

# Accessibility

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One issue that has loomed large in our community, and on STIC's advocacy agenda since our inception in 1983, is public transportation, or the lack thereof. In Broome and surrounding counties that means bus service.

Managed care has decimated transportation over the last few years, as counties lost Medicaid dollars when the service was incorporated into managed care and subcontracted by the state to a few large providers (in our case Medicaid Answering Service, MAS). Tioga County had to end its transportation program completely, and Broome lost a great deal of funding as well.

Other issues have also contributed to what is now a service that is a shadow of its former self, with fewer stops and routes. This includes the rigid, dysfunctional political environment and the drive to "save" at all costs.

The state claims that managed care is saving money, but in the transportation arena, what's the price we're paying for loss of dollars and service? Some stories below taken from peo-

ple whose only form of transportation is buses illustrate the cost:

A single working mom has a son who is in pre-K in Binghamton. The school does not provide bus transportation for children who attend pre-K. This mom does not have a car. She has to take her son to school, then catch a bus to her job in Vestal. This became unworkable when the most recent route changes were implemented. Eventually, she was fired for being late too many times.

A STIC consumer who lives in Endwell has staff support to travel on the bus and had learned much about traveling in the community on regular buses. Since the recent route and stop changes, it now takes her one hour and forty-five minutes to get from her home to STIC's offices on the east side of Binghamton to see her peer counselor, and another hour and forty-five minutes to get home. The total time required for this one-hour counseling session is therefore nearly five hours. The round-trip would be only 40 minutes by car, but this is not a Medicaid-

reimbursable trip, so a cab would not be an affordable option.

Another bus rider explains that her main transport bus is the #35, which she uses to attend medical appointments and to go to work. She will soon have surgery and the appointments are very necessary. She also started a new position in March on the east side of Binghamton. Due to the new and very confusing bus schedule, she has missed 5 doctor's appointments and has been late to work several times.

She has two options: the #28 or the #40 bus to get to work. The #28 drops her so far from her job that she is late many days. The #40 is much closer but runs only every other hour, instead of the more frequent runs that existed in the past. Therefore, she is often late. She also has an option for a better job, but may not be able to accept it due to the bus schedule.

Typically, it is low- and very-low income people who rely on buses for their livelihood, medical

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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.

care, ability to participate in their children's education and more. Yet instead of improving and increasing services, we keep cutting. When people want to improve themselves by going to school or to a higher paying job, they are thwarted because the work and class schedules significantly conflict with the limited and confusing transportation runs that are now in place.

So what price are we willing to pay to save a few bucks? Unfortunately, it is these same people who often don't vote, and because they are low-income, they don't pay as many taxes, so politicians count them out. They feel disenfranchised and see no reason to participate in a system that seems to have forgotten them.

Enough is enough though! It is time for bus riders to make some of their own demands and to back them up with a visit to the polls on Election Day. It's only going to get worse if people don't step up to the plate and let the powers that be know you're here and you aren't going away!

STIC has a team called the Transportation Advocacy Group (TAG) that dedicates its time and action to transportation concerns. Visit TAG online and see what it's all about at: <https://www.facebook.com/TransportationAdvocacyGroup>. Or Call Susan Ruff or Susan Link at STIC (607) 724-2111, or via video phone at (607) 238-2694.

# Police Violence against People with Disabilities

Over the past couple of years, unwarranted behavior by police resulting in the deaths of African-Americans and other people of color have been big news in the United States. The names of some of the victims have become famous. Less well known is that several of them also had disabilities.

Eric Garner was confronted by police for selling "loosies" (single cigarettes) on the street. His disabilities included obesity, asthma, and heart disease, all of which put him at high risk for breathing problems. He died while in an illegal chokehold, face down on the sidewalk, his nose and mouth mashed into the concrete and a police officer's knee on his upper back, pressing his lungs against the ground. He told them he couldn't breathe, over and over. Witnesses reported that the police laughed at him.

Kajieme Powell was an obviously irrational man who stole a couple of cans of soda from a small store. He put them on the sidewalk and paced around them at a distance, muttering. The store clerk called the police. Two police officers drove their car up on the sidewalk, got out and confronted Powell. Powell walked toward the officers, yelling "Shoot me now!" He then walked away from them, then back toward them. A cellphone video clearly shows him moving at a moderate walking

pace, never getting closer than about six feet from the officers, his hands down at his sides. Suddenly the police fired several shots, killing him. The officers claimed that Powell became progressively more agitated and reached into his waistband, pulled a knife, and raised it in the air. It is not known what prompted his behavior, but one witness reported that in the video he "looks sick more than he looks dangerous."

Tanesha Anderson had diagnosed psychiatric conditions of bipolar disorder and schizophrenia. She was at times very difficult to handle and was capable of aggressive behavior. She was in crisis, and her family was also in crisis and felt they had no choice but to call the police to help. The police came and talked to Tanesha and her family, and Tanesha agreed to let them take her to a hospital for evaluation. The police claim that she began kicking at them as they escorted her to their car, but the family says she got into the car voluntarily and then became agitated due to the confined space. The situation ended with Tanesha on her belly on the ground outside the car, with a police officer's knee in her back—the same position that killed Eric Garner. She stopped breathing and died.

Sandra Bland was apprehended by police after she became verbally abusive during a traffic

stop. She also told the officer she had epilepsy—a seizure disorder. She died by hanging while in jail, and her death was ruled a suicide. Her family protested that she would never kill herself and claimed that the police or jail guards must have killed her. Later it emerged that the medication she was taking to prevent seizures had side effects including aggressive behavior, depression, and suicidal thoughts.

Freddie Gray, who had a long record of criminal behavior and arrests, died of complications related to a broken back that he sustained while being transported in a police van. Media reported that he was not strapped down in the van as required by a newly-issued policy. However, several people suspected that he was intentionally subjected to a “rough ride,” a form of police brutality in which a person is placed unrestrained in a van which is then driven erratically in order to cause the person’s body to be thrown around the interior of the vehicle. It was not reported until much later that Gray had neurological and developmental disabilities due to lead poisoning he sustained as a child. According to Zosia Zaks, a rehabilitation counselor writing in the Baltimore *Sun*, “Individuals with disabilities resulting from childhood lead exposure have brain-based differences that impact self-regulation, social cognition and decision-making. When individuals with these types of developmental disabilities are frightened, they tend to dart away. Frequently, these adults lack the executive functioning skills needed to manage or effectively self-advocate in high-stress moments. These adults have social and communication challenges that may be too easy for police to misinterpret as non-cooperative behavior.” Gray’s criminal behavior may have originated as a response to his disabilities, and after repeated arrests and incarcerations his fear and anger toward the police deepened and made him progressively more difficult to deal with.

Then there was Ethan Saylor, a white man whose Down syndrome and obesity predisposed him to breathing problems. He was killed by police while being removed from a movie theater he didn’t want to leave. Ethan, who also had a significant intellectual disability, had just finished watching a movie with his attendant. He wanted to stay and see it again but didn’t have another ticket. A clear description of what happened next isn’t available, but theater personnel called the police to remove

Saylor from the theater. The attendant warned the theater staff and the police that Saylor would “freak out” if touched, told them that his mother was on her way with money to buy another ticket, and asked that everyone back off and just delay the start of the next show until the situation was resolved. The police ignored her and ordered her out of the theater. Then they physically grappled with Saylor and put him on his stomach on the ground, in the same position that killed Eric Garner and Tanesha Anderson, where he died with a crushed larynx.

**But there’s more to this issue. A growing body of brain research suggests that human will just isn’t as free as we used to think.**

Being African-American certainly predisposes people to police harassment and violence in this country. Now it seems that having disabilities may do so equally. It is difficult to get comprehensive statistics because, until quite recently, police agencies weren’t required to report the disability status of the people they confronted. Various data sets gathered in a March 2016 report from the Ruderman Family Foundation indicate that between 25% and 50% of the people killed by police in the United States have disabilities. The highest credible estimate of the overall incidence of disability in the nation is 20%, so this is clearly a disproportionate response.

The Foundation’s report focuses on the fact that the media often don’t report, or they misrepresent, the disabilities in these cases. For example, it is typically reported that the dead person was “mentally disturbed” or had a “mental illness” when s/he actually had an intellectual disability, autism, traumatic brain injury, or other disability that can affect behavior or interfere with communication. Sometimes a “mental” disability is reported as though it were a formal diagnosis when in

fact the person was under extreme stress due to fear and/or experiencing medication side effects in relation to a disability that is not mental at all. Substance abuse is a recognized disability that is frequently involved in these events. Often neglected are other facts, such as that disability predisposes people to low educational attainment, unemployment, and poverty—all risk factors for both substance abuse and involvement with law enforcement.

Some may poo-hoo the idea that so many people’s involvement with police may be “blamed” on disability. “Humans have free will,” these people say. “A person who knows right from wrong always has the choice of doing right.” This argument is often made when illegally obtained substances are involved. Sustained substance abuse, however, is usually a response to an underlying mental or physical disability or trauma. People use street drugs to “self-medicate.” Many people facing unbearable psychic pain, anxiety, depression, or traumatic memories, as well as painful physical disabilities for which effective treatment is often denied, such as fibromyalgia, severe dysmenorrhea, or migraine, lack insight into what is causing their misery. They just try to erase it with whatever psychoactive substances they can get. Also, once you’re identified as having a substance “abuse” or mental health issue, many medical professionals will refuse to acknowledge that you also have physical disabilities that cause severe chronic pain and will not offer effective treatment for them, leaving you with illegally-obtained drugs as your only option for relief.

But there’s more to this issue. A growing body of brain research suggests that human will just isn’t as free as we used to think.

The conscious parts of our brains evolved to mediate the flow of visual information from our highly sensitive eyes and help with pattern recognition. Seeing an odd movement on the horizon, we needed to know if it was a dangerous approaching lion, a tasty gazelle worth pursuing, or an optical effect of sunlight on breeze-blown grass that we shouldn’t waste energy to investigate. If the lion was much closer, we felt a rush of adrenaline and ran without thinking.

Science shows that it takes the human brain about a half-second to translate information from our senses into a “digest” of what is happening for our conscious minds. But humans

respond decisively to sensory stimuli much faster than that. It takes a fastball hurled by a big-league pitcher less than half a second to reach home plate. If it's not hit, it's in the catcher's mitt before the batter consciously "sees" that it has been thrown.

Many studies have shown that human memory is quite unreliable. That's not just true of our remembrances of long-ago events. Our short-term memory is equally deceptive. As shown by the baseball example, our conscious "present" is actually always a half-second in the past. That half-second is long enough to start an irreversible action, like swinging a bat—or a fist. Yes, a batter can stop in mid-swing, but he is not aware he has done that until after the fact. The decision is entirely out of his conscious control. His short-term memory will tell him that he saw the ball leave the pitcher's hand, thought about what to do, made a decision, started to swing, then made another decision and pulled back. But the only part of that story that is true is the first part; he saw the ball leave the pitcher's hand. He didn't think about anything or make reasoned decisions at all; he couldn't have, because by the time his conscious brain had the necessary information to do that, the ball would have been in the catcher's mitt.

Of course, people plan to do things and then do them. We can also plan ahead to help our unconscious brains make better short-term decisions. But when time is short, we humans "act first and ask questions later," and then we make up a story to tell ourselves about what just happened. In the best-case scenarios, the only real falsehood in those stories is the notion that we consciously exercised free will at the time.

Stress makes this much more problematic. We've all experienced carrying out a series of actions, such as driving a short, familiar route, and realizing, after we're done, that we don't remember doing it. That's because our conscious minds were occupied with something else while our unconscious brains acted. The more stressed we are, the less ability our conscious minds have to focus on the "present" and respond reasonably. This can multiply that half-second of unconscious action by a big number. If we're highly stressed, we may already have a distorted picture of the "present" occupying our conscious minds. We may suddenly realize that we've done

things we would never plan to do. Then the lies we tell ourselves aren't just about free will; we invent chains of events and convince ourselves of their truth, but they're false memories. Cases of physical abuse of children and other vulnerable people often fall into this category.

This complex, error-prone system of cognition is further weakened by some disabilities, and by some drugs prescribed for them. There are sleep disorders that cause some people to carry out highly complex tasks, such as leaving their homes and driving somewhere, or committing sexual assaults, while they are asleep. They have no conscious control of their actions, and no memory of them when they wake up. Some sleeping pills can cause this behavior in people who are trying to get help for insomnia. Most people know that severe cases of Tourette Syndrome can make people do offensive things that common sense tells us "must be" deliberate, yet are not.

The brain is an extremely complex organ, and damage or disease within it, as well as stressors on it, can have complex and subtle effects that don't involve conscious intentions at all.

Fear is one of the most powerful stressors we know, and one that is highly likely to distort our perceptions and put an end to conscious control of our actions. America has a huge problem with police violence against people of color. One reason for this is, of course, bigotry or hatred. But another reason is fear.

Police officers have come to fear black people because, for a host of reasons, most of which are out of their control, black people have become associated with crime in the public mind. People also fear those with behavioral disabilities because of their alleged unpredictability. People who have experience in dealing with these disabilities will tell you that, contrary to expectations, their behavior is usually very predictable, but that doesn't remove fear from the minds of those who are not appropriately trained.

Human consciousness helps us sort out complex information and make decisions based on it, when there is time to do so, and when our brains are functioning normally and not under excessive stress. But human consciousness clearly does not originate all of our actions, including complex ones, and it clearly can-

not control many of those actions once begun. Free will is not and has never been absolute, and the more stress we're under, the less of it we really have.

As scientific research piles up more facts about how consciousness and the brain work, our society will eventually reach a point where we must radically change how we think about the relationship of "free will" to much of the behavior to which police are called to respond.

Does that mean we should "excuse" criminals? Of course not. Some people certainly do plan in advance to commit crimes. However, we may find that most of the agitated behavior that results in police officers getting rough with people does not involve conscious intent.

If that's the case, then we have a moral obligation to take the only reasonable action that is available to our conscious assessment of what is really going on: The first priority for the police must be to try to prevent these situations from escalating until someone gets hurt or killed.

As anyone who has worked with people whose disabilities affect behavior knows, the proper response to someone in crisis is to be cool, relaxed, non-threatening, and to listen carefully, speak quietly, and act respectfully. Being confrontational is never appropriate, and carefully managed physical intervention is an extreme last resort.

Police are sometimes called "first responders." We need to train them to understand what that really means: Although they are in a "law enforcement" profession, the majority of crisis situations to which they must respond are *not* free-will-intentional "crimes in progress." These situations are about people in distress who have poor coping skills and need help to stay safe. The police cannot start by expecting defiance and planning to win a power struggle with a criminal. That approach just raises their own adrenaline levels and puts their own brains into a mode that makes careful, conscious evaluation and decision-making less likely. Two highly stressed, adrenaline-charged brains colliding with each other doubles the potential for damage just as two speeding cars racing toward a head-on collision do.

We require people who work with behavior-related disabilities to get extensive training in how to defuse tense situations before they escalate, and to be retrained regularly. All police

need to get the same training. And they need to internalize the understanding that it's only rarely necessary to win a power struggle with anyone in order to maintain public safety.

Eric Garner was, in effect, murdered by police officers for the petty crime of selling loose cigarettes on the street—an offense that had virtually no impact on public safety. The belief of those police officers that they must “win” every power struggle, no matter how trivial, helped kill him. Garner, of course, also had that belief—but he was the man in distress, and the police had a responsibility to apply professional judgment. Instead, their confrontational behavior created the crisis. There are many situations in which the police should simply issue a warning and walk away. There are other situations in which police can safely apprehend a person if they only take the time to relax, back off a bit, and help the person do the same.

Some people in the disability services industry claim that this idea is unrealistic and that workers frequently need to do whatever is necessary to protect themselves from highly dangerous people with disabilities. In our experience, such situations are extremely rare. In almost all cases, those who make these claims are just ill-suited to these kinds of jobs. Non-confrontational crisis-response techniques work well for people who understand them and apply them in good faith. But it isn't enough to train every worker in these skills. It is equally necessary to identify those who shouldn't be doing this kind of work and remove them. That also applies to police agencies.

There are also those who use these events to argue that people with disabilities aren't safe in open society and need to be “sheltered” to protect them from misunderstandings. The reality is that human beings who are under extreme stress and having trouble coping are in danger of mistreatment, injury, or death no matter where they are. Segregated settings, large and small, have been shown to be at least as unsafe as the streets for such people, and perhaps more so. Moreover, a constant percentage of human beings always has, and always will, find themselves in that position. The only variable is how much we can learn about the human mind, how much we can learn about how to respond to people in distress in ways that protect them and ourselves. We've already learned more than we practice. Practice makes perfect.

# Disability Integration Act: Can It Work?

In January, NY Senator Charles Schumer introduced the Disability Integration Act (DIA) in the Senate as bill number S.2427. On March 21, Senator Schumer visited STIC to speak in support of the bill.

The bill is the successor to the “Community Integration Act” which now-retired Senator Harkin introduced in 2014. Unlike that bill, the DIA is a stand-alone civil rights bill that does not modify the ADA. It was written by ADAPT in consultation with various other well-respected disability rights advocates, including the Autistic Self Advocacy Network and the Bazelon Center for Mental Health Law. Its supporters say that this collaboration and the bill's language effectively address all significant concerns. Although we support the bill, we aren't completely sure it is free from problems, as we'll explain below.

The bill starts out by codifying many of the recently-issued federal “community based” settings regulations (see page 8) into federal law, but it goes far beyond that.

Notably, the only type of group home that meets the DIA definition of a community-based setting

is one that complies with the federal Home and Community Based Services (HCBS) requirements for group homes, *and* has four or fewer residents. And unlike the HCBS regulations, the DIA contains no rules allowing the basic rights of those residents to be abridged for “health and safety” purposes. However, since the bill does not affect the federal Medicaid program in any way, it does not prevent the application of those rules to smaller group homes that are funded by Medicaid—which is likely to be the only available funding source for them.

The bill contains a definition of “long term services and supports” that must be available in community-based settings that is both broader and more specific than any currently in federal or NY law or regulation. This is intended to prevent state governments from conveniently (read “deliberately”) “misinterpreting” the requirements or leaving critical things out of the lists of services they will pay for. It includes the three categories that appear in the regulations for the Community First Choice (CFC) program:

- “Activities of daily living” (ADLs), which means basic hygiene and self-care tasks such



*STIC Executive Director Maria Dibble and Binghamton Mayor Richard David listen to Senator Schumer*

as getting in and out of bed, bathing, using the toilet, dressing, and eating.

- “Instrumental activities of daily living” (IADLs), which is supposed to mean any non-medical thing, within reason, that needs to be done in order to make it possible, or desirable, to do the things in the above list. (That’s right, getting out of bed in the morning is an ADL, and IADLs are supposed to include anything that gives you a reason to get out of bed in the morning.) This category has historically been very narrowly interpreted. Various, it has included cooking but not shopping for food, getting out of bed but not out of the house, doing laundry but not buying clothes, and transportation to medical appointments but not to work. More recently a few things have been added by some states, such as money management and shopping. Many Medicaid waivers have also created separate categories of service that really should already be covered by this category, such as help getting a job or participating in community activities. This has created a patchwork of differing service eligibility and qualifications requirements that still has a lot of holes. Of course, “anything within reason” is not a legal term, and it freaks out bookkeepers at the federal and state levels, so the bill explicitly states that “environmental maintenance” of the home (tasks like shoveling snow, raking leaves, and cleaning gutters), and “care of others,” including children and pets, are listed. The bill also requires availability of “safety monitoring” services; it includes explicit support for “responding to emergent situations or unscheduled needs requiring an immediate response” and to “help the individual with orientation, memory, and other activities of independent living.” Behavioral support, and assistance to enable a person to form meaningful relationships are also included.

- “Health-related tasks” are things that a nurse or medical aide might do. The CFC regulations leave these largely undefined, but the DIA specifically includes medication administration and maintenance of ventilators, catheters, and ostomies.

There’s also a catch-all category that covers “other functions, tasks or activities related to an activity or task described in” the first three categories.

Oddly, the bill is limited to assistance provided directly by human beings. It doesn’t include requirements to make assistive technology or

environmental modifications available (though money spent on the latter is incentivized).

The second striking provision of the DIA is that it effectively makes illegal a state’s failure to ensure adequate funding to make all of this stuff available. It explicitly prohibits applying cost or service caps to individuals if they would result in denying any needed service of the types listed. It also requires states to set rates of payment high enough to ensure ready availability of all of those services. It even prohibits waiting lists for services. However, since the bill doesn’t touch Medicaid, it may not be possible to argue in court (it will inevitably go to court), that the DIA requires states to increase Medicaid spending, or that it requires the federal Centers for Medicare and Medicaid Services (CMS) to let a state use Medicaid for things that aren’t explicitly covered by Medicaid law or regulations.

The third major component of the bill is its housing requirements: Under the DIA, it would be illegal for a state to fail to make available adequate affordable, accessible and integrated housing, “including the availability of an option to live in housing where the receipt of services is not tied to tenancy.” In other words, “supportive housing” can’t be the only option. Plus, the law requires states to make housing for people with disabilities who have “the lowest incomes” top priority over any other housing development until there is adequate housing available for that group.

The bill allows states 42 months to prepare a transition plan to comply with the law, and up to 12 years to achieve full compliance. The plan must include annual targets with specific numbers for transitioning both individuals and funds from “institutional settings” to community-based services and supports as defined in the bill. For each year in which states comply with their own transition plan, their Federal Medical Assistance Percentages (FMAP) for any type of HCB services will increase by 5 percentage points. This is a nice incentive—but it refers only to Medicaid funds. With Medicaid funds come Medicaid regulations, some of which are more restrictive than DIA permits. Especially concerning are the Medicaid requirements regarding “health and safety,” which are frequently interpreted to encourage or permit restrictions on the exercise of civil rights by people whose disabilities affect behavior. If Medicaid regulations are not modified to mirror the DIA rules, then states

would have to use state-only money to provide some DIA services, and the increased FMAP won’t help them do that.

The bill lets individuals collect both actual and punitive damages for violations, and requires the federal Department of Justice to monitor state’s performance in order to detect violations.

According to ADAPT, the DIA “avoids changing Medicaid policy, including the HCBS setting rules,” in order to prevent operators of less-integrated so-called “community-based services” from opposing it (typically service providers for people with developmental or mental health disabilities). However, it does require new regulations from the federal Department of Health and Human Services (DHHS), which oversees CMS. The bill’s definition of “community based services” is fundamentally different from the one in the CMS HCBS regulations. It is hard to see how DHHS could respond except by writing a separate set of rules, based on the DIA definition, that don’t apply to any program funded under the HCBS regulations—but such a separate program would not have a federal source of funding. In order to understand why this is a problem, we have to think like CMS regulators, so bear with us for a moment.

Like Medicaid-funded services, the DIA is dependent on partially-defined concepts of “institution” and “institutionalization” for determining eligibility. Medicaid HCBS services, including CFC, are only available to people who meet an “institutional level of care.” Those who meet that requirement can then choose to be served either in the “institution” or through the HCBS program. The DIA, similarly, only applies to states that operate “institutional settings,” and its services only have to be available to people who are eligible to be placed in them, but it does not define that term. Since the bill’s authors want to avoid changing the Medicaid regulations, they may think we can defer to a definition in those regulations. But the federal authority to issue those regulations comes from the provision of Medicaid funds, and those regulations require some things in return for those funds that the DIA does not permit, which may mean a state can’t use Medicaid money to pay for them, which would in turn make everything in the Medicaid regulations completely inapplicable to DIA services.

DHHS regulators will probably conclude that what the DIA does is interpose another level of “choice” into the selection process. One might assume that the choice comes after selecting “institution” vs. HCBS. But the DIA language does not justify that. The DIA does not regulate Medicaid. That choice only exists within Medicaid. DHHS may assume that your choice is Medicaid services or DIA services. Medicaid comes with money; so if you choose Medicaid and then HCBS, you stand a decent chance of actually getting services. The DIA does not come with any money, so if you choose DIA, it falls to the states to come up with the funds.

Now the bill’s authors are probably saying, “that’s absurd.” But they don’t think like regulators. Regulators will say that the DIA does not provide any statutory authority to change the Medicaid program in any way, and they will likely refuse to do so.

Do you think we’re kidding? Various federal courts have found that the *Olmstead* decision does not allow states that provide any amount of community-based services while also operating institutions to claim an undue burden when asked to expand those services, because in the aggregate, the costs of those services are equal to or less than the equivalent institutional services, such as nursing homes. In other words, Medicaid money is fungible, and states can be expected to shift it around to meet the needs of people coming out of nursing homes. It is a well-accepted legal principle that a US Supreme Court decision erases any federal laws or regulations that conflict with it. There is no need for Congress to rewrite any law to put that erasure into effect. However, although a nursing home, among other things, provides a place to live and food to eat, CMS is still refusing to accept the notion that *Olmstead* has pre-empted Medicaid law’s prohibition on using the Medicaid funds that paid for a person’s nursing home stay to then pay for food or housing when s/he leaves the nursing home. CMS certainly won’t agree that a new law not ordering them to change the Medicaid program somehow still requires them to change it.

That means that Medicaid funds will not be available to pay for anything the DIA requires but which Medicaid does not permit. You won’t, for example, be able to claim that under the DIA, operators of group homes with four

or fewer residents can’t restrict the availability of food on the basis of a “health and safety” exception. The Medicaid regulations specifically grant that option to group home operators, and the DIA *does not change Medicaid*. Get it? This problem will be apparent to the first federal judge who has to address it, and that will happen as soon as the law takes effect, because states are not going to stomach a massive new unfunded federal mandate.

But let’s assume we get past this legal hurdle, and that choosing HCBS instead of “institution” confers the ability to use Medicaid funds under the DIA to pay for additional services not regulated the same way Medicaid services are. The HCBS regulations don’t clearly define “institution” once we get beyond the level-of-care determination and a person chooses HCBS. Yes, HCBS is not available in nursing facilities or ICFs formally designated as such. But there are places that look a lot like them without going by those names. The HCBS regulations refer to those places in terms of whether they have “qualities of an institution.” Those “qualities” are only vaguely described, and our interactions with CMS officials indicate that what they actually mean is determined by the personal opinions of CMS Regional Office staff who have more or less cozy relationships with the state officials they are supposed to oversee.

Remember that the DIA only applies to states that actually operate “institutional settings” but does not define what that means. Since the CMS HCBS regulations only permit use of HCBS funds in settings that, in those potentially biased regulators’ opinions, do not have “institutional qualities,” it is possible that by 2019, when those regulations take full effect, some states may be operating what disability rights advocates would consider to be institutions that do not violate those regulations. Would the state then have *any* legal obligation to comply with the DIA, at least in relation to the disability classes that are no longer in, or at risk of placement in, “institutional settings” as loosely defined by whatever statewide HCBS transition plan state bureaucrats succeed in getting past their buddies in the regional CMS office? Suppose, for example, in its post-“institutional” service system, a state relies primarily on 12-bed group “homes” and congregate “day habilitation” programs for people with developmental disabilities, and does not have an effective way to ensure that

every person in those settings made an uncoerced informed choice to be in them and not in real homes or real jobs? What does the DIA offer those people in terms of effective enforcement? Probably nothing.

It is not enough to redefine “community based.” We must also clearly define “institutional” as any setting that does not conform to that new definition. For example, if the only “community based” group home is one that has four or fewer residents, then any group home that has five or more residents should be defined as an institutional setting, and the existence of such homes in a state must trigger the requirement for that state to fully comply with DIA. Even better, why not make a clean break with the tradition of defining people’s needs in terms of their eligibility to be “institutionalized” if those needs aren’t met? Having a disability that requires you to get help with any significant life activity should be enough to make you eligible for that help. Period.

Medicaid drives the provision of all long-term supports and services in the US (Medicare coverage for some similar things is sharply time-limited). It is Medicaid’s “institutional bias”—the requirement that all state Medicaid programs must pay for nursing facilities, while paying for adequate community-based substitutes is optional—that causes people to be kept in Medicaid-funded institutions instead of receiving Medicaid-funded community services. It is safe to say, if Medicaid did not exist, neither “institutional” nor “community” services would be available, except for rich people. We cannot change the balance of “institution” vs “community” without changing Medicaid and the regulations that control what it will pay for. And we cannot convince either CMS regulators or federal court judges that Congress had the desire or intention to make those kinds of changes unless it makes them explicitly, in legislation.

We want to be clear: we fully support the intent of the DIA and most of the ideas in it. We just want those ideas to be contained in legislation that will actually work.

It seems clear that the DIA will not be passed in 2016. Assuming the November elections result in a government that has a prayer of passing such a bill in subsequent years, there should be time to modify the DIA language to address these issues, and we hope that will happen.

## Under New Management

On May 6, 2016, the federal Centers for Medicare and Medicaid Services (CMS) published a long-awaited final set of regulations for Medicaid managed care. At press time we had read about 400 of the document's 1425 pages. We'll finish reading it if we live long enough, but in the meantime we wanted to let you know about a few points of interest to advocates.

### Community Based Settings

The regulations clearly state that the new CMS definition of "community based settings" applies, in full, to any type of Medicaid managed care program. This is good news.

That definition was issued in March 2014, but it only formally applied to three specific Medicaid programs that pay for "Home and Community Based Services" (HCBS): Section 1915(c) Medicaid waivers, Section 1915(i) "state plan" HCB Services, and the Section 1915(k) Community First Choice program.

The definition requires that any setting in which HCBS is provided, as well as any setting in which any HCBS recipient lives, whether or not HCBS is provided there, must not have "qualities of an institution," must optimize and not regiment the autonomy of individuals, must not isolate the person from the community, and must afford options for community participation, interaction with nondisabled people, and paid competitive employment, that are the same as those options available to nondisabled people. HCBS participants also have the right to choose a private living situation in or out of a disability-specific residential setting, and the right to choose one's roommate. Further requirements pertain to any residential setting that is not the person's own (or rented) home or that of his/her family. They include the right to a lease or lease-like agreement, lockable doors to one's bedroom or apartment to which the individual has a key, freedom to come and go at any time, access to food at any time, freedom to have visitors at any time, and freedom, and adequate staff support, to have an individual activity schedule that may differ from those of other residents.

Equally good, the new regulations also specifically require all Medicaid managed long-term care plans to follow the same person-centered planning rules that appear in the HCBS regulations, including the conflict-of-interest provisions.

Although Medicaid managed care falls under different program titles from the HCBS pro-

grams listed above, the programs designed by states may provide services that are identical, or very similar, to HCB services. CMS had stated previously that it "expects" any state Medicaid managed care program that offers such services to comply with the HCBS rules. CMS also sent a letter to the NYS Department of Health (DOH) that said as much. Now, this requirement is formally on the books for all Medicaid managed care programs, whether they are part of a Section 1115 "experimental" waiver or not. These changes may have closed the door on any increased "flexibility" that NY thought it could get by using an 1115 waiver amendment to bring managed care to OPWDD.

Unfortunately, CMS took a step back on the issue of self-direction; they said they will not require self-direction options in Medicaid managed long-term care. We don't know how this will affect NY's "Transformation Agreement" with CMS, which requires the state to offer that option.

### Internal Appeals

The new regulations also contain a troubling change: Every Medicaid managed care participant who has services reduced or denied, and objects to those changes, must follow their managed care plan's internal appeals process before they can request an unbiased Medicaid fair hearing.

States used to have the option of letting people go directly to the fair hearing in these cases. But CMS wants to make the rules as uniform as possible between Medicaid, Medicare Advantage, and private insurance, including subsidized insurance available from "Obamacare" healthcare exchanges. The option to skip an internal appeal doesn't exist for other types of insurance.

However, CMS did limit internal appeals to one "level," after which you can get the fair hearing. The new rule "shortens the managed care plan resolution timeframe for standard appeals from 45 days to 30 calendar days and shortens the managed care plan resolution timeframe for expedited appeals from 3 working days to 72 hours." And it lengthens the time you have to request a fair hearing from 90 to 120 days. States can also opt to offer an "external medical review" of service decisions. States that do this can't require people to use it, must make it available free of charge, and can't change the timetable for internal appeal resolutions or fair hearing requests.

### Rates

Some of the new rules appear to tighten requirements ensuring that rates paid to managed care plans are high enough to cover the costs of services, including paying providers enough to ensure that they have adequate staffing to meet service needs. Rates must be "actuarially sound," which means they must be separately determined and adequate to cover the rationally-projected costs of meeting objectively-documented needs. The actuaries who set rates may be directly employed by the state, but not by managed care plans, and their work must conform to generally accepted actuarial principles. It will be reviewed in detail, and must be approved, by CMS before rates are finalized. And it must be re-done annually, with more recent data, thereafter. The rate-setting process must also be designed so that no less than 85% of rates paid to MCOs will be used for actual service provision, or for "workforce enhancement" or "quality improvement" activities (such as better training, pay or benefits for direct service workers). The rules clarify that any other factors that some states have applied to rate setting, such as reaching cost-cutting targets or incentivizing some types of services and discouraging others, cannot be used. We can't really analyze these new provisions in depth since we don't know enough about what's in the old rules.

The rules will phase out the use of "pass through" payments in Medicaid managed care. This is money that a state specifically intends to go to certain hospitals, nursing facilities, or physicians for any number of reasons. The funds are given to the managed care organization, which is directed to hand them over to the designated providers, without "managing." We think the Cuomo Administration has been doing this in order to keep some "pet" downstate hospitals and nursing facilities open that would otherwise go out of business due to under-use.

States would be able to provide extra funds outside the capitated rates paid for individual services to managed care plans and direct those plans to use them for across-the-board rate increases for all of their network providers, in order to improve availability of services. They would also be able to tack on small (no more than 5%) performance incentives to the rates.

States could also impose penalties for poor performance on MCOs, but must limit those penalties to ensure that actuarially sound rates can still be paid to the service providers.

These regulations could go a long way toward addressing the problem of enforcing the federal Medicaid law Section 1902(a)30(A) requirement that states must pay Medicaid service fees

that are “sufficient” to ensure that services are adequately available to people who need them. We’ve covered that issue previously; see, for example, *Armstrong v Exceptional Child Center, Inc.* in *AccessAbility* Spring 2015. As we wrote then, “At bottom, this is a dispute about the politics of government spending. Must states rationally consider facts, such as how much it actually costs to deliver services? Or can they simply say that budgeting is a political matter between the state legislature and the governor, and let people who are rich enough to make campaign contributions, and who don’t want their taxes raised, control the process?”

The new regulations come down pretty heavily on the side of rationally considering facts. They don’t apply to “fee for service” Medicaid, but those programs have been steadily shrinking as managed care becomes the norm.

Most of these rules will begin to take effect for new managed care contracts that start in 2017 or 2018. The phase-out of pass-through payments may take up to ten years. Hopefully we will finish reading them before then and pass through our interpretation to you.

## State Budget Wrap-Up

Disability rights advocates scored some victories in the final state budget legislation.

As usual, Cuomo’s efforts to end “prescriber prevails” and “spousal refusal” were defeated by the legislature.

The governor’s proposal to allow granting of waivers of various special education requirements to specific school districts was included in the Senate’s budget bill but the Assembly rejected it.

The budget does include a one-year delay of the Department of Health (DOH)’s plans to transition the state’s Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid waivers to managed care. DOH is also directed to ensure that “comparable” services to those provided by those waivers are included in managed care plans. At press time DOH had done little on this issue beyond what we reported in March, raising concerns among advocates that the extra time will not be used productively to generate a better transition plan.

Advocates succeeded in getting the governor to introduce his own bill to modify the Nurse Practice Act in order to enable the Community First Choice program to cover “health related tasks.” Unfortunately, at press time there was no action on this bill to report.

## OPWDD Double-Talk

As we reported last time, the state Office of People with Developmental Disabilities (OPWDD) had released its application to the federal Centers for Medicare and Medicaid Services (CMS) to renew its Medicaid Home and Community Based Services (HCBS) waiver for public comment.

They responded to that comment on March 28, and reported that CMS had approved the application on April 5. Although OPWDD thanked the 90 individuals and organizations that provided comments and claimed that they were “crucial,” the agency announced that it was not changing much of anything in the application. Instead, CMS’s approval notice requires OPWDD to submit an amendment later this year to address some fiscal changes and to begin to implement actual service reforms. Those reforms will follow the agency’s Transformation Panel recommendations, on which we’ve previously reported.

We can report that OPWDD finally responded to our repeated calls for a discrete “safety supervision” service. As we’ve said, in the future OPWDD can no longer rely on segregated congregate residential or “day” programs to bring supervision “along for the ride” for people who need it. It is elitist, judgmental, and psychologically harmful to demand that people continuously pursue self-improvement goals and participate in “meaningful activities” in habilitation programs in order to get a supervision “side-effect” from habilitation workers.

We’ve been repeating these points for several years now. OPWDD finally said that it intends to work with DOH to create a service like this later this year.

That probably just means they expect the new Community First Choice (CFC) program, which can provide stand-alone “supervision and cueing,” to be available to OPWDD-eligible people. CFC is a “state plan” as opposed to waiver service. That means that people on Medicaid waivers can use it for things that aren’t available from their waivers without being accused of “double dipping.” So this would effectively create a service similar to the Home and Community Support Services option that TBI and NHTD waiver participants have. Doing it this way isn’t as flexible as the proposed federal Disability Integration Act (DIA) claims to make it (see page 5), but it may turn out to be workable. It depends on the final design and regulations for the CFC

program—which won’t be completed this year no matter what OPWDD says.

Meanwhile, more evidence emerged that OPWDD expects to be allowed to weasel out of its agreement with CMS to close sheltered workshops. The agency’s guidance for workshops that want to convert to “integrated employment settings,” which allows those facilities to be almost completely and permanently segregated, was part of the waiver application that CMS approved. OPWDD also said, in response to comments, that it expects to pay for supported employment services in those bogus settings, even though the agency’s own regulations require that supported employment can only be provided in settings that employ the “general workforce.” Once these facilities get their fake “conversion” plans approved, they’ll be free to start admitting new people again. It would appear that CMS lacks the intestinal fortitude to enforce its own rules in this regard, and that doesn’t bode well for federal enforcement of any of the other new rules.

## Federal Mental Health Reform, or Not?

At press time advocates were warning that partisan feuding in Congress might derail passage of any bill to improve services for people with mental health disabilities this year.

As we reported last time, the Comprehensive Behavioral Health Reform and Recovery Act had been introduced in the House of Representatives to clarify HIPAA privacy provisions allowing release of information to prevent an imminent threat to self or others posed by a person with mental illness, beef up enforcement of federal mental health “parity” rules for insurance companies, expand Medicaid and Medicare funding for short-term crisis admissions to psychiatric hospitals, and offer many new grant opportunities to enable states to increase mental health services. The bill excludes the worst elements of the so-called “Murphy bill,” which would require states to make more use of court-ordered treatment programs like New York’s “Kendra’s Law” as a condition of getting more money, and would prohibit federal Protection and Advocacy programs from advocating for the civil rights of people with mental illness, including the right not to be forced into treatment or segregated programs. Neither the Murphy bill nor the Behavioral Health Reform Act has progressed in the House since our last report.

Meanwhile, a bipartisan group of Senators created a more limited bill, called the Mental

Health Reform Act of 2016, and got it through that chamber's Health committee. It was awaiting debate on the Senate floor at press time.

This bill seems to have some of the same provisions as the "good" House bill but does not appear to be identical. Notably, it does not contain an expansion of Medicaid funding for in-patient crisis management services. Some Senators were vowing to introduce an amendment to include that feature, and other amendments were also being discussed, including, perhaps, inclusion of the bad Murphy bill provisions. However, the Congressional Budget Office estimated that the various new grant opportunities and service expansions would cost between \$4 and \$6 billion per year, and Congress watchers suggested this price tag might kill any chance for passage.

Some mental health advocates are firmly opposed to any expansion of funding for services in psychiatric hospitals. While STIC understands that this objection is rooted in fears of a return to forced long-term institutionalization, we don't think that's a real worry.

Short-term inpatient crisis stabilization services are not "institutionalization." They

are acute medical treatment, just as short-term inpatient treatment for a heart attack or pneumonia isn't "institutionalization." Serious mental illness exacerbations cannot be effectively treated on an outpatient basis any more than serious acute physical problems can. Both kinds of services are essential to a community-based health system; they make it possible for people to live in their own homes and participate in the community to the maximum extent of which they are capable.

There is a severe shortage of these services in our region. That means that people in crisis may get temporary assistance to delay an immediate disaster in the making, but they can't get the evaluation and service planning necessary to regain productive stability. This is what leads to homelessness and encounters with law enforcement. More community-based crisis response services are certainly needed, but for some people their role is only to temporarily keep the person out of serious trouble, including jail or the emergency room, while treatment is arranged. Not everybody in crisis needs a hospital admission, but for those who do, there is no viable alter-

native, and never will be. We could increase funding for all types of community services and supports by 1000%, and we should; but there would still not be enough inpatient crisis stabilization services to meet the real, irreducible need.

We think mental health advocates would better serve their constituency by recognizing this critical distinction between short-term crisis stabilization services and long-term institutional placement. It really doesn't matter whether the service is provided in a general hospital, a "clinic," or in a psychiatric hospital or "institution for mental disease" as the archaic Medicaid and Medicare regulations call it. The name of the facility doesn't matter. The availability of "beds" for temporary intensive treatment does. More high-quality service "beds" need to be added in whatever building can most easily and quickly add them.

We'll continue to follow this issue and hopefully members of Congress can set aside their partisan wrangling long enough to produce something of value before the campaign season begins in earnest.

## courts watch



### ***Myers v Schneiderman: Exercise in Futility?***

This suit sought a ruling that New York State's law prohibiting physician-assisted suicide violates the state constitution. It was filed on February 4, 2015, in the Supreme Court for New York County, where the plaintiffs lost. They appealed, and now Judge Mazzarelli of the NY Supreme Court Appellate Division has ruled against them.

Twenty years ago the US Supreme Court ruled, in *Vacco v Quill*, that the NY law does not violate the federal constitution. Some of the Myers plaintiffs were plaintiffs in that case. Some people just don't give up.

The plaintiffs made three weak arguments.

First, they claimed that the state law does not prohibit "aid in dying," it only prohibits "assisted suicide." Their main justification for this was that other states have passed laws renaming assisted suicide "aid in dying." The judge replied that courts are usually bound

by commonly-used definitions of terms. She pulled out her Merriam-Webster and found that "suicide" is "the act or instance of taking one's own life voluntarily and intentionally," especially "by a person of years of discretion and of sound mind." Plaintiffs' argument that the people who want to do this don't really want to die, they want to escape suffering associated with inevitable death, is irrelevant to the definition. Assisted suicide laws require the individual to voluntarily and knowingly self-administer a lethal dose of drugs prescribed by a physician. They are committing physician-assisted suicide as the dictionary defines it, no matter what they call it.

The plaintiffs also claimed that NY's law violates the state constitution's due process and equal protection provisions because, while the state allows people to refuse medical treatment and die as a result, it doesn't allow physician-assisted suicide. *Vacco* was decided in favor of the NY law on that same point. This is not a case of one class of people being arbitrarily denied le-

gal protections that are granted to another class. NY law allows everybody to refuse treatment and die, and prohibits everybody from having doctors help them kill themselves. Further, as the Supremes said, the difference between refusal of treatment and physician-assisted suicide is well-accepted by most medical authorities, and the government can rationally assert a compelling interest in both protecting the rights of individuals to do what they wish with their own bodies, and in protecting the integrity of the medical profession by not blurring the line between helping and harming patients. As Mazzarelli said, the plaintiffs don't have a new reason why the "New York State Constitution should be construed to extend the right to refuse treatment, and let nature take its course, to a fundamental right to receive treatment that does the opposite."

That leaves the plaintiffs one more option: The Supremes said in *Vacco* that, over time, public attitudes may change, and it may become reasonable to revisit the issue. However, they said, "a particular plaintiff hoping to show that

New York's assisted-suicide ban was unconstitutional in his particular case would need to present different and considerably stronger arguments." To support this contention the plaintiffs referred to four medical associations that have issued public statements in favor of assisted suicide. These groups are frequently cited by national assisted-suicide lobbyists. But two of them, the American College of Legal Medicine and the American Medical Women's Association, have also said that not all of their own members agree with that position. Notably, the American Medical Association, arguably the most influential such association, remains opposed to physician-assisted suicide. The plaintiffs also referred to two 2013 public opinion polls frequently cited by assisted suicide proponents. One found that "70% of

Americans are in favor of allowing doctors to help terminally-ill patients end their life by painless means" and the other that "62% of Americans believe that patients should be able to end their life if suffering great pain with no hope of improvement." The judge pointed out that these polls are ambiguous; they could simply mean that people are in favor of the options that are already available to address end-of-life suffering. The judge concluded that the plaintiffs had not demonstrated that there has been a true shift in overall public opinion on this issue since *Vacco*.

It's certainly true that courts may reverse older decisions as social attitudes change. Some people compare the recent Supremes' ruling in *Obergefell v Hodges*, the gay marriage deci-

sion, to this issue. However, that decision did not come until civil unions or gay marriage had already been legalized by state legislatures or court decisions in a majority of states across all regions of the country. The fact that three Pacific coast states and the tiny state of VT have legalized assisted suicide does not create the same impression of a fast-moving wave of social change—yet.

And so this may not be the end of this case. The plaintiffs could take it to the highest NY state court, the Court of Appeals. They could also take the foolhardy step of returning to the federal courts, though in view of *Vacco v Quill*, they would be unlikely to even get a hearing there.

# No Longer Shocking?

In April the federal Food and Drug Administration (FDA) requested public comment on its proposal to ban the electric shock devices used to punish people with disabilities by the notorious Judge Rotenberg Center (JRC) in Massachusetts.

The JRC, a private residential facility for children and adults with developmental disabilities, is the only known program in the world that uses the devices. The agency claims that it only does so as a last resort to specifically control dangerous aggressive or self-injurious behavior (such as head-banging or hand-biting) by people for whom all other possible treatments have failed. The devices are allegedly used only in immediate response to specific dangerous "target" behaviors.

Those claims have been conclusively shown to be lies. Former JRC employees have reported, and in some cases provided video to prove, that the devices are routinely used to punish people for minor misbehaviors such as refusing to take off a jacket or "talking back" to staff. One video shows a resident of the facility being tied down and repeatedly shocked over a period of several hours while exhibiting no behaviors other than cries of pain and pleas for mercy. The JRC records indicate that few if any attempts to use other forms of treatment, such as positive behavioral support, to address undesirable behavior, were made before using the devices. Several parents of

facility residents reported being pressured or "intimidated" by JRC staff into accepting use of the devices even if they requested that different treatments be tried. Although several other parents have said that "nothing else worked" at other schools and residential programs before the JRC began using the devices on their children, investigators have found that in at least some cases, the previous programs in which their children were enrolled never tried to use state-of-the-art treatments. There are also cases in which people who received shocks at JRC were withdrawn from the program and then obtained good results from positive behavioral supports.

The JRC claims, in allegedly "scientific" research papers, that the shock devices are effective at reducing and eliminating highly dangerous behavior. However, almost all of those papers were written by the founder of JRC or its employees; none were published in peer reviewed scientific journals, and they all suffer from flaws that render their conclusions unreliable. There is evidence that shock devices can be effective to immediately stop a behavior, although they are no better at doing so than a simple spray of water mist to the face. There is no scientifically valid evidence that the devices produce any long-term reduction or elimination of undesirable behaviors.

The JRC and some other facilities began using the devices some 40 years ago, at a time when

the causes of aggressive and self-injurious behavior in people with developmental disabilities were not well understood, and before research on strictly "behavioral" treatment (using rewards and punishments to increase or decrease "target" behaviors without investigating the causes of negative behavior) began to show that it was less effective than other forms of "applied behavioral analysis." As evidence grew showing the efficacy of properly-conducted positive behavioral support treatment, other programs stopped using the devices. In fact, these methods are so successful that most experts now believe that any type of "aversive" (punishing) response to undesired behavior is unnecessary in most cases, and some states have banned their use. (In New York, OPWDD has banned the use of any "aversive therapies"; however, the State Education Department, while tightly regulating their use, still permits some "aversives," but not shock devices, in schools, and no longer permits use of state funds to pay for New York students to receive the treatment in the JRC.)

Research has also shown that the shock devices pose significant risks of harm to those on whom they are used, including burns, nerve and muscle damage, and serious long-term psychological effects such as severe anxiety and withdrawal into a noncommunicative state. Use of positive behavioral supports carries no risks beyond the small chance that it will not work.

Despite these developments, the JRC has clung stubbornly to its use of skin shock as punishment, a technique that the United Nations has deemed to be torture. The agency can also count on the dedicated support of a few dozen parents who insist that the practice helps their children when nothing else that was tried did. Massachusetts tried to issue regulations outlawing the practice but those parents sued the state and also convinced some politicians to block the regulations. As it stands today, the only people who can legally be shocked at JRC are specific individuals who have been court-ordered to receive the treatment.

The FDA has concluded that it can ban the devices because the risks of their use outweigh the benefits, because there is no reliable evidence that they are effective, and because better and less risky methods are now available to address dangerous behaviors. If the ban is adopted, it may put a complete stop to this barbarous practice. We at STIC wholeheartedly support the ban.

Unfortunately, the ban will not prevent an exception for “research” to determine if such devices can be designed to make them more permanently effective while eliminating all significant risks of harm.

The law does require anyone who wants to conduct research to submit exhaustive information demonstrating, in advance, that there would be a beneficial purpose for the tests, and that the device is likely to be effective and not harmful. The FDA can reject the application for a variety of reasons, including those it has stated in the proposed ban: that there are better and safer methods already available to accomplish the same goals.

That being said, we remain somewhat concerned about this. The JRC administrators are “on a mission” and they will not be deterred by any scientific findings. If they think they can get permission to continue to use the devices under a research exception, they will certainly try. It is also clear that some of these families would do anything to keep this treatment in place because they are convinced beyond all reason that nothing else could ever work for their children. So if the JRC gets a research exemption they will have no trouble obtaining parental consent to conduct “tests” on several subjects. In our comments on the ban proposal, we will make these points to the FDA and urge them to use every possible justification to avoid granting a research exemption to the JRC or to anyone the facility petitions to act on its behalf.



## Get RIPPed!

by Elizabeth Berka

Delivery System Reform Incentive Payment (DSRIP) Program is the largest part of NY’s Medicaid Redesign. It is a statewide program with goals to reduce avoidable hospital use by 25% in five years, support safety net providers, encourage statewide community level collaboration, and transform the health care delivery system. Care Compass Network (CCN), previously called Southern Tier Rural Integrated PPS, is the local nine county Performing Provider System (PPS) involved in implementing eleven chosen projects and meeting DSRIP goals. Please visit the CCN website to learn more: [www.carecompassnetwork.org](http://www.carecompassnetwork.org)

STIC is a member of Medicaid Matters New York (MMNY), a statewide coalition representing the interests of Medicaid beneficiaries. STIC is working with MMNY to inform community based organizations (CBOs) about DSRIP and CCN through a New York State Health Foundation (NYSHF) grant. We’d like community based entities of any kind to take a few minutes to complete the MMNY survey regarding CBO engagement in DSRIP by visiting the following link: <http://medicaidmattersny.org/policy-advocacy/payment-delivery-system-reform/>.

The survey results will inform MMNY of CBOs’ needs in terms of engagement in DSRIP and will assist MMNY in conducting state level advocacy to ensure the DSRIP process engages CBOs in ways that acknowledge their value and address barriers to their participation. Survey results will be shared in the aggregate and individual responses will not be shared. Thank you for your assistance in gathering this valuable information.

If you are involved in DSRIP related work or would like to be and you’re interested in

connecting with MMNY’s work, please contact Elizabeth Berka: [healthinformation@stic-cil.org](mailto:healthinformation@stic-cil.org). Please visit <http://medicaidmattersny.org/> for information related to DSRIP and other health care advocacy topics we’re working on.

## CATting Around

The Collaboration Action Team (CAT) is a monthly meeting in which a variety of community agencies come together to discuss and problem-solve complex challenging case scenarios. The purpose of this group is to learn about what other agencies offer and to see “what else is out there” when the agency isn’t sure how else to help or what to do next.

The focus is on issues related to individuals with mental health and/or developmental disabilities. Any agency is welcome to join us for discussion, or to present a scenario on which they are working.

Meetings are held at STIC (135 E. Frederick St., Binghamton) on the fourth Tuesday of every month from 11:30 am until 1 pm. Lunch is provided.

There is a confidentiality statement that participating members must sign. Notes are taken and distributed via a password-protected ZIP file. One or two scenarios are presented depending on the size of the group and the number of scenarios we receive. We ask that people RSVP by the Friday before the meeting date so that we can have a head count for lunch. Also, if you have a scenario you would like to present, let us know by the Friday before the meeting as well.

RSVP to either Jessica Arnold ([jessicaa@stic-cil.org](mailto:jessicaa@stic-cil.org)) or Jo Anne Novicky ([joannen@stic-cil.org](mailto:joannen@stic-cil.org)) or by phone: (607) 724-2111.

We hope we’ll see you!

# Make That a *Triple Shot ...* of *Exciting Entertainment*

by Bill Bartlow



#1.) Once again in March we attended “TransWorld”, the National Halloween and Attractions trade show in St. Louis. There were over 10 thousand hunters from throughout the county making sure that they kept on the leading edge of industry standards, products and technology. We returned with some new, guaranteed to get your heart pounding, additions to the Haunted Halls of Horror as we prepare for our seventh annual event coming this October.

We are also very proud to announce that one of HHH’s founding creators, Todd Fedyshyn, was elected by members to a position on the board of the Haunted Attraction Association, the official association of the haunted house industry. The HAA advocates haunts that keep activities on-site and follow standards of ethical, responsible behavior at all times. A key goal of our organization is to promote the safe operation of haunted attractions through affordable, quality safety education and training. Each year, HAA partners with TransWorld’s Halloween and Attractions Show and Mobile Midway Safety Institute to offer the Certified Haunted Attraction Operator Seminar (CHAOS) safety program. Both Todd and I attended the requisite seminars and became certified in those safety courses. The HAA board was thrilled to add Todd to its membership and his and STIC’s advocacy for the inclusion of those with disabilities will now have an increased national impact. Congratulations Todd!



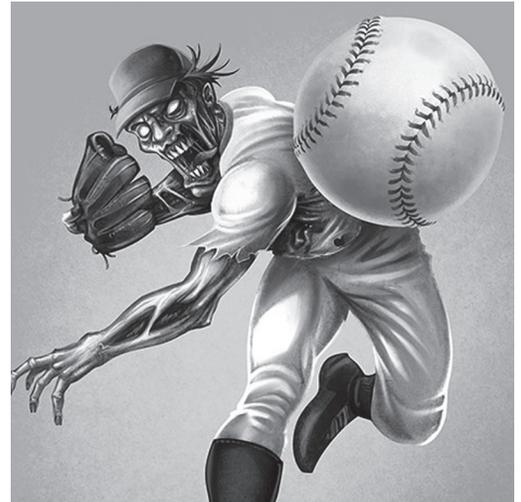
#2.) On May 5, STIC opened the first escape room in the Southern Tier, bringing an innovative new form of entertainment to the Binghamton area. This attraction, like the Haunted Halls of Horror, is a fundraiser for the organization. However we can offer Xscapes all year long.

What, you may ask, is it? Escape rooms are a rapidly growing popular entertainment adventure. You are part of a team of players who are placed in a room filled with puzzles and the clues that you need to solve within a time limit to escape successfully. Choose your team of up to eight people. Can your team do it? Are you and your companions observant, logical, problem solvers with the inherent talent and knowledge to win in record time?

The theme of this premier room is “Valley of the Kings: An Egyptian Adventure”. Enter the study of the Egyptologist explorer. Solve the puzzles and riddles and follow your clues to ultimately reach the pharaoh’s tomb and find the secret passage out.

We encourage you to assemble your own team, cooperatively pool your talents and take on the challenge of “The Valley of the Kings”. Book your group online at [www.xscapes-stic.com](http://www.xscapes-stic.com). We’re open Thursday, Friday and Saturday evenings at 5:00, 6:30 and 8:00.

#3.) It’s baseball time again! We have tickets for two great B-Mets games coming up: Saturday July 2 vs the New Hampshire Fisher Cats at 5:35 pm, and Zombie Night, Tuesday August 23 vs the Hartford Yard Goats, at 6:35 pm. If you buy those tickets from us, a portion of the proceeds benefits STIC.



## Backup Watch

There is a fundamental problem with most so-called “community-based” services for people with disabilities: Lack of reliable backup.

If you have a personal care attendant come into your home to get you out of bed in the morning, what happens when that attendant doesn’t show up? Here’s the basic scenario:

If you get the service through an agency (“traditional” homecare), then you can call the agency and ask for a substitute. Will you get a substitute? Maybe, or maybe not. It depends on the wages the agency pays workers, other benefits it provides, and the size of the community you live in.

The smaller your town, and the crummier the wage/benefit package the agency provides, the less likely it is that a paid substitute will show up to get you out of bed before your next scheduled attendant visit. When this happens, many people call a friend or relative—an unpaid caregiver—to come and help. But not everybody has those relationships to draw on. Some people get stuck in bed for most or all of a day in these situations. If that happens enough, they end up in nursing facilities. Not because they need to be in a nursing facility—there isn’t anything special about the nursing facility that meets their needs any better; you can spend long hours in bed in a typically short-staffed nursing facility too. But some inspecting authority will conclude that they “aren’t safe” at home, and cut off the funds for homecare.

If you use Consumer Directed Personal Assistance (CDPA) services, you can’t call an agency for a substitute. You must make your own arrangements for backup. People using CDPA have a better chance of actually getting that substitute to show up, since it’s been pre-arranged. But being able to identify a pool of people who can work for you, including providing backup, is one of the reasons why only a fairly small number of people can actually use the CDPA program.

Either way, if there is backup, it’s likely to be a relative or friend. Which means that people who have extensive support needs, but no friends or relatives who can help, can’t really live in the community at all—except in the most densely populated urban centers.

Why does this work better in big cities? First, they have larger pools of un- or under-employed people who will take low-wage personal care jobs. Second, there are more people who need homecare, so the traditional agencies have more customers and income to pay backup wages. Agencies in large cities can maintain big-enough “pools” of backup workers on their payrolls to meet the need, whereas agencies in smaller communities may only have one or two workers available. Third, big cities have good public transit systems, allowing these low-paid, often car-less workers to get to people’s homes on short notice. Those in smaller communities typically rely on friends or relatives for transportation, and if they aren’t available, it may take hours to get to work because buses don’t run often enough or in enough places. So even if a backup worker is available, s/he may not be able to get to you fast enough to make much difference.

This isn’t just about traditional or CDPA homecare. It’s a problem with all of the Medicaid waivers that provide similar services. It’s also a problem with hospice services. Having large numbers of service hours “authorized” by these programs is no help at all when there are no workers to provide the service. It just means there will be more unfilled hours in your schedule.

Creating new kinds of personal attendant programs such as Community First Choice (CFC) will not fix this problem in New York State. Availability of workers provided under CFC will be just as spotty in small communities as it is now for CDPA or traditional homecare. That people with more types of

disabilities will be eligible for services provided by CFC workers will be irrelevant if those workers do not show up. It’s not about eligibility. It’s about paid backup.

This is not about “isolation,” either. People seem to think that if somebody doesn’t have a big “circle of support” that’s a bad thing that needs fixing. That’s a false assumption. Many people are “loners” by choice. Does that mean that if they lose the ability to take care of themselves it is appropriate to place them in a nursing facility? Or alternatively, is it appropriate to demand that they suddenly become sociable and outgoing as a condition of being able to get out of bed in the morning? And people should think about whether sitting in an “activity room” (and in some places it’s just the hallway) in a wheelchair all day, staring at your shoes, with a group of other people who are doing the same thing, is really an alternative to “isolation.” Not to mention the fact that an older person may have several relatives or friends who are as old as, or older than, them. Homecare is frequently hard, heavy physical work. There are plenty of vivacious, active older people with strong support networks who still don’t know anybody who can get them out of bed in the morning. All it takes is one hard fall to put them in a nursing facility—permanently.

We don’t need do-gooders telling us that our solitary lifestyles aren’t “healthy”, and we’d better not be told that in order to be a viable community member we are required to have friends or relatives who are not disabled. It’s not about social isolation. It’s about paid backup.

Getting reliable paid backup, even in smaller cities, is not a complicated problem. It’s very simple, really. There are two elements: 1. Pay enough to recruit and retain enough workers to do it. That includes a wage high enough to enable workers to have cars in places that don’t have adequate public transportation. It includes providing health and other benefits that can compete with those offered by other jobs. And it includes paying time-and-a-half overtime when necessary. 2. Recognize that overtime is sometimes necessary.

Residential facilities can mandate workers to put in overtime when needed to cover for unexpected absences because adequate staffing is a fundamental issue of health and safety. It is no less fundamental if you live in your own home. Many private businesses operate on the assumption that overtime is a requirement, and they offer paid overtime and additional benefits to workers. Home-care agencies need to do the same thing—offer an attractive pay and benefit package to attendants who agree to be available for overtime, and mandate that a worker who is on the scene stay there if necessary when the next-scheduled worker can't make it.

Of course, since all ongoing homecare is paid for by the government, this solution requires government to budget more for the service, and pay higher rates to organizations that provide it. This is not an economic problem. We can certainly afford to apply a 20% increase across the board for Medicaid-funded homecare and similar programs; mandate that the funds can only be used for wages and benefits for direct-care workers, not for administrative salaries or perks; and tie future rate increases to some accurate measure of health-service cost inflation. Such a program would still be only about half as expensive per capita as a nursing facility, on average.

So it's not an affordability problem. It's a political problem. And there's a potential political solution on the far horizon called the Disability Integration Act (see page 5), though right now it's probably not a viable option. We'll continue to make the same points in this newsletter until a viable solution emerges.

# COMMUNITY PROGRAMS

## Want to Grow Your Own Food?

by Scott Lauffer

The Gregory Lane Community Garden has a wheelchair-accessible raised bed available for someone who can make use of it. The garden is in the First Ward, across from the parking lot of St. Cyril's Church. There is a bus stop nearby on Clinton St. Help is available for tending your bed and watering. The cost is \$10 but scholarship funds are available. If interested, contact Scott Lauffer at (607) 341-3746.

This is a project of VINES, a non-profit organization committed to developing a sustainable and just community food system in Binghamton. We hope to have more accessible beds in the future.



**Discovery Golf**  
**Golf FORE Good**  
 Miniature Golf Tournament for the  
**Discovery Center Foundation**



**August 18<sup>th</sup>-21<sup>st</sup> 2016**  
**11 am to 9 pm**  
 Inside in air conditioned comfort  
**Oakdale Mall Center Court**

*The Discovery Center Foundation is the group that works to ensure the long term sustainability of The Discovery Center of the Southern Tier. The Foundation has developed a great new concept to help us reach our goals...AND to promote local businesses.*

### Discovery Golf...Golf FORE Good

#### Indoor Miniature Golf

A new, UNIQUE way to support The Discovery Center Foundation and showcase your business or organization

We're setting up 9 miniature golf holes at the **Oakdale Mall** so visitors can take part in **Discovery Golf** during peak Back to School shopping days. Why not be a part of the fun by making or sponsoring a challenging or humorous putting green? Here are just a few examples from last year.

*We'll even help you plan!*



Interested? Call The Discovery Center at 773-8661 ext. 206 or email [nhargrave@stny.r.com](mailto:nhargrave@stny.r.com) for details





This newsletter is also available in large print, on cassette, and online, at: [www.stic-cil.org](http://www.stic-cil.org)

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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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