

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

# AccessAbility

Summer 2015  
Number 119

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By Maria Dibble

In 1983, when I assumed the leadership of Southern Tier Independence Center, the world was a much different place than it is today.

Three out of four corners of an intersection didn't have a curb cut, making the one that existed virtually useless. Most people didn't know what a sign language interpreter was, nor why one would be needed. Handicapped parking spaces were rare, and when they existed were poorly designed. Doorways were too narrow to accommodate a wheelchair, and were often too heavy for a person with a disability to open. Seldom did you see a person with a disability shopping or moving down the sidewalk, and never did you see a transit bus carrying a wheelchair user.

It was an era when most believed that people with disabilities belonged in institutions and sheltered workshops, where they could be "safe", "cared for" and "protected". The phrase "out of sight, out of mind" was the accepted policy regarding people with disabilities.

Skip ahead 5 years to March 1988, when a watershed moment marked the beginning of a new movement for people with disabilities everywhere. Gallaudet University, in Washington, DC, which served primarily deaf and

hard-of-hearing students, appointed a hearing president. The school erupted in protest, followed by supporting demonstrations around the country, including at STIC. Students demanded that their president be deaf like themselves. The university refused for a while, but facing massive pressure, finally appointed a deaf president: I. King Jordan.

Around the same time, behind the closed doors of Congress, people with disabilities were fighting for legislation that would empower them with the same civil rights as other groups. It was called the Americans with Disabilities Act (ADA), and it was signed into law two and a half years later by President George H.W. Bush, on July 26, 1990.

The law raised hopes for the dawning of a new age for people with disabilities, opening up opportunities never before imagined. It addressed employment, state and local government, public accommodations, telecommunication access, and more. It was not a "gimme" bill, it was a law guaranteeing civil rights, the same as those enjoyed by all other Americans. It didn't offer "special treatment"; it called for equal access.

Has it lived up to the promise? In many ways it has. There are curb cuts on most corners

now, ramps leading into stores and apartments, power doors that can be opened by the push of a button, lifts on buses that can accommodate wheelchairs, sign language interpreters at many public meetings, some captioned movies, even some described for those who are blind or visually impaired. Today it is commonplace to see people with disabilities riding buses, wheeling down the street, shopping or attending concerts and, in general, participating in all that the community has to offer.

This is great, but we still have a good way to go before people with disabilities are on a level playing field with their nondisabled friends and neighbors.

I can list dozens of examples of disability-specific issues that still need to be addressed, but there is one overarching area that still lags far behind, and which cannot be fixed by legislation: public attitudes and beliefs about disabilities and the people who have them.

Mental health disabilities in particular still carry a strong stigma, and our society seems to be unable to see them for what they are, instead either turning away and ignoring 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.

homeless denizens of riverbanks and underpasses, or confronting them with police power and imprisoning, injuring, or killing them. But even when public perceptions of citizens with disabilities aren't so dark, they are still stifling and demeaning, and just as wrong.

In his 1993 history of the disability rights movement, *No Pity*, Joseph Shapiro suggested that the ADA was passed largely out of a reflexive good-hearted desire to do something "nice" for "the disabled", without a real understanding of what we meant by disability rights or a belief that we could enforce them. He wondered what would happen when authority figures realized what they had actually done.

Well, the attitudes of decision-makers haven't changed much since 1993. They still don't understand what we meant, and they still don't think we can do much about it. The medical and education professions remain rife with the view that we are helpless, needing to be cared for and protected, and less competent than nondisabled people with similar qualities and qualifications. These professionals still transmit these beliefs to worried family members of children with disabilities. And, of course, there is still much money to be made by restricting people with disabilities behind closed doors, and those who do that are skilled at protecting their interests while discounting ours.

Together, these attitudes still keep hundreds of thousands, perhaps millions, of people with disabilities in institutions large and small, most of them deprived of basic civil rights like freedom to choose their friends and associates, to travel, to decide when and what to eat, to make a decent living and spend the proceeds as they wish. Neglect of personal hygiene needs, and use of drugs to keep people quiet and compliant, are routine in nursing facilities, where many languish forgotten and without hope. People in all types of group living situations, of all sizes, lack the basic right to control their own homes. They sometimes face verbal, physical, or sexual abuse that makes our skin crawl when we hear about it, but we quickly manage to brush it under the rug and forget it. It's certainly not a pleasant topic for mixed company, but it goes deeper than that. We all know someone who is in one of those places, and we need to make peace with that. And at least subconsciously, we know that as we age, we may end up there too. Most of us can't face that truth. So we shut down, and let indifference, and, often, denial, take over.

In 2015, our NYS legislature is arguing over a bill to create a new kind of licensed medical caregiver—"Advanced Home Health Aides"—that would help get people out of nursing homes and allow them to control their

own care. Legislators who oppose the bill are repeating the age-old mantra, "We need to protect these people and make sure they are safe." These politicians don't say that because they actually believe it. They know that a few of us are already safe in our own homes using the limited homecare services that some, but not all, of us can get. They oppose the bill because the people who pay for their campaigns oppose it. They trot out the "safety" thing because they know that most of the general public will accept it without question.

Most disturbing of all, however, is that many people with disabilities buy into this belief system. They view themselves as helpless, unable to work, needing to be "taken care of" and needing to stay in sheltered workshops, nursing homes and group homes. They have, seemingly, almost willingly given up their power! But that willingness is an illusion. It begins, for many, with the need to "get along by going along" among people whose very lives depend on pleasing, and not angering, their caregivers, and over time it hardens into acceptance, because people with disabilities have to make peace with themselves, too.

The ADA has changed many things, but it largely has not changed attitudes. So if we can't legislate a fix, then what can we do about this?

We can go back to basics and do old-fashioned "consciousness raising", something that was very effective for the feminists of the 1970s. There were some sexist husbands and fathers who were able to keep "their womenfolk" away from the influence of those who wanted to tell them about their rights. But that was nothing compared to the barriers society sets before those who would like to inform people with disabilities that they don't have to do what their families or paid caretakers tell them to do, that they can expect more of themselves, and achieve more, than the gray, closeted existence that is the best, or perhaps just most convenient, life that those people can imagine for "their special folk".

We can also empower people with disabilities by serving as role models for what is possible and urging them to take their rightful place in society. Many of those with disabilities who have achieved the most choose not to get involved. We know that being reminded of the horrors you've escaped, and the risk of being associated with people who are widely discounted and demeaned, can seem like too much to bear. But you are the ones we need the most. Please help us stand up for the rights of those trapped in artificial lives, and demand their release.

No one in power willingly gives up that power, but we can take it from them, if we use all of the tools available to us. When nondisabled people see us wielding power, that is when they will begin to believe we can do it, and not before.

Help finish what those deaf students started! Make your voice be heard. When STIC tells

you about people whose rights are being violated, don't stay silent. Write a letter, make a phone call, pay a visit to a legislator. If enough of us do it, we can make change happen. Enough people wanted a deaf president and they got one. People demanded passage of the ADA, and we got it! Much more is possible if more than a few of us shout from the pulpits,

in the schoolyards, on the streets, and in the halls of government.

45 years ago, funky old George Clinton said, "Free your mind, and your ass will follow." 25 years after the signing of the ADA, we still need you to free your mind, and join us to Free Our People!

# News & Analysis

## Good News Budget

Disability rights advocates fared pretty well on the money side of the annual state budget process this year (see page 5 for non-money issues).

Probably the most important result is yet another year of big increases for housing for people with disabilities.

But before we praise Caesar for this, we need to bury him. NY is still too focused on "supportive housing," that is, housing that comes "bundled" with support services. These programs can be good for some people with significant cognitive or psychiatric disabilities that make it hard for them to manage their own support services. However, such people are a relatively small percentage of people with disabilities who need a place to live. Tens of thousands of people are in nursing facilities primarily because they just need accessible housing and can't get it.

We know it sounds too simple to be true. But it is. People don't always go to nursing facilities because they need supervision or special medical care. They go because they have a physical disability such as extremely severe arthritis, or multiple sclerosis, that has progressed to the point of requiring a wheelchair. Because their homes are inaccessible, they can no longer do critical life-support tasks like using the toilet, taking a shower, cooking a meal, or going shopping or to medical appointments. They have low incomes because they're retired or disability has cost them their jobs, so they can't afford to modify their homes. Now their health is in danger because they can't take care of themselves—and that makes them eligible for nursing facility placement.

These people could care for themselves *with little or no help* in an accessible home or apartment. Yes, it's an amazing medical miracle! Accessible living CURES nursing-home-itis!

A level entrance or ramp cures the shopping symptom. An accessible bathroom cures the toileting and showering symptoms. Accessible kitchens cure cooking and eating symptoms. Many people who are said to "need a nursing home" don't. They don't even need the "supported" part of "supported" housing. They just need accessible housing.

There's no doubt that as state-operated or -funded developmental centers, smaller Intermediate Care Facilities (ICFs), and adult "homes" are closed to comply with federal CMS and court orders, there are many who need housing with some supports. But NY's alleged *Olmstead* "plan" calls for fewer nursing facility residents too, and officials have at least paid lip service to cutting admissions to those places. Advocates keep asking the state to take a more balanced approach to funding housing. Accessible housing without supports only requires the initial construction cost; it's much cheaper than supportive housing with ongoing service costs, so NY could get a big bang for relatively few bucks spent on accessible housing. But the state keeps ignoring us. This year, NY had a golden opportunity to do the right thing. The JP Morgan settlement provided \$5 billion, a one-time lump sum that won't be around to pay for recurring costs such as support services, with no Medicaid restriction on using the funds for straight housing. Advocates asked for less than 10% of this money to be invested in accessible housing. Our elected leaders refused.

There's a pattern emerging from these kinds of decisions; see page 11.

That being said, over the past few years NY has made an unprecedented effort to expand housing for people with some types of disabilities, and this year that effort got bigger. The Medicaid Redesign Team's supportive housing initiative got \$354 million over 2 years, a \$32 million increase over last year's allocation. There's also \$74.5 million for another

statewide supportive housing project, and \$10 million a year for 5 years to help providers of "scatter-site" supportive housing (the best kind, in ordinary apartments not grouped together in the same building) cope with cost increases in high-rent areas like New York City.

The Access to Home program provides money to help people with disabilities make their homes accessible so they can stay in them. It's only for people who can't get that kind of help from other sources. It has been funded at \$1 million for several years, a completely inadequate figure. This year the program for ordinary people is continued at \$1 million, but there's another \$20 million for disabled veterans. Some veterans do need that support, but disabled veterans are a relatively small percentage of New Yorkers with disabilities facing institutionalization due to inaccessible homes. This is another unbalanced response.

The Consumer Directed Personal Assistance (CDPA) program got some good news this year.

The budget sets aside \$20 million for CDPA programs to pay overtime wages if needed. We'll need it if the feds get their way on new rules for homecare workers. Their proposal is simple and fair: if you're a homecare worker and work more than 40 hours a week, you should get time-and-a-half for the hours over 40, like other workers. But for that to happen, NY's Medicaid rates for CDPA must be increased. Right now CDPA fiscal intermediaries (FIs) like STIC, which handle the paperwork, bill for services, and pay CDPA attendants, barely get enough money for straight wages plus administrative costs. This is a dicey problem. CDPA participants prefer to work with people they know and trust, and since FIs aren't allowed to recruit workers, most have a pretty small pool of people to hire from. They may not be able to find enough workers to keep them all at 40 hours. But some advocates have argued that, therefore, it's okay for CDPA workers to be abused and not paid over-

time. These advocates got the new rules held up in federal court, but the feds have appealed and will likely win. In that case, the extra \$20 million will come in handy.

But that's not all. The budget contains language—admittedly vague—that requires NY to see that rates paid to managed-care organizations that provide CDPA services are “adequate” to ensure provision of services. This is similar to language in federal Medicaid law that was weakened recently by the US Supreme Court (see page 10), so this is welcome news.

As predicted, the annual red herrings tossed into the net by Governor Cuomo—ending “prescriber prevails” in Medicaid drug coverage, and ending “spousal refusal” for people seeking Medicaid long-term care in community settings—were rejected.

On the mental health front, there is a modest \$1.5 million increase for Crisis Interven-

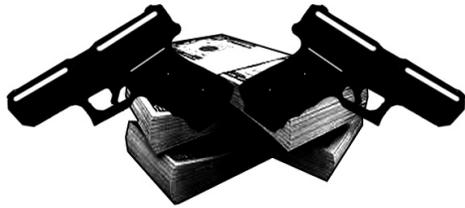
tion Teams, including funds to train police in “mental health first aid”, and for programs that divert people with mental health disabilities from the criminal justice system and into treatment. There is also \$22 million for pre-release planning for, and provision of, supported housing and community services for people with mental illness being discharged from state prisons. Some state psychiatric centers will be downsized (none in our region), with some of the money “reinvested” in “community-based services.” This goes to county mental health departments, which can use it for things they pick from the “wish list” developed by the “Centers for Excellence” so-called “planning process,” without public input. So the impact on real needs is unknown.

OPWDD was a big winner. They got a 3.2% overall budget increase (remember, NY is supposed to have a 2% cap on total Medicaid growth). Of this, the agency says, they'll use \$42 million for services for people leaving developmental centers and ICFs, and \$4 mil-

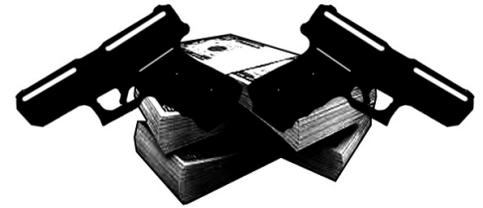
lion “specifically targeted to helping individuals living at home with caregivers who can no longer support them and need residential supports.” That group has been lobbying for more group “homes.” \$4 million won't go very far in that direction, even if most of them have four or fewer beds as required by the federal Money Follows the Person program. So maybe OPWDD has heard our advice that people with disabilities can't be segregated in congregate facilities merely because they need housing.

Also, people who work at not-for-profit agencies that get OPWDD or OMH money to provide community services will get 2% cost-of-living increases this year.

And, last and almost least, Centers for Independent Living like STIC finally, after 11 years of level funding, got a modest \$1 million increase in their general operating contracts. Divided equally, each center gets a bit less than \$25,000.



## Lawyers, Guns and Money



NY's Office of People with Developmental Disabilities (OPWDD) has faced bad publicity recently. The agency settled a lawsuit with the family of a 22-year-old man who died while a resident of the recently closed O.D. Heck Developmental Center. The man, “K.C.,” was forced by staff to stay on a rubber floor mat while they watched TV. If he moved off the mat, they beat him with a stick or stepped on his fingers. If he spit at workers, his mouth was stuffed with rags or socks. Staff called him “The Thing,” the “Sparrow,” or the “Walking Plague.” However, when his family visited, K.C. got to sit on a couch and workers treated him like a human being. On February 28, 2011, K.C. was taken to the emergency room. He was malnourished and had pneumonia. He died a month later.

The suit alleged that none of the five OPWDD employees directly involved were disciplined for their abusive behavior. According to the Albany *Times-Union*, “Sworn depositions in the case indicate that the OPWDD employees named in the suit remained on the job for at least several years after K.C.'s death.” In April 2015, the paper reported that three of the workers are *still* OPWDD employees; two are

working directly with people with disabilities, and the third was on a “leave of absence.” One worker was fired in 2013; another kept her job until earlier this year.

A witness to the abuse, who had only recently been hired at the time, said in a sworn deposition, “I was terrified to come forward and say anything. I was told by [the worker now on ‘leave of absence’] on one of my first days that I would do fine at O.D. Heck as an employee if I kept my eyes open and mouth shut.”

OPWDD paid \$2.25 million to K.C.'s family; in return no one had to admit wrongdoing. The agency, which claims to be changing its “organizational culture,” and that it “considers any abuse of an individual in its care completely unacceptable,” refused to explain why it agreed to this and why three of the abusers are still on its payroll. No criminal charges were filed, but OPWDD said the state's Justice Center for People with Special Needs was investigating.

You may say this is old news (the incident appeared in abuse scandal media reports some years ago). But in late May another settlement was announced: \$2.15 million

for the family of Rasheen Rose, who was crushed to death by staff at Bernard Fineson Developmental Center in Queens in 2012. The family's attorney said most of the 13 employees involved still work for OPWDD. In early April the Justice Center said it was prosecuting five employees of OPWDD's Sunmount Developmental Center for beating an 18-year-old resident and trying to cover it up. Later that same month the Justice Center announced the arrest of three more Sunmount workers for attacking a 35-year-old resident. According to Susan Arbetter, a public radio reporter, 12 Sunmount employees have been arrested since January for abusing residents or other crimes. A North Country OPWDD group home worker was arrested in November 2014 for 3 misdemeanor charges involving failure to give medications to a resident and faking the paperwork on it. The employee still worked in an OPWDD group home at the time of his arrest. The month before that, it was reported that the Justice Center was investigating a Bronx OPWDD group home for abuse of residents by staff, including food deprivation, beatings, and at least one sexual assault. At least 17 employees of the facility were placed on “administrative leave.”

A spokesman for the Civil Service Employees Association, the union that represents most OPWDD direct-service workers, called the incidents “mistakes.” He said, “We’ve been very clear over the years that the likelihood of mistakes being made are increased when people are working on mandated overtime. It’s not healthy when people work under those conditions.” Beating people with sticks, stepping on their hands, denying food, and sexually assaulting them are “mistakes,” according to the union, that apparently can only be corrected by hiring more employees who will pay union dues; otherwise, things might get “unhealthy.” In other settings—the NYC garment district, for example—this would be considered extortion.

But union tactics to deflect this kind of bad publicity have not been limited to claims that vicious abuse is a kind of “mistake.”

In February, someone organized a media event in Norwich to attack OPWDD for allowing residents of its Valley Ridge Center for Intensive Treatment to participate in community events.

It seems that somebody told some community leaders in 2002, when the facility opened, that it would only contain people guilty of criminal acts who would never be let out. The facility was heavily promoted at the time by Senator Tom Libous as bringing jobs to Chenango County. However, the same official press release from April 3, 2002, that quoted Libous as saying, “I’m excited to have more than 200 new jobs added to our local economy,” also had the Senator describing the program as “more *rehabilitative* services for developmentally disabled individuals who need intensive *treatment*” (emphasis added). And OPWDD Commissioner Tom Maul said, “New York State will enable these individuals to become productive citizens by increasing their understanding of their offending behaviors, developing their sense of community, bolstering their educational and vocational skills and ultimately maximizing their potential for success.”

In fact, OPWDD has always been required to enable people with the most significant disabilities to participate in community life to the extent they are capable, with support and supervision as necessary. The Norwich *Sun* article said, “the rules for mental health treatment have since changed,” but that is not correct. The rules have been the same since at least 1988; what has changed is that NY State was busted by the federal government for violating them. OPWDD has never been legally authorized to operate a prison.

We don’t know who generated this media panic, but CSEA has openly urged OPWDD

workers to publicly claim that the people they are paid to serve are dangerous criminals who will threaten the community unless they continue to get paid to serve them.

One useful result came from this though: OPWDD finally publicly admitted that most of the people in its supposedly criminals-only IT units are not criminals at all, and only a tiny number are the much-feared “sex offenders.” Regional Director Mark Lankes revealed that out of 45 people in Valley Ridge, only 19 are there involuntarily, and only 7 have been charged with a crime and deemed incompetent to stand trial. Only 6 are registered sex offenders.

Meanwhile, in Ithaca, local politicians learned that three registered sex offenders would be living in a new group home that OPWDD was developing there. Two were “level 3” offenders, the most serious category, but one was “level 1.” The politicians claimed that “nobody notified” them about this, meaning, we guess, no official formally told them directly. There was a public meeting at which Broome Developmental Services officials tried to explain the plan. At the meeting, some people handed out applications for gun permits and told people they’d better prepare to defend themselves and their families.

People seem to be misinformed about the NY sex offender registration law. Here’s how it works: people convicted, in court (not just accused), of sex offenses are judged, as individuals, by an impartial panel of experts and assigned a level based on the seriousness of the offense and their chances of re-offending. It is a myth, spread by TV crime shows, that all sex offenders are likely to re-offend; they are not. Information about all levels goes to local law enforcement agencies. Information about level 2 and 3 offenders is also placed on a public registry, where anyone who can read, even politicians, can find it. But in all cases, it is up to the local law enforcement agency to decide whether to officially inform anyone else, and how.

Assuming politicians aren’t lying when they say “nobody” officially informed them about these cases, then, if such a politician reports the release of a level 1 offender from an OPWDD secure facility, that can only mean that someone with access to the records who doesn’t work in law enforcement told him about it. That was most likely a state employee union member, and the release of information was a criminal act.

“Level 1” offenders are people who have committed minor, non-violent, technically illegal acts such as being a teenager and having con-

sensual sex with another teenager, or being a person with a developmental disability and having consensual sex with another person with a disability who lacks formal “capacity to consent.” No law enforcement experts consider them to be a threat to the community. Level 3 offenders can be a different story. But all of the individuals involved were slated to live in a 24/7 supervised home and none of them would have been allowed to get into a situation where they could re-offend.

This is a good law. Local law enforcement agencies have discretion on whom to inform because they are in the best position to know how to keep people safe. They must decide whether the community at large is more in danger from a handful of individuals who, due to their disabilities, have difficulty learning how to handle their sexuality, or from gun-toting vigilantes, some of whom may be union thugs trying to show just how “unhealthy” things can get.

## More Good News

People with disabilities got a few more big wins out of the budget process this year.

The best-sounding one was the allocation of all the bonus money that NY gets from the Community First Choice (CFC) Medicaid option to carry out the state’s *Olmstead* “plan.”

CFC allows people with disabilities to get a range of person-centered homecare-like supports. The program can serve people not eligible for the various Medicaid waivers that offer similar services, and who can’t use CDPA because they aren’t “self-directing” and don’t have anyone to serve as their “designated representative.” Eligibility for the program is based on a universal functional assessment of need, rather than age or diagnosis.

The feds will give NY a 6% higher matching Medicaid rate for CFC users than it provides for other Medicaid programs. That could be tens of millions of dollars annually if CFC is fully used. Putting that money into things that really help people with disabilities live in the community, such as accessible housing, increased public transportation, or more supported employment, would have a big effect. But the *Olmstead* “plan” contains other less useful ideas, like “studies” to coordinate inadequate amounts of public transportation, and vague “linkages” of disability employment services to NY’s Department of Labor, whose track record on helping *anyone*, let alone peo-

ple with disabilities, get jobs is poor. The budget doesn't say where the money will go.

But there may not be any money at all. The budget process ended without a Nurse Practice Act (NPA) amendment. For CFC to be usable by anyone who can't already get homecare, NY must amend its NPA to create a new type of homecare worker. The commission to determine duties and requirements for so-called Advanced Home Health Aides (AHHAs) completed its task. It essentially defined AHHAs as a new kind of licensed practical nurse (LPN), subject to similar training and licensure requirements. AHHAs won't be allowed to do anything that unlicensed, not-formally-trained CDPA attendants don't already do safely and well. This time, Assembly member Glick supported a bill, which passed in her house. The holdup was Senator LaValle, who took up the chant for her, claiming that CFC will be unsafe for people with disabilities because they won't have real nurses. Legislators, seemingly without a fact-based rationale, have played "good cop/bad cop" on this for 3 years. For an explanation that makes sense, see page 11.

The win with the most real systems change potential was adoption of Cuomo's plan for an Office of Community Living. The OCL would combine the work of NY's Office for Aging with that of the Independent Living Administrative Unit now under ACCES-VR, in a new state agency. This agency would oversee a "No Wrong Door" system of local single-entry points for long-term care services that would give uniform unbiased information to people seeking help, regardless of age or diagnosis. Later, the agency may take in other disability support programs such as Access to Home and the Technology Related Assistance for Individuals with Disabilities (TRAID) centers. Even further down the road, OCL could become the locus for Cuomo's Spending and Government Efficiency (SAGE) Commission's suggestions for consolidating state disability service agencies. We might eventually get everything under one roof, with one set of rules.

The first step is modest. A committee of stakeholders from the aging and disability communities will hold public hearings and collect input on how to design the OCL. This committee will make recommendations to the governor by year's end, and perhaps we'll see legislation to create the new agency next spring. We'll keep our fingers crossed.

Finally, the item with the most immediate positive impact was the legislature's rejection of a plan to let school districts get waivers to avoid complying with some NY special education rules.

## Feds Tighten the Screws on Exploitation

In April, the federal Department of Education proposed new regulations for employment programs for people with disabilities. The rules are mandated by the latest version of the federal Rehabilitation Act, the Workforce Innovation and Opportunity Act. When adopted, they will spell the beginning of the end of sheltered workshops and subminimum wages. They include:

- States and schools could no longer contract with organizations that pay less than minimum wage. That will eliminate a major source of funding for many workshops.
- VR agencies would have to spend more of their funds on supported employment for people with the most significant disabilities (see page 9), and fund those services for up to four years.
- Unpaid work would no longer be an acceptable employment "outcome" for VR programs.
- People with disabilities age 24 and younger would not be allowed to work for subminimum wages unless they have been through a real school-to-work transition program where they were provided "meaningful opportunities" to get a real, integrated job at competitive wages.
- Anyone working for less than minimum wage will have to get annual career counseling, where they will be told that other, better, options are available and how to access them.

## ADAPT Storms Washington

National disability rights advocates were in the nation's capital in April to promote new legislation that could finally bring critical mass to the deinstitutionalization movement.

The idea is to close the loophole for government and private insurance programs that was built into the Americans with Disabilities Act (ADA) 25 years ago. The ADA says, "nothing in this act shall be construed" to require insurance companies to change their policies. Federal courts have ruled that the ADA doesn't require Medicaid or Medicare to provide specific types of services to people with disabilities, because it does not touch on "quality of care" issues.

ADAPT is proposing the Community Integration Act (CIA), which would add a new

title to the ADA that specifically requires insurance programs that pay for long-term care to adequately cover integrated home and community supports. States, in particular, could not limit access to integrated supports by capping "slots" or using waiting lists, and both states and private insurers would be prohibited from paying rates that are too low to make the services widely available. States would also have to "develop plans to increase the availability of affordable and accessible private and public housing for individuals with disabilities."

There are lots of good ideas in this bill. For example, the prohibition on inadequate rates neatly gets around the Supreme Court's recent decision limiting enforcement of a similar provision in Medicaid law (see page 10), by explicitly making it a civil rights issue and providing suits for damages as an enforcement mechanism.

Introducing quality of care into the ADA could also head off segregationists who have been trying to twist the Supreme Court's *Olmstead* decision's statement that the ADA doesn't require people to accept integration to mean that the ADA created a "right to be segregated." If Congress amends the ADA to address quality of care, and the only way it does so is to require states to ensure that government-funded insurance must offer and fully fund adequate personalized integrated supports of all kinds, then the Supremes would have to conclude that since Congress didn't include a similar mandate for segregated services, it must not have intended to create one.

However, opening this can of worms would also be likely to give segregationists, who are very well funded, an opportunity to lobby for such a mandate. And Congress might easily be induced, like Solomon, to "split the baby" by adding mandates for both to the law. That would be very, very bad. ADAPT seems to have confidence in its ability to prevent this, but we aren't so sure.

In any case, about 150 hardy ADAPTers swarmed the White House on April 20, and 53 of them were arrested. They wanted Obama to support the bill, and also to issue an Executive Order "that acknowledges the inhumane warehousing of people in nursing facilities and other institutions and implements specific steps to end this practice, including increased *Olmstead* enforcement, implementation of policies to assure that state Medicaid rates for home and community-based services support adequate wages for attendants

and greater oversight of state Medicaid programs.” The next day they hit the Department of Justice (DOJ) to demand better enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA), and that DOJ intervene in states that don’t pay adequate Medicaid rates for integrated supports.

No specific results from these actions have been reported, but we’ll let you know if any emerge.

## Who’s on First?

by Frank Pennisi

“Everyone has the right to work” is the underlying premise that precipitated an Executive Order by Governor Cuomo in September 2014 to establish an Employment First policy for people with all disabilities in New York State.

The Employment First Commission released its report and recommendations in March. The goals are to increase the employment rates of individuals with disabilities, decrease their poverty rate, and register at least 100 businesses as having formal policies to hire people with disabilities as part of their workforce strategy.

The NY Association on Independent Living (NYAIL) and the NY State Independent Living Council (NYSILC) held a series of meetings with government officials in 2013 and 2014 to make recommendations of issues we felt were critical to an Employment First policy.

The majority of our recommendations were included in the final report. Some are:

- Overhaul the 55-b program and reinstate the position of 55-b Coordinator (preferably someone with a disability).

The 55-b program allows qualified people with disabilities to be considered for various entry-level state jobs without having to take a civil service exam. In the past, after a person was certified eligible, it was all but impossible to get information on how to proceed from that point to actually getting a job. The report recommends that the process be made more user-friendly, and that lists of qualified individuals be submitted for any job openings in all state departments. The report also recommends that the position of 55-b Coordinator be reinstated.

- Expand the Developmental Disabilities Tax Credit.

Last year the state established the Developmental Disabilities Tax Credit, whereby businesses who hired people with developmental disabilities could receive a tax credit. NYAIL and NYSILC have been urging the state to establish a tax credit for businesses that hire people with *all* disabilities, not just developmental disabilities. The report recommends that the Developmental Disabilities Tax Credit be expanded to include individuals with all disabilities.

- People with disabilities are a minority too!

NYAIL and NYSILC have also been advocating for years to add disability-owned businesses to the state’s Minority Women Owned Business Enterprise program, which receives a significant amount of contracts from state agencies. The report also recommends that businesses owned by people with disabilities be added to this program.

- Increase use of the Medicaid Buy-In.

The Medicaid Buy-In for Working People with Disabilities allows a person with a disability who is working full time and earning up to \$60,000 a year to keep their Medicaid if it provides more and/or better benefits than their insurance would. For example, those who need attendant care to get out of bed and ready for work may not be able to receive such services under any insurance policy, but if they retain their Medicaid eligibility, they may then be able to hold a job. For over a decade since it was established, the Medicaid Buy-In has been significantly under-used, averaging about 10,000 individuals enrolled, whereas it is estimated that approximately 150,000 people statewide are eligible. The state will be taking over administration of this program from the local districts, which should make applying for it more consistent.

- Expand transportation availability.

Transportation is often a huge barrier to people with disabilities becoming employed, particularly in rural areas. The state is proposing a cross-agency task force to address the transportation needs of people with disabilities, and to explore innovative ways of providing transportation. The report also recommends that the state pursue a rural transportation tax credit for employers providing resources or direct transportation to employees.



## That Which, by Any Other Name, Would Smell as Sour...

Earlier this year the federal Centers for Medicare and Medicaid Services (CMS) released long-awaited “guidance” on how the new regulations defining “home and community based settings” (HCBS) for Medicaid programs apply to non-residential services. The guidance is vague, but the regulations could result in eventual closure of most segregated “day programs” in NY. Once the guidance came out, OPWDD issued its HCBS Transition Plan for non-residential services. The plan relies on broad statements in the guidance rather than the specifics of the regulations.

STIC, the largest provider of OPWDD-funded integrated day services in our region, answered OPWDD’s request for comments on the plan with a detailed explanation of what the regulations mean. But the agency’s later proposals, for regulations for “site-based” prevocational services and sheltered workshop “conversion” options, almost completely ignore what we said. Instead, OPWDD seems to be scrambling to find ways to justify business-as-usual for these programs.

We mention our role as the largest integrated day services provider not to pat ourselves on the back, or in an effort to take funds from our competitors, but to highlight our experience. When we say there is no earthly reason, financial, organizational, or programmatic, to group people with developmental disabilities together in one room for 5 or 6 hours a day for “training,” we are not talking off the tops of our heads. We’ve been successfully providing well over 300 people with integrated one-on-one community habilitation services for several

years, and we have people beating down our doors to get more of the same.

But OPWDD’s proposed rules for “community” prevocational services would let programs keep people together in segregated facilities up to 4 hours a day, and even when they spend an hour or two in real community settings, they could be marched around in groups of as many as 8 people to get their alleged “individualized” services. So, OPWDD doesn’t feel any need to pay adequate rates for a one-on-one approach for the service. We know you’ve been waiting patiently for us to offer this service since we announced we would do so over a year ago. But we have to say now that it doesn’t look good. We won’t compromise on the one-to-one integrated model that you say you love, and we also will not operate the service at a loss. If you want this service from us, you need to contact OPWDD directly and ask why they won’t pay what it costs to provide it.

In another disturbing development, OPWDD has asked CMS to let them comply with CMS’s order to close sheltered workshops by simply renaming them “integrated employment settings.” This spring OPWDD shopped two “options” around to workshop operators and family members of workshop inmates. Both options would let operators keep their segregated congregate models.

Option 1 would allow the facility to have a workforce of which 60% are not people with developmental disabilities receiving OPWDD services. Support staff would not be included in the 60%, and no more than 10% of the workforce could “consist of supervisors and production staff.” You may say, hey, 60% nondisabled isn’t bad. But that’s not what they’re saying. They are saying, 60% not *developmentally* disabled. They could be people with other kinds of disabilities. In other words, a pretty typical multi-purpose sheltered workshop.

Option 2 is even worse. That option requires only 25% of the workers to not have developmental disabilities (but again they could have other kinds of disabilities).

In fact, the CMS regulations require *all* HCBS non-residential services to comply with the same rules that apply to residential settings. That is, they must “optimize, but not regiment, individual initiative, autonomy, and independence in making life choices,” and they must be “integrated in and support full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in

the community, to the same degree of access as individuals not receiving Medicaid HCBS.”

What’s the definition of “sheltered workshop”? A program that groups people with disabilities in one location where they work for payment that may be less than minimum wage. What’s OPWDD’s proposed definition of “integrated employment setting”? A program that groups people with disabilities in one location where they work for pay without anything being specified regarding wages. Maybe it’s just us, but we’re having a really hard time seeing the difference.

We hope CMS feels the same way. But OPWDD has been working so hard to wear them down that they may be getting fatigued. We’ll send them a note about this to help bolster their resolve. If you thought OPWDD was serious about increasing integrated competitive employment and are as shocked as we are, you may want to write them too.

## You Can’t Always Get What You Want

We would like to thank Assemblywoman Lupardo for supporting the Centers for Independent Living (CILs’) successful request for a budget increase this year. We were also happy to hear, from her aide, that she supports the concept of requiring accessible voting machines for all elections in all precincts, though we were rather surprised, since she has voted for bills granting exceptions for inaccessible lever machines in the past. We were less happy to hear that she wasn’t sure if she could support our call for a Nurse Practice Act amendment this year.

And we are saddened that she still opposes full integration for people with developmental disabilities. She and Senator Libous both support two bills to block reforms. One would require OPWDD to keep people in developmental centers indefinitely if they “want” state-operated residential services and none are available outside of those facilities. The other would require OPWDD to keep sheltered workshops open for people who “want” them in order to be able to “be with their friends.”

While the bills don’t mention money, they would violate federal law if NY tried to use Medicaid to pay for them. Developmental centers are ICFs. ICFs have rules for admission and discharge. People can’t be admitted to ICFs unless they meet specific criteria. ICFs can’t be permanent residences; people in them must all be actively working toward discharge to more integrated settings. CMS can, and will, decer-

tify ICFs that don’t comply with those regulations, making them ineligible for any Medicaid funding, and making spending NYS dollars on them legally challengeable. The federal Medicaid Inspector General has found that the type and quality of services that state-operated ICFs provide do not differ from those of not-for-profit ICFs. The only difference is cost; state-operated ICFs cost the taxpayers about twice as much as the not-for-profit variety. And anyone who receives Medicaid funded-services must demonstrate that they are medically necessary. Nobody can get Medicaid services simply because they “want” or “prefer” them, and certainly nobody can ask Medicaid to pay for services merely so they can “be with their friends.” Individuals who do not objectively need to be segregated for demonstrable medical reasons cannot legally be segregated at public expense, and that’s all there is to it.

The people who are promoting these bills know this. And they know that CMS will not approve any such things. It’s just more political pandering to the public employee unions and sheltered workshop lobbyists who fill their campaign coffers.

## Tune Up Your HARPs

OMH has been promising new home and community-based services for adults with significant mental health disabilities for quite some time. These will be offered by a new kind of managed care service called Health and Recovery Plans (HARPs).



HARPs are a subset of services offered to people with some types of mental health disabilities, along with physical and “behavioral” health services, through managed care organizations (MCO). Some of the services are similar to those in NY’s Medicaid home and community-based services (HCBS) waivers, like habilitation, pre-vocational services, and supported employment. Others are behavioral-health-specific, such as crisis intervention and psychosocial rehabilitation. Peer counseling is also a HARP service. HARPs must comply with the same new regulations for person centered planning, and definitions of “home and community based services”, that CMS recently

issued for other Medicaid HCBS programs. That includes offering self-directed services, although currently OMH only plans a “pilot” for self-direction.

The state is supposed to know who is eligible for HARP services already (yeah, right), and they are supposed to send you a letter if you are eligible. If your MCO offers a HARP, you are then supposed to be automatically enrolled in it. If your MCO doesn’t have HARPs, and you want one, you’ll have to respond to the letter to switch to an MCO that offers them. If you think you should be eligible and you don’t get a letter, don’t sit on your hands. Ask questions.

The program is rolling out in New York City first, beginning October 1, 2015. It will be available upstate starting in April 2016. The non-HCBS services will be available first, with HCBS services phased in later—most likely because the state is *still* arguing with the feds about requirements for the “Partnership” managed care waiver.

HARPs are a good idea, at least in theory, and could bring a lot of services to people that haven’t previously been available. But the devil is in the details, and one of them is that MCOs must find, and contract with, providers of HCB and peer counseling services, at rates those providers will accept, before the plans will be worth more than their weight in paper. So expect log-jams over the next couple of years, before the system really starts to get off the ground.

## What Do We Get for Our Money?

The Deputy Commissioner of the State Education Dept. for ACCES-VR has said that he doesn’t know what the state gets for the money it gives to Centers for Independent Living like STIC. In return, STIC asks, what is the state getting for the money taxpayers give to ACCES-VR?

Recently an ACCES-VR official answered complaints that the agency has cut supported work for people with multiple needs in favor of post-secondary education assistance and/or simple job placement for those with mild disabilities by saying that the agency “doesn’t have to” serve people with the most significant disabilities. This is false. The federal Rehabilitation Services Administration (RSA), which oversees funds for state vocational rehabilitation agencies, prefaced its July 2014 report on ACCES-VR by stating: “The State Vocational Rehabilitation (VR) Services Program is a state-federal program that has been established to assist individuals with disabilities, *particu-*

*larly those with significant disabilities*, to achieve high quality employment outcomes in integrated settings” (emphasis added). The data below are from RSA.

There are two major “pots” of federal VR funds: the State Vocational Rehabilitation Services Program and the State Supported Employment Services Program. RSA reports show a big drop in ACCES-VR expenditures from both programs between 2010 and 2013, a time when the agency’s successful employment outcomes also fell. One might assume the mean old federal government cut ACCES-VR’s budget. In fact, the agency got tens of millions of federal dollars that it did not spend during this period; it *returned* much of it to RSA. NY was so focused on achieving budget cuts of any kind that it witlessly downsized a solely federally-funded program.

RSA did a comprehensive 5-year review in 2012, covering the years 2006-10, in which it found ACCES-VR out of compliance with its own standards for services for transition-aged youth, and identified several negative trends: “The overall percentage of individuals who did not achieve successful employment increased from 22.8% in FY 2008, to 29.4% in FY 2010, compared to the national average of 24.8% for general agencies. During the same period, the percentage of individuals who achieved successful employment decreased from 33.8% in FY 2008 to 24.9% in FY 2010. Likewise, the employment rate declined from 59.79% in FY 2008, to 45.86% in FY 2010, which was below the national average of 52.56% for all general agencies in that year.”

To be fair, NY entered a serious recession in 2008, and a more recent, though less detailed, RSA report from 2014 shows some improvement. But the 2014 report, covering events through 2013, largely supports what ACCES-VR’s critics have been saying:

ACCES-VR has been reducing referrals for supported employment, most likely because it is difficult to get quick “successful outcomes” from that service. Instead, it has been increasing spending on simple job placement for people with disabilities who probably could have gotten jobs without the agency’s help, and on post-secondary education support for people who, perhaps, might not have gotten quite as comfy jobs as they got with college degrees, but still would have been working for a living even if ACCES-VR had never existed.

In 2013, the agency spent 9.83% of its funds on “post-secondary education,” compared to the national average of 8.03%, and a whopping 24.66% on “other training and education,” as

compared to the national figure of 13.65%. In the “all other services” category, which includes supported employment, ACCES-VR spent only 2.02% of its funds, as opposed to the national average of 10.21%.

NY has had a few years to recover from the recession, but its 2013 figure for cases “closed with employment,” 12,025, is still lower than its high point of 13,236 in 2008. And despite ACCES-VR’s preference for simple job placement without supports, the agency’s percentage of people who achieved “competitive employment” (as opposed to just “employment,” which can mean “supported employment”) is still below the national average.

In 2012 the agency failed to meet 3 out of RSA’s 6 quality indicator minimums. In 2013 it met 5 out of 6, but the one it didn’t meet was a big one: the “ratio of the average hourly wage of individuals who achieved competitive employment to the average hourly wage of all employed individuals in the state.” In other words, most of the larger number of jobs that ACCES-VR’s direct placement emphasis got for people were crummy, low-wage positions—the sort of thing that happens when an agency focuses on getting quick “success” numbers instead of producing quality results. This also led to OP-WDD’s report that between 80% and 90% of people with developmental disabilities who are placed in jobs through ACCES-VR lose those jobs each year.

So what do the taxpayers get for the money they give ACCES-VR? A “quick and dirty” VR system that is focused on gaming the federal reporting requirements to quickly generate pretty-looking numbers, while producing little long-term benefit for individuals, and largely ignoring the people with the most significant disabilities which the agency “particularly” exists to serve.

Come to think of it, that sounds like the general thrust of the new reporting requirements that ACCES-VR has been trying to force on Centers for Independent Living (CILs), including STIC. If you would like to know what we do with the general operating funds administered by ACCES-VR (in STIC’s case, approximately 5% of our total funding), here are a couple places to look:

Deinstitutionalization cost savings (2001-2014):

[http://www.acces.nysed.gov/vr/lsn/ilc/deinst-costsave\\_statwiderep.pdf](http://www.acces.nysed.gov/vr/lsn/ilc/deinst-costsave_statwiderep.pdf)

Systems Change (most recent report): <http://www.acces.nysed.gov/vr/lsn/ilc/results1213.pdf>

## *DRNY v Justice Center*

As we reported last time (*AccessAbility* Spring 2015), Disability Rights New York (DRNY) filed suit in federal district court against the NYS Justice Center for the Protection of People with Special Needs for failure to provide records of investigations of abuse and neglect of people with disabilities. We've read DRNY's complaint and have some more details to report.

DRNY is the new name of Disability Advocates, Inc., the not-for-profit agency that inherited the official "Protection & Advocacy" role of the now-defunct NYS Commission on Quality of Care (CQC). The Justice Center took on the CQC's state investigative work. Federal law assigns Protection & Advocacy (P&A) agencies oversight of state agencies that serve people with various types of disabilities, as well as oversight of any state investigations of those agencies.

DRNY's complaint describes four cases for which it requested records: "F.S.", a person with mental illness who allegedly committed suicide in a state prison while under treatment from OMH. DRNY says it has "probable cause" to believe F.S. was abused and neglected. "L.B.", a person with mental illness living in an OMH facility who, DRNY says, was physically abused while under restraint by OMH staff. "A.T.", a child with developmental disabilities living in an Office of Children and Family Services residential school, who DRNY alleges was abused or neglected, resulting in eye and head injuries. "R.T.", a person with developmental disabilities living in an OPWDD-licensed facility, whose eyes and hands were bruised due to alleged abuse by staff.

DRNY says it requested complete records on these investigations from the Justice Center, and provided releases signed by guardians as appropriate. The Center did not comply with any of the requests in a timely manner (for developmental disabilities, federal law says information must be provided within 3 business days; for mental illness, the law is not specific but the regulations say "promptly"). DRNY had to submit multiple requests for the records, and in one case the Center took ten months to respond. In all cases, the infor-

mation the Center eventually provided was "heavily redacted." The missing information included "the identity of individuals reporting ... abuse or neglect to the Justice Center; mental health provider/clinical records or information; individual service recipient information; the identity of the staff member who is subject of an abuse or neglect allegation; the identity of individuals cooperating in investigations." In other words, everything necessary to establish accountability.

The Justice Center claims it doesn't have to give information to DRNY about investigations not yet completed, and that state law allows it to redact this kind of information.

DRNY seems to have an airtight case. The federal laws and regulations governing P&A agencies are very clear: They say that such agencies "shall have access to all" records of the type DRNY requested, within specified, or at least suggested, time frames. "All" means all; no redactions. The law and regulations do not provide exceptions for delays due to uncompleted investigations. And the federal laws explicitly say that any state laws to the contrary do not apply.

We have not seen the Justice Center's response to the complaint; when we do we'll report on it.

## *Armstrong v Exceptional Child Center, Inc.*

This case about whether Medicaid service providers can sue a state to force it to raise Medicaid rates was decided by the US Supreme Court in March (see *AccessAbility* Spring 2015). At issue was federal Medicaid law Section 30(A), which says that state Medicaid programs must "provide such methods and procedures relating to the utilization of, and the payment for, care and services ... as may be necessary to ... assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area." The court ruled that the Constitution's Supremacy Clause grants no private right of action to sue a state for such a reason, and that Medicaid law specifically precludes such suits.

Rather unexpectedly, the "swing vote" this time was not Justice Kennedy, who joined Justice Sotomayor in dissent, but Justice Breyer.

Justice Scalia, who wrote the majority opinion, said the Supremacy Clause "instructs courts what to do when state and federal law clash, but is silent regarding who may enforce federal laws in court, and in what circumstances they may do so." The opinion is heavy on the alleged Founders' original intent but light on logic. According to Scalia, Alexander Hamilton, in *The Federalist Papers*, "wrote that the Supremacy Clause 'only declares a truth, which flows immediately and necessarily from the institution of a Federal Government.'" In other words, if there's a federal government, its laws must obviously override those of lower governments. Scalia cited another early source who "described the Clause as 'a positive affirmation of that, which is necessarily implied.'" He went on to say, "These descriptions would have been grossly inapt if the Clause were understood to give affected parties a constitutional (and hence congressionally unalterable) right to enforce federal laws against the States." Why isn't it equally a "necessarily implied truth" that affected parties can enforce the federal supremacy over states? On this, Scalia, who tends to cherry-pick the opinions of the Founding Fathers to find those that support him and ignore those that don't, is silent.

But he moved on to repeat the point that federal Medicaid law contains only one specific remedy for noncompliance by states: the Secretary of the federal Department of Health and Human Services (HHS) can withhold Medicaid funds. That being the case, he inferred that Congress must have intended that to be the only remedy, and so people who sue a state for violating Medicaid law are misdirecting their efforts. They should file a complaint with HHS, and then, if that agency doesn't provide satisfaction, they can sue *it*.

The dissenting opinion, written by Justice Sotomayor, quoted a "friend of the court" brief from several former HHS officials, who, she said, "noted that HHS is often reluctant to initiate compliance actions because a 'state's non-compliance creates a damned-if-you-do, damned-if-you-don't scenario where the withholding of state funds will lead to depriving

the poor of essential medical assistance.” To which Scalia responded, “The dissent’s complaint that ... the cut-off of funding is too massive to be a realistic source of relief seems to us mistaken. We doubt that the Secretary’s notice to a State that its compensation scheme is inadequate will be ignored.” This is highly disingenuous. Chief Justice Roberts’ 2011 opinion in the Obamacare case, which found that the feds could not legally threaten to cut off Medicaid funds to a state that refused to expand its Medicaid eligibility rules as prescribed by the Act, clearly shows that such a sanction would indeed be considered too massive a response to an even more limited violation like inadequate rates. Given this precedent, Scalia is correct that such a threat would not be ignored

by a state; the state would promptly sue HHS and the Supremes would rule in its favor.

Justice Breyer, though concurring with the majority, filed a separate opinion in which he said the issue of Medicaid rate setting is far too complex for federal courts to handle, and emphasized his support for the idea that people can use federal courts to get HHS to enforce the law without suing state governments. This was out of left field, given the actual history of federal courts’ involvement in rate-setting cases.

Scalia’s opinion is judicial activism, intended to sweep away at least 70 years of precedent directly related to cases like this. Sotomayor

cited several Supreme Court decisions that specifically upheld the use of federal courts to enforce federal laws that contain no private right of action, including Medicaid law, such as *Porter v Warner Holding Co.* (1946) and *Virginia Office for Protection and Advocacy v Stewart* (2011). In response, Scalia could only find one case where the court took a different view of similar facts—pretty slim pickings, even for him.

But what’s done is done, at least until some other judicial activist decides to undo it.

## Feeding the Elephant

As we’ve noted elsewhere, NY State is still far too focused on “supportive housing,” and the state’s housing policy seems to be irrational in terms of the goals of cutting costs and improving outcomes for people with disabilities (see page 3).

We’re in the third year of debate over passing a Nurse Practice Act amendment to maximize the Community First Choice program’s ability to keep people out of nursing facilities and in their own homes. The history of that debate has seen various legislators, and both houses, taking turns supporting and then opposing the bill, allowing them to claim to be “our friends” while delaying implementation indefinitely (see page 5).

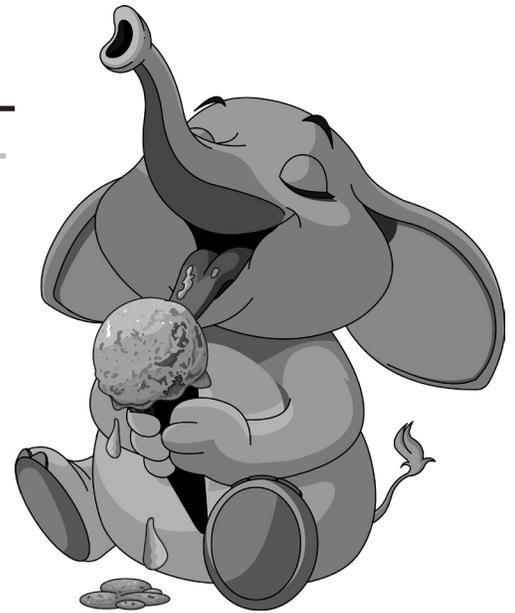
Then there’s the managed care nursing facility “rate cell”: we recently learned that managed long-term care organizations (MCOs) may have convinced NY to provide a \$10,000 *per month* “bonus” payment, on top of the very large rate they already get, for each person they serve who lives in a nursing facility. The MCOs said they couldn’t afford to keep people in those institutions without the extra payments. So much for NY’s health policy gurus’ claim that they want managed care to incentivize use of home-based services and reduce the number of people in highly expensive nursing facilities. State Department of Health officials have refused to answer questions about it. We will keep trying to find out more.

There’s a pattern emerging here—an “elephant in the room” whose presence is beginning to be felt. Consider:

NY is trying to cut Medicaid spending, and it can do so by closing institutional settings owned and operated by the state and moving the residents into the community. Supportive housing in the community is cheaper than institutional settings by 3 to 5 orders of magnitude. Who lives in state-operated institutions? Mostly people with significant cognitive, intellectual, or psychiatric disabilities—people who often need paid support services at home.

Now, NY can also save Medicaid dollars by reducing spending on nursing facilities and moving their residents into the community. There are a lot more people in those places than in disability-specific institutions. But the state doesn’t own, operate, or staff nursing facilities. Who does? Private organizations that have well-paid lobbyists and a mostly unionized workforce.

Nursing facilities and supportive housing both keep the money within what might be called the “health-related housing industry.” This is a huge economic engine in NY, and it’s not just about profits. State-operated programs are staffed by public employee union (CSEA and PEF) members. A lot of nursing facilities (and so-called “assistive living” facilities, most of which are renamed nursing homes and no less institutional in nature), and group home operators, and some supportive housing programs, also have unionized employees, members of SEIU, especially in New York City and surrounding areas, where the state’s most influential politicians live.



See the pattern? State legislators will support at least some efforts to cut Medicaid spending on state-operated programs, but they oppose things that would lead to nursing facilities and other private congregate living settings losing residents, especially services that make it easier for people with significant physical disabilities to live in their own homes.

Rich nursing facility owners, well-funded lobbying organizations hired by them, and CSEA, PEF, and SEIU have huge war chests of funds that they distribute to state legislators. Legislators’ law firms and consulting businesses are likely getting even bigger chunks of undisclosed funds from some of these “stakeholders.” All of these organizations are major players at the table in every state budget negotiation in NY.

So say we close a downstate developmental center and move its residents into group homes. The state workers at the developmental center lose their jobs, but many of them can get hired by the group home agencies, which must expand to accommodate the influx of

people, or by nursing or assistive living facilities, and still get union jobs.

And if we close nursing facilities and move residents into supportive housing? Again, this keeps the (mostly Medicaid) money in the health-related housing industry, and nursing home operators can even, given enough time, shift operations into running that kind of program, so the money can stay in the operators' pockets. Life is good for workers and owners both.

But what happens if we use non-Medicaid money to construct accessible housing units, and move the large number of people who are in nursing or assisted living facilities merely because their homes were not accessible, into those units? The money disappears from the health-related housing industry. People who

don't need support services won't be using unionized workers, and they won't be generating income for nursing-home-cum-supported-housing operators. The money goes into a completely different market: the generic housing industry. "Bad idea," say the unions and owners. They communicate this message to our elected officials, who go public with the "they're not safe!" message while smirking and tucking the money into their wallets.

We at STIC are as good as anyone at generating rational, fact-based explanations for why state government should get behind integrated services and supports for people with disabilities. It's always cheaper for the state, and provides better quality of life for people.

But we have also, always, been aware of the elephant in the room. It's rational too: politicians like fat campaign chests, and they

love off-the-record income to support their extremely comfortable lifestyles. What is irrational is to expect them to forego all that good stuff by supporting public policies that the people who pay for it don't like.

The elephant in the room is why carefully reasoned position papers, "consumer participation" on advisory panels, and submission of public comments don't get the results we want. It's really very simple. As former jail-bird Alan Hevesi told some STICsters back before he was a crooked state Comptroller, when he was still just a crooked NYS Assemblyman: "You have no influence because you give us no money." Well, sadly, disability is a well-known cause of poverty in America. This is why lawsuits and civil disobedience remain critical necessities in getting disability policy changed. It is also why we need to up the ante on both.



## **Accessibility Systems Advocacy Committee (ASAC)**

by Susan Hoyt

STIC's ASAC continues to advocate with local businesses and municipalities in an effort to make our community more accessible for people of all abilities.

ASAC would like to recognize:

The City of Binghamton – for correcting the handicapped spaces in the area of the diagonal parking on Hawley St., across from City Hall.

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

The poster for the ADA-to-Z event is framed by a border of black and white balloons. The title "ADA-to-Z" is prominently displayed in a large, bold, black font. Below the title, the text "Join STIC in our celebration of the ADA's 25th anniversary!" is written in a smaller font. The event is co-sponsored by the Ross Park Zoo and is scheduled for July 23, 2015, from 11:00 am to 4:00 pm at STIC, 135 East Frederick St., Binghamton. The event is free fun for children and adults, featuring games, a wheelchair obstacle course, adapted sports demos, interactive displays of technology, and storytelling for children read from braille presented in sign language. The Zoo Mobile will be present from noon to 3 pm with exotic animals to see and pet. Free snacks are also provided.

# **ADA-to-Z**

Join STIC in our celebration of  
the ADA's 25th anniversary!

Co-Sponsored by the Ross Park Zoo

**July 23, 2015**  
**11:00 am - 4:00 pm**  
**STIC**  
**135 East Frederick St.,**  
**Binghamton**

Free Fun for Children & Adults

- Games
- wheelchair obstacle course
- adapted sports demos
- Interactive displays of technology
- Storytelling for children read from braille presented in sign language

The Zoo Mobile will be there from noon to 3 pm  
with exotic animals to see and pet!

**Free Snacks!**



# HAUNTED HALLS GETS THE ST. LOUIS BLUES

by Bill Bartlow

St. Louis was incredible. In March, three of HHH's founders attended the TRANSWORLD Halloween and attractions show. That's the big one for everything Halloween. Yes, there's a convention for that industry too.

As soon as we arrived at the St. Louis airport we began to get a sense of how large the event would be. Banners welcoming ten thousand attendees, aficionados, and vendors were a prelude to what was ahead. Three days of workshops, exhibits, and discussions with other haunters from around the country, combined with an 80,000 square foot vendor's floor that housed all things Halloween. Talk about Halloween treats; this was the candy store. Surpassed only by Christmas, Halloween is a \$6.7 billion-per-year holiday. Todd, Dennis, and Bill took it all in to bring back to STIC's fundraiser the latest concepts and technology.

One attraction that we returned to over and over was the "Vortex." The first time I tried to go through the vortex, I froze white-knuckled on the railing, then retreated. It was an overwhelming experience, the kind that we absolutely had to bring back for the Haunted

Halls. We had a wonderful conversation with the owner of 1031 Effects, the manufacturer. After we explained our charitable haunt to benefit people in our community, Mr. Roberts made us a generous and philanthropic offer, allowing us to bring this thriller to Binghamton. So hold on to the rail folks, the VORTEX of TERROR: 3D will be the huge new addition to the Haunted Halls of Horror for 2015. If you close your eyes, you might make it through. See you in the fall.

For now, however, it's summer, and we deserve some summer fun after a tough winter.



Our hearts are blacker than Joan Jett's, and when we do the polka, we do it on your chests, so look for us along with Joan and her Blackhearts and Dennis

Polisky and his Maestro Men at the Spiedie Fest & Balloon Rally in Otsiningo Park, July 31- August 2.



Celebrate with STIC's HHH and Binghamton's boys of summer: the B-Mets at NYSEG stadium. On August 29, come enjoy baseball along with some unexpect-

ed creepy fans. Not the field of dreams, but the field of nightmares will be populated by the characters of the haunted halls and the downtown Zombie walk. Arriving in "Christine the cadaver coach," our troupe will also be prepared to airbrush and gorify your look in time for the late night fireworks display. Make sure you get your \$5.00 tickets in advance from STIC to assist our fundraiser.



Do a little dance macabre to the music at Blues on the Bridge in September. We'll be there, along with our HHH hearse.

Prepare yourself for October: The Vortex, Blood Creek Massacre, Blackout, The Necropolis, and Outbreak. Stay plugged into our website, [www.hhh-stic.com](http://www.hhh-stic.com), for the latest information on this year's Haunted Halls of Horror.

It's Coming . . .

October 9-31

Friday & Saturday Nights

6:30 to 9:30



# SELF HELP

## The 70 Point Solution

On May 20, STIC held our first cross-training event for people who work with those with both mental health and developmental disabilities, and to begin coming together as a community to find solutions for the problems they face. "Hands Across the Service Systems" was a huge success. 200 people attended from the mental health, developmental disabilities, education, and law enforcement fields. Just about everyone learned things they didn't know about services and programs of which they weren't fully aware. That's the first step. When we are armed with more complete knowledge, we can better use the scarce resources available to us.

Cross-training is a continuous need, because disability workers come and go, and knowledge is constantly lost and must be restored. So we will offer more of these events, the first one this fall. We'll also bring together those who expressed interest in working to increase the resources our community has to serve people with dual developmental and mental health disabilities.

Here is a follow-up on a few of the many important points presented:

Some service providers appear to believe there is a concrete rule that people whose IQs fall below 70 can't receive certain mental health services. This is not correct.

There is a "memorandum of understanding" that explains how decisions about who provides services to whom are to be made. This "MOU" says that, as a general matter, one can assume that mental health programs, operated or funded by the state Office of Mental Health or the county department of the same name, serve people with IQs above 70, and OPWDD and its subcontractors serve those who fall below that number.

But that's just a starting point. The MOU says, explicitly, that this rule of thumb is *never* to be used to deny appropriate services to someone in need. With the exception of a few people who have made incorrect public statements in

the past, just about everyone working in this field locally agrees that there are many people who truly have both developmental and mental health disabilities. The MOU makes it clear that when such people's needs can best be addressed by a particular service, then the person should get that service, regardless of who funds it.

Sometimes the concept of "primary diagnosis" is used to exclude people from services, and some people misunderstand that term. It is not a permanent designation. The MOU clearly states that if a person has both mental health and developmental disabilities, then his/her "primary diagnosis" is whatever is causing him/her the most trouble *at the moment*. For most people with dual diagnoses, sometimes mental illness is the primary diagnosis, and sometimes it's developmental disability. When the problem that leads a person to seek your help fits your services, then you serve that person, regardless of diagnostic label.

We all know that there is far too little money to serve everyone, and sometimes hard choices must be made. But the MOU does not permit us to make those choices on the basis of diagnostic category. "Triage" means serving those most in need first, and delaying or perhaps even denying services to those with less immediate needs. But a diagnostic category of "mental illness" or "developmental disability" doesn't say anything about the immediacy of the need, and it is not an allowable basis for delaying or denying services.

That being said, another problem caused by the scarcity of services is that every program gets bombarded by people seeking services they can't provide. For example, the OPWDD Article 16 Clinic is not an emergency program, and CPEP is an emergency stabilization, assessment, and referral program, not an ongoing support service. But people show up at CPEP expecting permanent solutions, and they get referred to Article 16 when they're in crisis. Knowing who does what best allows for more effective service provision.

Something that we at STIC didn't quite understand before May 20 is that certain symptoms of some mental health disabilities can depress

IQ scores. A person with a poorly managed chronic persistent mental illness may have an IQ below 70, but after treatment may show a higher score.

This underscores the questionable validity of IQ tests' ability to measure "intelligence." At least theoretically, "intelligence" should be constant and a valid test should produce the same results regardless of what else is going on with the person. If it doesn't, then it's measuring something other than "intelligence."

But intellectual disability is only one of several types of developmental disability, and it's not the only, or most important, qualifier for OPWDD eligibility. Yet, some misinterpret the regulations to use a sudden increase in IQ to cut off services. This is often challengeable, and no one should accept such a decision without appealing it.

When people spend most of their lives in institutions, it can permanently damage their ability to function in a self-reliant way. We used to call this "institutional retardation." We don't use that term any more, but the phenomenon persists. People have been damaged, and thus need and deserve ongoing support services. NY State and OPWDD must accept responsibility for it. It is unconscionable to turn such people away because now, with allegedly "better" testing, they no longer meet the eligibility criteria. NY and OPWDD owe a permanent debt to such people and must provide services to compensate for the damage they have perpetrated.

Some providers said they exclude people in certain diagnostic categories to avoid "harming" them with inappropriate services. One of the educational challenges we face is that people being trained to provide these services, especially medical professionals, are not exposed to people with dual diagnoses, and they simply don't understand their needs or abilities very well. They are understandably reluctant to act. We will try to address this by improving training for medical and paramedical people in our region.

Often it's not the technical diagnosis that determines the services the person needs but the state of their functioning. People with intellectual and/

or cognitive disabilities frequently need, and benefit from, the same kinds of support services, because their functional profiles are close to identical, regardless of whether their needs result from mental illness, intellectual disability, autism, stroke, dementia, or traumatic brain injury. Approaching the provision of crisis de-escalation services, ongoing counseling, assistance with taking medication, life-skills training, or residential supports, from a mental health perspective will not harm a person with developmental disabilities, and vice versa. We know that traditional training does not teach this, and we will work to ensure people are trained, and re-trained, properly.

## Video-on-Demand Children's TV for Students with Visual or Hearing Disabilities

(from a press release)

In March, the US Department of Education announced the availability of free, video-on-demand children's television programming for thousands of students who are blind, visually impaired, deaf or hard of hearing.

Dozens of children's and family TV episodes may now be viewed online featuring closed captioning and descriptions through the Education Department's Accessible Television Portal project. It includes video-on-demand content provided at no cost by the major television networks, as well as producers and distributors like PBS Kids, Sesame Workshop, Cartoon Network, Sprout, the Fred Rogers Company, Scholastic Media, Litton Entertainment, Out of the Blue, and Fremantle Television. Among the shows: "Ocean Mysteries," "Magic School Bus," "Bill Nye the Science Guy," "Daniel Tiger's Neighborhood," "Expedition Wild," and "Peg + Cat."

To view the content, teachers and school personnel, parents, and other professionals working with qualified students can visit [www.dcmp.org](http://www.dcmp.org) and apply for access to the portal.

Once approved, accessible content can be used with, and by, students in the classroom and at home via the Web, mobile phones and tablets, mobile apps, and set-top boxes. The portal itself is fully accessible to those with sensory impairments. Children with disabilities can locate any featured program without difficulty.

Initially, the site will include 73 episodes of 19 different children's television programs. Additional content from other producers will be added over the next two years.

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## Free Access Is Not Free

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

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

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

**THANK YOU!**

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