Sheltered Workshop is not ... an Integrated Employment Setting.”

Compare this to OPWDD’s recent proposals for “Integrated Employment Settings”—part of the agency’s plan for sheltered workshops to “transform” themselves. OPWDD’s proposals allow a place to call itself “integrated” if as many as 99% of the people working in the setting have disabilities, not including support staff, as long as there are at least two “co-workers” who don’t have disabilities (see page 6).

“Small Group Employment’ refers to work performed in regular business, industry, and community settings by groups of ... individuals with I/DD. It is not Competitive Integrated Employment, which is the much-preferred and optimal form of employment for Oregonians with I/DD, but it can have value as a way to offer additional opportunities for integration and employment. Small Group Employment support is provided in an Integrated Employment Setting and in a manner that promotes integration into the workplace and interaction between participants and people without disabilities. Small Group Employment must allow an individual to interact with non-disabled persons in a manner typical to the employment setting. The ... individual must maintain goals to pursue Competitive Integrated Employment opportunities.”

The RI decree outright prohibits use of such settings to achieve its targets; the OR settlement just discourages them. But compare this definition to the “enclave” and “mobile crew” models used in NY. In NY, an “enclave” is typically an isolated room inside a much larger ordinary job site, where only people with disabilities work, and their ability to interact with typical nondis-

abled workers at the site is severely restricted. A “mobile crew” involves paid staff shepherding people with disabilities from one location to another, and usually these locations are devoid of other people. For example, mobile crews do after-hours cleaning in office buildings or highway rest stops, or landscaping at people’s homes during the day while most people are at work.

Perhaps now that we have both a mandated court order and a voluntary settlement for OPWDD officials to peruse, they, too, will see the writing on the wall. Dropping their efforts to preserve sheltered workshops fundamentally unchanged may be an attractive alternative to being sued and forced to make a more radical “transformation.”

Choice is Not Prime

In October, the federal Centers for Medicare and Medicaid Services (CMS) finally approved New York’s proposal to add the Community First Choice option to its Medicaid State Plan.

As we’ve reported (see *AccessAbility* Summer 2015), Community First Choice (CFC) is a part of the Affordable Care Act (“Obamacare”) that lets states offer a range of Medicaid-funded homecare-like support services to people with disabilities without requiring a waiver. These services must fully comply with the federal regulations for “Home and Community Based Services” (HCBS) that took effect in March 2014. There are some additional federal rules that allow them to operate more like the CDPA program.

That’s a lot of acronyms, we know. Let’s break it down:

Who will be Eligible?

Any person who is Medicaid eligible and would qualify for admission to a nursing facility, an institutional setting for people with developmental disabilities or mental health disabilities, or a long-term hospital stay, will be able to get CFC services. Your services will be decided by a “functional needs assessment.” However, you must live in your own or your family’s home, and services won’t be available in group homes, “supported apartments,” or other specialized disability settings.

What Services will be Available?

You’ll be able to choose to get your services from a “traditional” homecare agency or hire the people to help you from among your family and friends (but not your spouse or parents). If you choose to self-hire, you can get training on how to manage your supports, and you will use an agency only to handle record-keeping, billing, and paying workers. Even if you go for the “traditional” agency, you will have the right to expect the agency to send only workers whom you approve, and those workers can

be trained by you and must follow your preferred schedule.

If you are in a specialized disability residential setting, you’ll be able to get one-time help to move out, including security deposits, first month rent, basic furnishings and supplies, and moving costs. You’ll be offered help with self-care tasks such as getting in and out of bed, dressing, bathing, and using the toilet. You may also get help with certain kinds of daily living tasks, such as cooking, shopping, money management, and cleaning. For any of these things, you’ll be able to get “cueing and supervision,” which means that if you are simply forgetful about some things that you are able to do, or if you need somebody to keep you in sight so you don’t get lost, you can get reminders or someone to monitor you. All of these services will be available at home or anywhere you need them in ordinary community settings (but not in any specialized disability “day programs”). You’ll be able to have a “behavior support plan” developed for you, and your workers could be trained to carry it out. If a home modification or a piece of equipment would enable you to be more independent, you may be able to have that paid for through CFC, including personal emergency response systems (PERS; think “LifeAlert”—“I’ve fallen, and I can’t get up!”) and remote medical monitoring devices. Home-delivered meals will also be available. And if any other Medicaid service you need isn’t covered by CFC, you can get it from one of the state’s waivers (if you’re eligible) or from State Plan Medicaid.

All of your services, including any backup arrangements you are able to make, will be listed in a person-centered plan. A Service Coordinator will help you develop that plan, keep track of your services, and provide other help to ensure the plan is working for you. “Person centered” means that you drive the development of the plan as much as possible, including running your own planning meetings and inviting whomever you want to attend them.

You won’t be able to get services or supports that your functional assessment doesn’t show you needing, though.

How is this Different from Other Programs?

Right now, most of the differences are minor. CFC is not likely to make many services available to many more people who aren’t already getting what they need elsewhere.

People currently on any of NY’s HCBS waivers, including the OPWDD waiver for people with developmental disabilities, and the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) waivers available through the Department of Health (DOH), can already get most or all of these specific types of services. All waiver participants have Service Coordinators, and all of the waivers include transition costs, home mods, assistive technology, and behavior supports and “cueing and supervision” (but the latter is limited to respite services under the OPWDD waiver). People on the OPWDD waiver can self-hire and/or self-direct some of their services. People on the DOH waivers can’t self-hire or, officially, self-direct, but many people on those waivers have flexible service providers who allow some consumer control.

People in the Consumer Directed Personal Assistance program (CDPA) can get all of the self-care and daily living task services listed above for CFC, plus many tasks ordinarily performed by medical staff, such as medication administration, catheterization, and ventilator maintenance, none of which is currently allowed under CFC. All services are self-hired and self-directed. However, CDPA does not include “cueing or supervision”; if all you need is reminders or somebody to watch you, you can’t get CDPA. People in CDPA must be able to direct their own services or have an officially-designated representative; CFC doesn’t formally require this. And there is no person-centered planning for CDPA, although people

whose CDPA services are paid for through a managed long-term care organization are supposed to be getting it (see page 9).

Adults whose primary disability is mental illness currently don't have any HCBS services available to them. However, the Office of Mental Health (OMH) intends to roll those out through its "HARPs" plans over the next year or two.

Finally, it's important to understand that all we have right now is a piece of paper from the feds saying the state can develop this program. The program itself does not exist. There are no CFC service coordinators, person-centered planners, or service providers. There are no state regulations governing how the program will operate. There is no money allocated for these services. There's nobody you can call up to schedule a functional assessment or get your service planning started. And there won't be for quite some time, a couple of years at least.

Could this Potentially be a Better Option?

Yes, but in order for CFC to really help a large number of people who can't get these services today, three things have to happen:

1. The NYS legislature must enact a change to the state's Nurse Practice Act (NPA) to enable people who aren't nurses to be "designated" to carry out nursing-type tasks in people's homes. But, you say, CDPA workers can already do that; why do we need this? Basically, because the NPA exemption for CDPA assumes that the workers will be self-directed; in other words, that the workers will be directly and immediately overseen either by the person who is being served or his/her designated representative. If we are going to allow people to go into the home of someone who is not able to direct their own services and doesn't have a representative to do it for them, and perform medical tasks, then we need to make doubly sure that these workers are well-trained and supervised—so the argument goes. Currently there are limitations on what trained and licensed "traditional agency" personal attendants and certified home health aides can do under existing NPA rules, so the proposed route is to create an entirely new kind of certified aide, Advanced Home Health Aides (AHHAs).

A-hah! you say. With an NPA exemption, then CDPA-like services will be available to large numbers of people now living in nursing facilities or group homes who, due to cognitive or intellectual disabilities can't direct their own services, and who don't have any living or interested relatives or friends who would be willing to be their representatives.

2. The limits on the "daily activity" tasks that homecare attendants can do need to be expanded and clarified. Currently, there is a limited list of tasks that traditional "personal care" and CDPA attendants can do, which only includes things believed to have a direct impact on the person's health. So "light housekeeping" is allowed (because a dirty house can make a person sick), but shoveling the front walk so the person can get in or out of the house is not. Also, purely to cut spending, so-called "level 1" personal care (light housekeeping) is limited to a maximum of 8 hours per week. The wording of the CFC State Plan Amendment implies that these limits must be removed. It requires that "essential household chores" be performed as needed, and while the 8-hour limit is mentioned, it says that the types and amount of tasks to be provided are to be determined only by the person's functional needs assessment and person centered plan, and no arbitrary limits can be imposed. But this clearly conflicts with the state regulations for personal care services, including CDPA, so it's likely that those regulations will have to be re-written before DOH will let your attendant shovel your walk or feed your cat.

If those limits are removed, this will also help open up home-based supports to people who don't have friends or relatives available to fill in the gaps in services that are vitally necessary for someone to remain in their own home.

3. The backup problem still must be solved. Although a CFC person-centered plan should include a backup strategy for when workers can't show up, and the State Plan Amendment commits NY to pay for any backups that are arranged, it doesn't require the state to ensure that adequate backup is provided. As with all other homecare services, the availability of reliable backup and the ability to recruit enough workers to provide the authorized hours of service depends on the size of your community and the wages and benefits that are offered to workers. Outside of New York City, it's impossible to ensure 100% reliable paid backup because wages and benefits are too low to recruit enough workers. That means that CFC recipients for whom backup is critical will need friends or relatives to help out.

In order to really open up homecare to people who can't already get it, the state is going to have to provide a substantially higher rate for CFC services than it now pays for most other homecare. Until it does that, homecare will remain a realistic option only for people who have interested friends or relatives, which means that there will be very few people who can't already get what they need from other programs who will be looking for CFC services.

So What Can We Do about This?

The State Plan Amendment indicates that DOH views CFC as an "umbrella" under which much of the service planning and monitoring for people needing extensive or specialized long-term care supports will be done, especially in managed long-term care. As usual with DOH, details on how that will be arranged are scarce. Until the agency comes up with a workable plan, there will be no CFC services "on the ground." So advocates need to pressure DOH at every opportunity.

The limited availability of "daily living" support in NY's personal care regulations illustrates the long-running failure of state officials to understand how critical this is to enable people with disabilities to have meaningful lives in the community. Governors have been trying to eliminate or cut level 1 personal care since the mid 1990s. It is very difficult to make them understand that having someone to shovel your walk or fix a broken door handle or change your baby's diaper is just as vital to your ability to survive in the community, if you can't do those things yourself, as having somebody help you in the bathroom or cook your dinner. Critics call all of this "luxury maid service." That's nonsense, of course. But why will the state pay for a "cook" or a "maid" but not for a "handyman" or a "nanny"? And if we succeed in adding "handyman" and "nanny" services to the list, then we really have to remove the 8-hour limit, or all of the work that some people need won't get done. We think it's likely to be a tough fight to get any of these changes made, so people need to be vocal about this too.

For three years running, efforts to get an NPA exemption have failed. As we've reported, it took a year to get the Cuomo Administration to propose it. Then two years in a row the legislature refused to pass a bill, claiming that it would result in people being left "unsafe." If it doesn't pass, you can kiss CFC as a practical alternative goodbye.

As for the recruitment issue: It might be best to pursue a strategy of supporting a minimum wage increase to \$15.00 an hour for all types of workers in NY. If that happens, the state will be forced to raise the rates it pays to homecare providers, or they won't be able to pay the workers. Given the current political climate, and Cuomo's ongoing crowing about cutting Medicaid spending, it may be easier to get this done than to directly ask for higher Medicaid rates.

Reign of Error

In September of this year, we submitted 13 pages of carefully-researched, evidence-based comments on OPWDD's proposed new regulations for person centered planning. This included both suggestions for making certain things clearer, and corrections for obvious errors. OPWDD ignored all of it and issued the final regulations without a single change.

We didn't just shoot them a memo off the tops of our heads. Thanks to the confidence that so many of you have placed in us, we have become highly experienced experts in providing all types of integrated individualized support services to people with all kinds of developmental disabilities. We provide service coordination to over 500 people, habilitation services to over 400 people, and other things, such as supported employment and positive behavior support planning, to lots more. We wouldn't be doing all that, and struggling to keep up with waiting lists of more people who want our services, if you didn't think we knew what we were doing.

Our comments were informed and full of expertise in integrated personalized services, about which most OPWDD planners know very little, but which the new regulations are going to require a lot more of in the future. Not only that, but OPWDD has only five people working on the plans to comply with the new federal regulations, replace sheltered workshops, close ICFs, rewrite the HCBS waiver, and work on the DISCO managed care project. You'd think they would be thankful for our assistance to make their regulations better. You would be wrong.

We don't have space to explain all the problems we found in the regulations or what we suggested to correct them; after all, it took 13 pages. But we'll summarize:

In 2013 the federal Centers for Medicare and Medicaid Services (CMS) published new regulations governing person centered planning for all so-called Home and Community Based Services (HCBS) programs, including Medicaid waivers like OPWDD's. Those regulations went into effect in March 2014.

So in late summer of 2015, OPWDD finally proposed state regulations to implement new federal requirements that had already been in effect for over a year. Despite all this lead time, the regulations contained a lot of problems.

We found four major errors of fact. These weren't obscure technical errors, but were in plain sight for anybody familiar with government regulations—which OPWDD planning officials should be. For example, OPWDD claimed that important requirements, like documenting that people made a free choice of where to live from a full range of required options, only applies to people who live in OPWDD-certified residences. The CMS regs, in fact, say this requirement applies to every HCB service recipient, no matter where they live, and CMS guidance explaining the regulation says that it is not limited to "certified" residences.

That sounds technical, we know. But what OPWDD is saying is that if you are homeless or in a homeless shelter, or you live in the "Y" or in a residential motel, or a domestic crisis center, or you are a self-directing adult living with family members who are unfairly restricting you, the agency doesn't have to make sure that you chose that place on your own, without being pressured, from a list of other options. Does that sound right to you?

There are other problems with the regulations as well. The CMS rules and the explanatory text that comes with them describe the person centered planning process in a way that suggests "supported decision making" (see page 11). They are quite clear on a few important points: The person "drives" the planning process to the extent feasible; the person decides who participates; when the person has a "legal representative," that representative must be allowed to attend, and if necessary, approve the final plan, but they cannot control the planning process if the individual can do it him or herself. OPWDD's regulations present these issues in a much more vague and confusing way than CMS did. This is likely to lead service providers to violate the civil rights that CMS's rules are intended to protect.

OPWDD used to be a lot more responsive to public comment than it has been for most of this year (see next column). In that same time period, according to inside sources, officials of the Department of Health (DOH), which has official responsibility for Medicaid administration, have become much more deeply involved in OPWDD's business. DOH has been cited more than once by CMS for failing to follow proper procedures to request, analyze, and make use of public comment. The change in attitude in OPWDD has a familiar scent to it: it smells like DOH.

Saying So Doesn't Make It So

STIC staff are on various OPWDD email lists, including the so-called "stakeholders" list that usually includes announcements of events and opportunities for public comment. However, none of us received an announcement that OPWDD was holding "Integrated Employment Regional Forums" at nearly the same time as its "Transformation Panel Forums" (see page 7). The employment forums featured a new version of OPWDD's proposal for enabling sheltered workshops to "transform" themselves into "integrated employment settings." We only discovered this when we happened to check the OPWDD website, and by that time, the forum in Binghamton was already over and it was too late to plan a visit to any of the other sites. Fortunately, though, we were able to submit written comments.

The first point we raised was the lack of advance notice of these events or of the release of this new document. This underscores a growing pattern of secrecy and disrespect for public input that we are now seeing at OPWDD (see previous article).

This summer we reported that OPWDD was presenting draft "options" for how workshops could become "integrated employment settings." Those options would allow workshops to continue to be segregated segregate special employment facilities while making a few minor cosmetic changes. We responded critically at the time and pointed out that the federal Centers for Medicare and Medicaid Services (CMS) would not permit Medicaid Home and Community Based Services (HCBS) funds to be used to pay for services in such places.

The new "draft" version making the rounds in October had only minor changes. There are still two options. Both would allow HCBS funds to be used in "transformed" workshops where nearly all of the "co-workers" have disabilities, as long as there are also "co-workers" without disabilities. These nondisabled "co-workers" could not be workshop training or support staff. Because "co-workers" without disabilities is plural, the requirement could be met if all of the "co-workers" except two have some kind of disability. The two options only differ, ostensibly, in the percentage of "co-workers" who could have *developmental* disabilities. One allows 40%, the other up to 75%. The rest could be people with mental health, sensory, physical or substance abuse disabilities—except for two people. But in this proposal, "developmental disabilities" only includes people who are receiving "services"

from OPWDD or some other state-funded program. People with developmental disabilities who don't need "services" but are just working in a segregated workshop would not be counted toward the percentage.

Can anyone explain to us how this is any different from the typical sheltered workshop? Most workshops have a few nondisabled "production workers" to satisfy contract quotas. Lots of workshops include people with varying types of disabilities. Some of the workers with developmental disabilities don't get special services at all, in the workshops or elsewhere.

There are some additional requirements not in the first draft of this proposal. For example, workers with disabilities must have opportunities for advancement equal to those for nondisabled workers, must be able to mingle with the nondisabled workers (all two of them), and must be able to leave the facility to eat lunch. The providers are also supposed to have recruitment policies designed to maintain a "diversified workforce" including people without disabilities, but there is no requirement that that they eventually achieve a workforce where the

ratio of disabled to nondisabled workers resembles those of ordinary businesses.

The proposals are clearly intended to allow every single sheltered workshop funded by OPWDD today to stay open and continue to operate as a sheltered workshop merely by changing its name to "integrated employment setting," even though CMS has ordered the agency to stop funding those places and move everyone out of them into either supported work or habilitation programs.

The US Supreme Court's *Olmstead* decision firmly established that illegal segregation of people with disabilities means keeping them separate from nondisabled people. Introducing people with other kinds of disabilities into a group of people with developmental disabilities does *not* "integrate" them. A special purpose facility for employing people with disabilities where up to 99% of the workers have disabilities and only 1% (or even 5%, or 10%, or even 25%) do not, is **NOT integrated**. It is segregated. It was, is, and always will be a sheltered workshop, no matter what it is called.

The recent lawsuit in Oregon over sheltered

workshops (see page 3) provides a much better common-sense definition of workshops. Here's their definition, shortened: "A 'Sheltered Workshop' is a facility in which individuals with [intellectual or developmental disabilities or I/DD] are congregated for the purpose of receiving employment services and performing work tasks for pay at the facility." It offers "few or no opportunities to interact with non-disabled individuals, except paid support staff" and it is not "an Integrated Employment Setting."

We don't know if it's going to take a lawsuit to straighten out OPWDD on this. We hope not. CMS has publicly stated that it's not likely to approve use of HCBS funds in any partially-integrated or cosmetically "transformed" workshop. We've sent a copy of our comments to them and we'll let you know what happens next.

If you want to help put an end to this nonsense, you can read OPWDD's proposals at:

<http://www.opwdd.ny.gov/workshoptransformationguidance>

And you can send comments to:

Employment.Forums@opwdd.ny.gov



Last Dance at the Disco

There were some rather shocking developments regarding OPWDD's efforts to develop a managed care system over the summer. The agency has publicly announced very little about this, but STIC is involved with various groups that have been working with OPWDD on these and related matters and we have collected information through them.

Are DISCOs Dead?

This summer we heard that a high OPWDD official had said something like "DISCOs are dead" at a meeting. Investigation suggests that reports of their death are premature, but just barely.

The model that OPWDD has promoted up to now is this: A DISCO is a not-for-profit organization in NY that has extensive experience in providing a variety of residential and non-residential services to people with developmental disabilities. The organization must have people with disabilities who use its services either on its governing board or on an advisory board. The organization must meet various NY requirements for a Managed Care Organization

(MCO), including having substantial cash reserves, but it may contract with an experienced MCO to handle the specific financial and acute-medical care management aspects. DISCOs are encouraged to reach out within broad geographic regions to pull as many participating service providers, and people with developmental disabilities, into their "networks" as possible. But a small total number of DISCOs would not be desirable because people with developmental disabilities are supposed to be able to choose from at least two DISCOs serving their region.

Important questions about this model were never fully resolved. For one thing, how can a DD service organization really function as a knowledgeable MCO without turning into a typical penny-pinching, service-cutting, appeal-denying medical-model tyrant? The experience necessary to manage health care financing doesn't exist in DD organizations, and giving full control of coverage decisions to a generic MCO would likely be destructive. It would also be illegal, because the new federal regulations governing person centered planning clearly define the planning process

as a good-faith negotiation driven by the person being served. Another big question is how to ensure that people with disabilities can continue to get the same intensive and frequent interaction with, and support from, service coordinators whom they know and trust when the DISCO "care coordinators" are "teams" that serve up to 100 people? Unlike managed care coordinators, OPWDD service coordinators do a lot more than write a plan and file it. Service coordinators are the "glue" that keeps a person's collection of discrete services and service providers from falling apart and leaving the individual stranded.

The main goal of the Cuomo Administration's push toward managed care is to cut Medicaid spending. When input from people who actually know something about serving people with developmental disabilities, including STIC, finally penetrated the skulls of Cuomo's team, they realized that the cost of services probably could not be cut as much as they had expected.

The way that government-financed managed care "saves money" is by only using tax dollars to pay a portion of the full costs; the

rest comes from the reserve funds of MCOs. Those reserves come from the money that other insurance buyers, usually private businesses and their employees, pay for premiums (including profits on investing those funds). In other words, the money still comes out of the pockets of taxpayers, but it is not collected as “taxes.” It apparently dawned on Cuomo’s team that the large group of relatively small regional DISCOs they were planning might not have enough reserves for the government to raid. This would explain why some people have heard OPWDD officials mention the idea of opening up the OPWDD managed care marketplace to large national for-profit MCOs.

So what is emerging is a flip-flop in the relationship between DISCOs and MCOs. Instead of the DD-experienced DISCOs running the show and making the final decisions, Cuomo’s people are now talking about demoting DISCOs to simple “provider networks” that would subcontract with ordinary (and probably very large, for-profit) MCOs to do the actual service provision. But they would not control the flow of money; the MCOs would. The MCOs would do needs assessment, but would not have to demonstrate experience with the needs of people with developmental disabilities, nor would they be required to include people from that group in their governance. Cuomo’s people seem to think that this organizational somersault would shield the MCOs from having to apply a person-centered approach to allocating funds; instead they could tighten the noose as much as they see fit, hand off the shrunken purse to the DISCO, and say, “Here, person-center-plan all you want, but it has to fit in this budget.”

We would challenge that assumption. It would be pretty easy to show that person centered planning would become a gutted concept if the individual’s specific assessed needs and goals don’t drive the plan, and the plan doesn’t drive the spending.

The state legislature took the possibility of the death of DISCOs so seriously that it passed a bill requiring MCOs that want to offer DD-specific services to “enter into an affiliation agreement with a non-profit entity that is experienced in serving individuals with developmental disabilities.” Rather surprisingly, Cuomo signed it. So DISCOs aren’t dead; they’re just on life-support.

Is OPWDD Trying to Dodge New Community Integration Requirements?

At a July 16, 2015 meeting of OPWDD’s “Transformation Panel,” an outline of this new concept

was presented and discussed. An agenda and minutes of this meeting did not appear on OPWDD’s website until at least two months later (it wasn’t there in early October but we found it on November 18). The PowerPoint presentation, at press time, still had not been publicly posted. However, STIC obtained a copy of it in September. When we asked an OPWDD official about it at a public meeting in mid-October, she tried to deny that it existed.

Along with the reversed DISCO-MCO model, the PowerPoint suggested asking the feds to approve a new amendment to the state’s Medicaid 1115 waiver to implement the managed care changes for OPWDD. The PowerPoint said this could provide “regulatory flexibility for community-based, individually tailored services & person-centered planning process.”

That sounds good, right? It’s got all the good words in it: “community,” “individually tailored,” “person-centered.”

But there’s another way to look at it.

The Medicaid Home and Community Based Services (HCBS) waiver that OPWDD has now is governed by the new federal regulations defining “home and community based settings” and “person centered planning” (see *AccessAbility* Spring 2014 and Summer 2014). If you use an 1115 waiver to provide the same kinds of services, the requirements aren’t so black and white. They *are* there. The feds have said generally that 1115 services must follow HCBS rules, and the language in NY’s 1115 waiver is tied to federal law governing HCBS waivers, which brings those regulations into play. But some of Cuomo’s people, especially those in DOH who, we think, are behind this proposal, may believe that the rules don’t apply.

OPWDD tried to get the feds to approve this 1115 thing a few years ago, and it was rejected. The agency has had a very hard time negotiating with the feds on how to reform its system to comply with the new regulations (see *AccessAbility* Fall 2014 for example). And it’s getting a lot of push-back from frightened families and segregated service providers. Things are moving more slowly than Cuomo had hoped. We can see why they would look for a way to bring in managed care while not having to ensure that people really get services in the most integrated settings. We think that’s what the “flexibility” that the PowerPoint mentions is about.

Now, an official at the federal Centers for Medicare and Medicaid Services (CMS) sent

a letter to Cuomo’s Medicaid Director, Jason Helgeson, in December 2014, stating that the HCBS regulations do fully apply to all of NY’s 1115 managed long term care programs and plans (see below). It appears that whoever authored this PowerPoint didn’t know about the letter to Helgeson, or didn’t understand it. Because using an 1115 waiver is not going to provide any additional “flexibility” regarding integrated services or person centered planning.

During the July Panel meeting, some people kept pointing out that OPWDD needs to overcome fears that managed care is going to pull money out of the system and cut people’s services, because all the agency is really trying to do is “improve” things. These people apparently haven’t heard how the roll-out of Medicaid managed long-term care is going for people with other kinds of disabilities. Peremptory service cuts not backed up by any demonstrated changes in needs, and even refusals to serve people at all because they have “too many needs” or bogus “safety risks,” are commonplace. People’s “fears” are coming true. And if OPWDD managed care is really going to be run by big insurance companies instead of by the service providers that people with DD have come to know and trust, then there is a lot more to fear now than ever before.

When a Plan Comes Together

We’ve paid a lot of attention to OPWDD’s efforts to develop a “transition plan” to comply with the new federal regulations for Medicaid Home and Community Based Services (HCBS). But OPWDD isn’t the only state agency that needs to make a plan. All of the state’s Medicaid waivers are affected by these new rules, and really, the Department of Health (DOH), the official state Medicaid authority, is the top dog responsible for coming up with these transition plans.

Under the regulations, the state’s Traumatic Brain Injury and Nursing Home Transition and Diversion Waivers, and all of the Medicaid managed long-term care plans must: provide a full person centered service planning process, ensure that all service recipients live in settings that comply with the new definition of “home and community based,” ensure that all services are provided in such settings, and provide people with options to self-direct their services.

DOH has done virtually nothing about this. They did submit a “plan” last March to the federal Centers for Medicare and Medicaid

Services (CMS), which must approve the state's transition efforts. We reviewed it before it was sent and told DOH that it was extremely vague and failed to address several required points. As usual, our comments were ignored. But we weren't the only commenter.

On September 16, 2015, CMS sent a letter to the state's Medicaid Director, Jason Helgeson, about DOH's plan. What did the letter say? It said the plan was extremely vague and failed to address several required points.

Along with that, disability rights advocates got an unexpected bonus from the letter: confirmation that under the new regulations, people with disabilities cannot simply "choose" to be segregated using Medicaid funds.

The letter stated that settings that don't comply with all provisions of the rule requiring a residential setting to meet the definition of "home and community based setting" can't be funded with Medicaid waiver money, regardless of who chooses to live there. And the HCBS regulations require that if the place where the person lives is not compliant, then the person cannot receive any Medicaid HCB services anywhere.

You can "choose" segregation all you want, but the *waiver* won't pay for it. The law pertaining to institutions for people with developmental disabilities requires them to be temporary transitional programs, designed to help their residents move into more integrated settings. So even if you choose to live in an ICF, Medicaid will only pay for it until you learn what you need to return to the community.

Also backing up that point was Governor Cuomo, who vetoed the legislature's "continuity of care" bill in November. The bill would have let family members choose to have relatives with developmental disabilities get residential services from state employees (that is, public employee union members) instead of not-for-profit agencies, and if there were no state-operated residential "beds" available in their communities, OPWDD would have had to keep them in developmental centers until those beds materialized. This would have blown away the state's agreement with CMS to close all but two institutions for people with developmental disabilities, and would, as Cuomo said, "run counter to the *Olmstead* mandate, federal Medicaid guidance, and generally accepted practices for the care of persons with disabilities." Attaboy, Governor!

Clarifying our Clarification of the Clarification

"Haven't you always wanted a monkey?" — The Barenaked Ladies

Last time, we printed an article about new state legislation to "clarify" rules about use of "service animals" by people with disabilities. The issue is that some people try to get away with calling untrained pets "service" or "emotional support" animals. We said that the state law was bogus because it restricted the rights of people with disabilities more severely than federal law does.

Unfortunately, our article was wrong on that point. Here are the facts:

The federal Americans with Disabilities Act (ADA) has regulations governing service animals, but they differ depending on titles of the law. Title III, which prohibits discrimination by "public accommodations" such as stores, restaurants, theaters, medical service facilities, and parks, has the strictest regulations. It limits "service animals" to dogs that are trained to carry out specific tasks to assist a person with a disability to do certain types of things. Title II, which covers state and local governments, is a bit looser; it also includes miniature horses in the definition of "service animal" under some circumstances. Title I, which governs employment, is the loosest. It does not define "service animal" at all. It only says that a service animal *may* be a reasonable accommodation to enable an otherwise qualified person with a disability to carry out the essential functions of a job.

The new state law applies the same rules to the NYS Human Rights Law's list of "public accommodations," but it also says if there is conflict between the state law and the ADA, the ADA provisions apply. Last time we also reported that the NYS law had been modified to include some aspects of ADA Title II. This was done by redefining "public accommodations" to include similar types of venues to those listed above when they are owned or operated by state or local governments.

The new law actually strengthens the rights of service dog users in the workplace. ADA Title I considers all "service animals" as potential reasonable accommodations. The NYS Human Rights Law now deems professionally-trained guide dogs, hearing dogs, and other "service dogs" that carry out specific tasks to be an absolute right. They are allowed for any worker who needs them, period. However, any other type of "service animal," including

"emotional support dogs," remains subject to the "reasonable accommodation" rule.

Case law has shown that the "essential functions" part of that rule is important. Your boss can exclude the animal if it is not necessary to enable you to carry out essential functions of the job. Courts have found that if a worker has been doing a good job for a period of time, and is getting good reviews from his supervisor, then legitimate need for a new accommodation is unlikely. The animal can also be excluded if it is disruptive or not fully under your control, because it is not reasonable to expect employers to allow loud or aggressive animals to roam freely around the workplace, unless, perhaps, your job is "raccoon hunter".

What does all this mean? You, as a customer, can only bring a professionally trained service dog into any private business. A customer can also bring a professionally trained miniature guide horse into a government building. As an employee, if your boss won't let you bring your professionally trained task-specific service dog to work, that's an automatic violation of the NY law. If you want to bring a service monkey or an "emotional support dog" to work, you must first request it as a reasonable accommodation. If your boss just says, "we don't allow service monkeys or emotional support dogs," that's a violation of both the ADA and NY law.

Long May We Waive

As we reported last time, pressure from the NYS Legislature and the feds persuaded the NYS Department of Health (DOH) to delay conversion of the TBI and NHTD Medicaid waivers to managed care for one year. This provided time for DOH to convene a "stakeholders" group to discuss which specific services from those waivers will be available from managed care, and what will be done to ensure that people now in those waivers will not lose essential supports.

This forced DOH to cough up lists of services and their plans for them. As we suspected, DOH wasn't really planning to include much of anything from these waivers in managed care. In some cases, DOH officials claimed this was because the waiver services weren't used by very many people. In others, they apparently just expected that generic personal care or home health services would be enough. There are only around 5000 people on these waivers, and some of the services are only used by a few hundred, or even fewer, people. That's peanuts compared to the total number of Medicaid long-term care recipients in the state. From a bean-counter's point of view, forcing

a few thousand people out of their homes and into nursing facilities doesn't affect the bottom line that much. From the point of view of a nursing facility lobbyist, it's beautiful.

However, it was clear that these people were being prodded very hard from behind the curtains, so they were pleasant and cooperative, and they agreed to put almost all of the services back in. These included assistive technology, home and vehicle modifications, "Home and Community Support Services" (safety supervision and "cueing"), community integration counseling, independent living skills training, "Community Transition Services" (security deposits, first-month rent, basic household furniture, bedding, and equipment, but no "moving assistance"; DOH said care coordinators can "contact churches" to try to get volunteers), Structured Day Programs, and service coordination (but only for people with a diagnosed "cognitive deficit"). Some of the services will be added to ordinary "mainstream" managed care plans as well.

There was resistance to restoring Positive Behavioral Interventions and Supports (PBIS); DOH apparently thought it was the same thing as "mental health counseling," which is covered. Advocates pointed out that it keeps people out of jail, among other things. DOH agreed to "revisit" it, and later announced that they would add it.

All this seemed promising, but there remained the problem of ensuring that people continue to get the services after they move to managed care. MLTC plans are only required to continue all of the services that a person was getting before the move for 90 days. Then they can "reassess" the person's needs and services may be changed or dropped as a result. People with similar needs who aren't on the waivers are already being enrolled into MLTCs, and advocates report that the plans frequently do cut or eliminate services as soon as they can. They also, in some cases, just refuse to accept people into their plans because they are "high need," "unsafe" (even though they are similar to people who have lived with waiver supports in their own homes for years), or "non-compliant" (because they missed an appointment or two). In fact, MLTCs have referred such people back to the waivers for service. It doesn't happen to everyone, but it's not a just a few isolated cases either. To be fair, the rates DOH pays MLTCs, at least for some regions of the state, are far too low to support anyone who needs more than a few hours of homecare per week, and DOH has so far stonewalled efforts to get those rates adjusted.

People can appeal service cuts or cancellations. In August, advocates won a partial victory on this front. DOH announced that for certain types of MLTCs, the requirement for

people to exhaust the plan's internal appeals process before they can request a more objective Medicaid Fair Hearing has been dropped, and "aid continuing" will be provided automatically during appeals. And new federal rules can provide a new basis for appeals. The new regulations for Medicaid Home and Community Based Services (HCBS) and person centered planning apply to the state's Medicaid managed long-term care programs. NY Medicaid Director Jason Helgeson was told this in a letter from the Centers for Medicare and Medicaid Services (CMS) in December 2014. DOH has done nothing on the record to comply. That doesn't change the fact that all MLTC service plans must be developed based on an individual needs assessment, using a process that is "driven" by the individual to the extent feasible, only includes people the individual invites to participate, and must take the form of a good-faith, face-to-face negotiation among the parties to arrive at a mutually-agreeable plan. These rules apply to any plan changes as well. Therefore, MLTCs can't unilaterally cut or eliminate anyone's services. Such changes can only be made via the person centered planning process. We're quite sure that DOH hasn't grasped this fundamental point, and it certainly hasn't told the MLTCs about it. Most of the advocates fighting the "managed care wars" don't even know about this. Please, spread the word.



"Hey, That Really is the Sheriff on That TV!"

by Bill Bartlow

Over 3500 visitors were warned by Broome County Sheriff David E. Harder about the authentic danger of encountering carnage upon entering Blood Creek Massacre, the first of our five themed areas in 2015's Haunted Halls of Horror. They went in anticipating deranged mayhem and throughout the haunt we could hear their terrified screams as they arrived at the scene of the crime and came face to face with the perpetrator. Our thanks to the Sheriff for his service, and for setting our scene.

The thrills continued throughout the haunt, especially in our major new attraction: the Vor-

tex, which had people holding the rails or lying down to remain on the bridge. Dave Francisco's artwork exploded off the walls, dream creatures captivating the viewers. Great work Dave!

We also would like to thank Binghamton Mayor Rich David for his endorsement and support of STIC's primary fundraising effort and Binghamton's premier haunted attraction.

The Mayor, along with Chris Whalen of State Assembly member Donna Lupardo's office, were among the dignitaries who spoke at the news conference opening this year's Halloween event.

A reception was held for our generous sponsors and STIC's board members, who provide critical funding, followed by an exclusive preview tour through the attraction.

"Amazing, Incredible, Fantastic, the Best ever" were among the comments we heard. Those praises are to be directed to our roster



of nearly 100 volunteers who selflessly donated over 3000 hours through 9 performances and without whom the stage would be empty. Our "Scream Team" members also include many behind-the-scenes supporters who not only work while the event is open, but throughout the year preparing and building an ever-improving and fresh attraction.

A special thanks goes out to Paul Kotran, Mike Hefner, and the crew of the mega-attraction, "Reaper's Revenge," our neighboring haunters in the Scranton area, for their invaluable assistance in building and critiquing our Haunted Halls and participating with us in Sponsor's night, University Fest, Zombie Night at B-Mets stadium, and the Zombie Walk in Binghamton.

The safety and security of our visitors and crew are always our chief concern; therefore we wish to acknowledge the City of Bingham-

ton Bureau of Fire's Lt. Jeffrey M. DeRado, and NYS Department of Labor's Safety and Health Inspector, Kevin Barry for their vigilance, inspections, and suggestions ensuring we are in full compliance with safety regulations. Additionally, Rick Wheaton and our security team are on-site guardians preserving the family atmosphere and fun.

This year we welcomed many Binghamton University students to our attraction resulting from the efforts of BU interns Leo Minuskin and Sabrina Acks, along with the on-campus chapter of Autism Speaks.

Finally, a huge thanks to our growing number of HHH visitors and fans, who return year after year to see what new visions we have brought to life from the world of haunts.



A record number of children enjoyed themselves with age-appropriate Halloween crafts in our ECDC/PTAC kid friendly area.

Halloween's barely over and Todd Fedyshyn, HHH's tirelessly creative co-founder, is already planning for next year. We're serious about bringing the best Halloween attraction possible to the Binghamton area. Not sure how to top 2015, but by 2016 we'll have a plan to do exactly that!

See the Forest for the Trees

by Bill Bartlow

The Roberson Museum and Science Center's Home for the Holidays Christmas Forest will be open November 18 through January 10, 11 am to 5 pm (9 pm on Thursdays and Fridays). STIC's Parent Technical Assistance Center Director Sue Lozinak has again worked her decorative magic to bring season's greetings to the community in the form of two enchanted holiday trees. Our Halloween tree commemorates our successful sixth seasonal fundraiser, and the traditional Christmas tree extends best wishes to all for the holidays and the New Year.

We also invite you to see what Sue has done in the lobby of Binghamton's Kilmer Building as you shop for that special gift at the Goldsmith's or enjoy a warm holiday meal at Remlik's.

Thank you Sue, and Happy Holidays from Southern Tier Independence Center.

ASAC Thanks You

by Sue Hoyt

The ASAC committee is an advocacy group at STIC that works with local business and municipalities to help make our community more accessible for people of all abilities. ASAC would like to recognize and thank the following companies for correcting their handicapped spaces in their parking lots to meet ADA regulations:

Speedway Gas Station

1454 State Route 12 Binghamton

Veterans Association Outpatient Clinic

425 Robinson St. Binghamton

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

SELF HELP

Guarding against Unintended Consequences

Any bike rider can get hit by a car on a city street, right? According to the National Highway Traffic Safety Administration, in 2013, approximately 48,000 "pedacyclists" were injured in crashes with motor vehicles in the US. We wouldn't expect those accident survivors to be locked up, fired from their jobs, and have their computer access taken away as a result. It probably doesn't happen very often. But the one person we know it happened to was a person with a disability. Her name was Jenny Hatch.

Ms. Hatch, a young woman with Down Syndrome and an IQ around 50, was living with a friend in Newport News, VA, had a job at a thrift store, and was active as a volunteer in local politics. She used a bicycle to get around, and one day she got hit by a car while riding and was badly injured. After she got out of the hospital, Ms. Hatch needed some extra help while recovering. So the couple that owned the thrift store let her move in with them and provided extra care. But, frightened by the incident, her mother went to court and obtained guardianship over her, then put her into a group home. (Her mother may have had good intentions, but she clearly didn't know her daughter, or her capabilities, very well.)

The group home would not permit or enable Ms. Hatch to get to her job so she lost it. The facility also closed down her email and internet accounts and wouldn't let her use a computer. It restricted her in many other ways as well, and she was so unhappy that she tried to leave; her efforts to control where she lived were called "running away" or "elopement." Ms. Hatch was able to hire a lawyer to contest what had been done to her. But when the group home found out about it, it tried to force the lawyer to sign a "visitation agreement" stating that, in Ms. Hatch's "best interests," the lawyer would not discuss her case with her in any way, and if the lawyer wouldn't sign the agreement there would be no contact with Ms. Hatch.

STIC's Offices
will be
**CLOSED FOR THE
HOLIDAYS**

December 24 – January 3

We'll Re-Open

9 am January 4, 2016

Happy Holidays to All!

In legal terms, Ms. Hatch became “civilly dead.” Not only were her rights to control her own life taken from her, but mechanisms were put in place to keep her from challenging what had been done to her, to make sure she could never “come back to life” as a citizen.

We don't do this to convicted felons in this country, but it is routinely done to people with intellectual or cognitive disabilities, regardless of their ability to make decisions.

NY has two different guardianship laws: “Article 17A” and “Article 81.” Article 81 requires legal due process, including a face-to-face hearing before a judge and submission of evidence proving that a person's decision-making abilities are “incapacitated” in specific ways; this is what lay people think of when they hear about a “guardianship proceeding.” But most people with intellectual disabilities don't get that kind of process.

Instead, family members (usually parents) go the 17A route. Under 17A, a family member can obtain full guardianship over an adult with a developmental disability without proving that the individual has any actual incapacities that affect his or her ability to make sound decisions. All you have to do is get letters from two medical sources saying that the person has a developmental or intellectual disability, fill out a form, and send it to a judge. The process does not require the court to offer the person an opportunity to object. It does not require any evidence that the person lacks the ability to understand issues such as health care options, housing options, employment, personal relationships, or property or money matters. (An IQ below 70 is not evidence of incapacity; there are many people with low IQs who have slipped under the radar of the disability service system and are living on their own and making their own decisions without problems.) Although

a hearing can be held, it typically is waived. With no requirement to present or argue evidence before a judge, all that is required under 17A to permanently deprive an adult with developmental disabilities of most of their self determination rights—that is, to subject the person to “civil death”—is to fill out a form and send in a couple of doctors' notes.

You may have the best of intentions as a family member. But we must ask you to understand: this is not a good thing to do to a person. Once a person is under guardianship, it's not difficult to transfer that guardianship, and all of the assumptions of total incapacity that go with it, to someone else. While you are alive, you may respect your family member and encourage her to make her own decisions; you may only act on the guardianship in rare, specific circumstances. After you are dead, though, the guardian who takes over for you may not be so enlightened. What happened to Jenny Hatch may then happen to your child.

There are so-called “experts” who widely promote how easy it is for parents to get guardianship over their children, and how it's an important safety measure, “just in case.” Most of these people are promoting 17A guardianship; the Article 81 process, which requires proof of incapacity and a court appearance, and respects people's rights, is not “easy.” Some of these “experts” are just preying on family members to make money. 17A guardianship is not a good idea, but you don't need to pay a lawyer or other “expert” to get one for you, which is what these “helpful” people are actually after. It requires almost no work but it brings in a nice fee.

Ms. Hatch took her mother to court to get the guardianship lifted, and she eventually won. She did it by demonstrating that she could make sound decisions about herself and her life, with some help, using a process called “supported decision making.” Among other things, experts testifying on her behalf showed that her low IQ score didn't have much relationship to what she was able to do. She learns more slowly than other people, but what she learns she retains. When she doesn't understand something, she asks questions until she does understand. She knows when she is “in over her head” and gets help when she needs it. She is interested in staying healthy and safe and she has friends she can trust. In other words, she's just like you and me.

What is “Supported Decision Making”?

It is the way we all make decisions about things that we are not experts in.

For example, if you don't know much about cars, but something goes wrong with your car, how do you decide what to do about it? You may research the issue online. You may take it to your brother the shade-tree mechanic and have him look at it and tell you what he thinks. You may take it to a repair shop and have a professional technician look it over and give you a simple, not a technical, explanation of what's wrong and what your options are. You may do some or all of these things and then talk it over with people you know and trust. Then you will mull over this information and decide what to do about your car.

If you have a health issue, you will probably follow the same process, including seeing one or more doctors and then thinking over everything you've learned before deciding what to do.

In other words, we get help from sources we know and trust. People with intellectual or cognitive disabilities can do this too. And regardless of how significant their disabilities are, if they have shown that they can identify people they know and trust, and ask questions about things they don't understand, then they can get as good results from the process as anyone else.

But what if they don't have anyone they know or trust to ask? This is sometimes the concern of parents who want to ensure that their children will be safe after they are gone. Ask yourself, who do I know who doesn't live in an institution or other segregated setting who doesn't have at least some people they know and trust to help them with things? The answer is likely to be that you don't know anyone in that kind of situation. So there's no reason to believe that your child with a disability will be any different, as long as, while you are still here, you make efforts to help her form relationships with people who won't benefit from her need for support.

If your family member is going to get support services from the state, then, under the various new laws and regulations that are coming into effect, she will have those services set up through a “person centered planning process.” She will be at the center of that process. She will choose people she knows and trusts to participate in the process, and those other people will be required to help her understand her options and decide what will be in the plan.

People with intellectual disabilities learn slowly, but there is good evidence to show that when they learn something, it stays learned. They can improve their skills over time, skills

in deciding who to trust, in asking questions about things they don't understand, and in making sound decisions that balance their interests and goals with their needs. So even people who, right now, might be too friendly with the wrong people, or who don't "look before they leap," can, over time, get better at those things. The best way to help them get better is to expose them, with support and supervision, to a wide variety of real-world people and situations that require decision-making, and then help them work through the process of making those decisions.

There certainly are people who can't make informed decisions in a reliable way. But let's first consider what that really means.

It doesn't just mean they are "non-verbal." People who are non-verbal can sometimes use sign language or other communication systems to indicate what they know and think, or at least how they feel, about various things.

If the person has "behavior problems" that get in the way of decision-making, it's vital to understand that behavior problems don't "just happen," and disabilities don't "cause" them. Unpleasant behaviors in people with disabilities come from the same sources as they do in people who don't have disabilities. When people have difficulty understanding their physical or emotional feelings, and/or have difficulty expressing themselves, then any event that the person experiences as scary, painful, or irritating may result in him doing something that we would rather he did not do. So the first thing to do about these behaviors is try to find out what triggered them. The person may be sick, or frightened, or sad. He may have been expected to deal with people or situations that he really doesn't like, or someone may have inadvertently, or even deliberately, hurt or irritated him. The fact that his ability to cope with this kind of thing isn't as strong as that of many nondisabled people doesn't mean he didn't have a legitimate grievance.

Considering how hard it is for people with certain types of disabilities to stay calm and pleasant under stress, and how much effort it takes to help them improve their coping abilities, we must always consider whether it's really critically important that they continue to be exposed to specific people or situations that cause stress. We don't try to teach people with poor fine-motor skills to tie shoes; we give them slip-ons. We can take the same approach to many behavioral issues.

We should be suspicious when different people who spend time with a person report very

different descriptions of the person's behavior. Time and again, we at STIC hear from program or residential staff that so-and-so is "violent" or "dangerous" or has some other behavioral issue that we never can seem to observe ourselves. Putting in the time it takes to genuinely listen to a person, respecting the person's legitimate feelings and wishes, and working to set up situations that are "good fits" for them, go a very long way toward helping the person to behave better. This establishes trust, and makes the person more receptive to thinking about, and discussing, decisions instead of just acting without considering the consequences.

What about folks who tend to agree with whomever they're talking to? For them, a more formal supported decision-making process may be needed. Everybody involved in helping the person would get some training to learn how to avoid asking leading questions or expressing their own opinions and letting the person just agree with them. This can be very effective.

We also have to point out that adults who are capable of making good decisions might make ones that you don't agree with. It really goes beyond the pale of decent behavior to strip an adult of his rights merely so you can make sure he doesn't do something that makes you squeamish or doesn't match your personal beliefs.

But don't just take our word for it. Check out the facts. There is an overwhelming body of sound scientific evidence that depriving people of the right to self-determination is harmful to them, and that supporting people in exercising self-determination is beneficial. For example, according to the National Resource Center for Supported Decision Making:

When denied self-determination, people "feel helpless, hopeless, and self-critical" (Deci, 1975, p. 208), and they experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," decreasing their ability to function (Winick, 1995, p. 21).

People under guardianship can experience a "significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010, p. 354).

People with developmental disabilities with "greater self determination" are healthier, more independent, more well-adjusted, and better able to recognize and resist abuse (Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

Older adults with more self-determination have improved psychological health including better adjustment to increased care needs (O'Connor & Vallerand, 1994).

People who exercise greater self-determination have a better quality of life, more independence, and more community integration (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003).

Women with intellectual disabilities exercising more self-determination are less likely to be abused (Khemka, Hickson, and Reynolds, 2005).

Is Guardianship Ever Appropriate?

Yes, it is, but not as often as you may think.

First, the "just in case something happens" argument for guardianship is pretty much bogus. Ask yourself, just in case what?

If it's your own incapacity or death that you're concerned about, then you being the guardian won't help at all. But once a person has had guardianship imposed on them, it's easy to transfer that guardianship to someone who is not as nice as you are. You may think, for example, that one of your other children will take over for you after your death, but it may be that the child you expected to do that is himself incapacitated or deceased, or has other plans that s/he hasn't told you about. It's not pleasant to think about, but it happens. It's bad enough when that happens to someone who truly lacks capacity to make decisions. It's a lot worse when it happens to somebody who is functionally independent and who only has a guardian "just in case."

There are other, less damaging, ways to prepare for emergencies. Health care proxies can be used to designate someone else, or more than one person, to make health care decisions on someone's behalf. A person with a disability can discuss this with people she trusts and explain what she would like to have done in different cases, such as being near death from a terminal illness, as opposed to being temporarily unconscious at the time when consent for a procedure must be given, and she can designate who she wants to carry out her wishes.

Durable power of attorney is another option. This can be useful for handling complex situations. For example, your child may be able to understand, in simple terms, the uses of a cell phone and compare various phones and plans

and decide which one she wants. She may also understand the fact that a contract is required for phone service, and she may be able to pay for it. However, if there's a mistake in the billing she may not be able to resolve it herself. In a lot of cases, though, if you call the customer service number on behalf of someone else they won't talk to you unless you have their power of attorney. If someone grants you power of attorney, it doesn't mean she loses the ability to do anything herself, it just means that you now can also act on her behalf when needed. We do this for my elderly mother-in-law, for example.

Sometimes a **limited** guardianship may actually be necessary to maximize the independence of a person. For example, your child may be able to live in his own apartment and keep it clean and get to and from work every day. However, no matter how much training he gets, he just can't seem to stop giving his money away to strangers. In that case, you might be able to maintain him in his home and job but not let him have a debit or credit card or carry large amounts of cash. He might agree to this arrangement willingly. If he doesn't, then something certainly must be done, but just because you don't agree on this point isn't a reason to strip him of all of his rights. You have the option of using an Article 81 procedure to obtain limited guardianship over his finances. He may want to keep his home and job and, in order to do so, he may accept a specific court order to let someone else control

his money, accompany him on shopping trips, and dole out small amounts cash that he can afford to lose.

Where Can I Learn More?

If you're interested in supported decision making and alternatives to guardianship, the best place to start is the National Resource Center for Supported Decision Making, here: <http://supporteddecisionmaking.org/>

For specific help, feel free to contact your service coordinator at STIC. If you don't have a STIC service coordinator and you're on the OPWDD waiver, did you know you can get one? Call us at (607) 724-2111 (voice/TTY) to find out more.

How to Manage Anger

by Anonymous

I always thought that it was better to let my anger out, but I was wrong. Venting it is not a good choice, and often makes things worse. People may be afraid of you or lose respect if you can't control yourself or handle situations without anger.

If you treat people with respect, you will be respected in return. There will always be situations that you can't control, but you can control your anger without calling names, hitting, or doing other stupid things before thinking first. Even if someone pushes your buttons, you always have a choice about how to react to the situation at hand.

Anger is normal, and unfortunately people will let it out at times. Anger management is about how to be aware of feelings and needs and learning healthier ways to manage being upset. So learning to express it in better ways is best.

Anger damages your health. It raises cholesterol levels, weakens your immune system, gives you high blood pressure, clouds your thinking, increases stress, depression, and mental health issues.

With anger comes a bad reputation that

follows you wherever you go in life. It will destroy your family, children, friendships, and people will always be afraid to say anything to you because it may set you off. Children are especially hurt by your anger, and it leaves lifelong scars.

Anger stems from childhood, what you have learned from your parents. In order to get your needs met and express your anger in appropriate ways, you need to get in touch with your feelings. Are you embarrassed, insecure, hurt? Did you grow up in a family where all you knew was anger and screaming and fighting all the time? Do you believe that it's your way or the highway; are you controlling? Without the know-how to recognize, manage, and deal with emotions, you're gonna spin out of control. Keeping my anger in check is no easy task.

Dealing with anger in a positive way is better for us all. Think before you speak. Once you've calmed down express yourself in a positive way. State your needs without hurting others or trying to control them. Go for a walk to calm down; exercise can reduce stress. Instead of focusing on what made you mad, find a way to resolve the problem. Does your kid's messy room piss you off? Then shut the door. Is dinner not ready when you would like it to be? Set a time for later then, or fix your own—your arm's not broken. Treat people like you want to be treated.

Set boundaries, like what you will and will not stand for. Wait for when you both are calmed down to talk, and remove yourself from the situation if the other person is not calm.

Consider going to counseling or therapy, even if the other person won't go. Stand up for yourself, put your safety first, trust your instincts. If you feel unsafe or threatened, get away from the person and go somewhere safe.

Learn to recognize the signs. How does anger feel in your body? Do you have knots in your stomach, tightness in your jaw, headaches, fast breathing, pounding heart? If you do, chances are anger's coming on. Focus on the physical, take deep breaths, exercise, stretch, and massage areas of tension in your body.

Avoid places, people, situations that can bring on anger. If you want a positive life, swap negative people, places, for positive people and nice places. And most of all do not hurt yourself or someone else. Get medical help; it's out there. Don't be afraid, it happens to everyone. Get help before it's too late for you or a loved one.



COMMUNITY PROGRAMS

Southern Tier Mobile Integration Team

The Mobile Intervention Team (MIT) is a long-awaited, much anticipated support service for people facing mental health crises, now available in Broome, Chenango, and Tioga Counties. The MIT will serve, among others, people who have dual mental health and developmental disabilities. They strive to provide face-to-face support within a one-hour time frame. From the program's brochure:

Individuals participating in services provided by the Southern Tier MIT can expect:

- Support in their efforts to stay in their home and community
- Immediate access to treatment services designed to stabilize crisis situations
- Enhanced skills and knowledge to reduce environmental and social stressors
- Connection to programs and services to reduce demand on emergency departments and inpatient hospital services

The Southern Tier MIT provides an array of services delivered by a multidisciplinary team of professionals and paraprofessionals. These services may include, but are not limited to:

- Brief Therapeutic Support
- Skill Building
- Crisis Assessment and Intervention
- Consultation and Information
- Peer Support Groups and Skills Training
- Family and Caregiver Support and Skills Building
- Behavioral Support and Consultation
- In-home and Community Based Respite

Services provided by the Southern Tier MIT can be found by calling: 1 (844) HELPMIT (1 (844) 435-7648).

For 24/7 crisis services, please call your county crisis line:

Broome: (607) 762-2302

Chenango: (877) 369-6699

Tioga : (607) 687-4000, M-F 9 am – 5 pm; (607) 687-1010, all other times

If you are in need of immediate medical assistance, please dial 911.

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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.

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