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(Bureaucratic) Empire State since 1984

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INSIDE

Trumped-Up Health Care Reform

by Maria Dibble

We have all heard a tremendous amount of discussion about the Affordable Care Act (ACA), which some refer to as ObamaCare. Much of what we've heard is what President Trump's Counselor Kellyanne Conway referred to as "alternate facts", and latched onto by the media. I'm going to try to offer some real facts, not popular nowadays I know, but my preferred style of communication.

First, I need to clear up one thing. Many people with ACA insurance hear stories about all the problems with ObamaCare, and want to get rid of it, while at the same time enjoying the lower cost coverage they've obtained through the ACA. The Affordable Care Act and ObamaCare are one and the same. If you or someone you know is getting health coverage through the New York State of Health, more commonly called the "Marketplace", that's ObamaCare.

To lay the groundwork for this editorial, I refer to a recent report released by the NY State Department of Health (DOH), which provides some startling and important statistics, as seen below:

NY saw a 39% increase in enrollment through the Marketplace for non-Medicaid programs between 2016 and 2017. Yet we keep hearing from the President and Congress that the ACA is unpopular and people want to end it. Certainly, statistics don't bear them out.

In 2017, individual premium rates for Qualified Health Plans continue to be 50% lower on average than before the establishment of the NY State of Health. And, even with the implementation of the Essential Plan for lower income New Yorkers, more than half of Qualified Health Plan enrollees are eligible for financial assistance to help further lower the cost of health plan premiums purchased through the Marketplace. Clearly, while some states may be having difficulty attracting plans and keeping costs down, NY is not. (See page 7 for a detailed explanation of what the bill passed by the US House of Representatives would do to the ACA.)

Lastly, about 68% of the people who have enrolled through the Marketplace are on Medicaid.

Why should you care about the potential end of the ACA?

Though many of the people STIC serves get private insurance through the ACA Marketplace, most of them are on Medicaid. The American Health Care Act (AHCA), the bill to repeal ObamaCare passed by the House, would also end the Medicaid "entitlement", the open-ended ability of New York State to draw down federal Medicaid matching dollars to meet the needs of each Medicaid enrollee. This would potentially seriously limit the number of individuals who will be covered, as well as possibly, perhaps even likely, reducing the number of services NY offers. For example, Personal Care is considered by Medicaid an "optional service", yet

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

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NY provides this as well as other critical so-called optional services.

For those who may not know, personal care, including STIC's Consumer Directed Personal Assistance (CDPA) program, provides assistance for people to bathe, eat, use the bathroom, clean, take medication, and much more. The programs keep people with significant disabilities living independently in their own homes, rather than in a nursing facility.

The service is optional, while nursing facility coverage is not, because when Medicaid was enacted 50 years ago, nobody ever heard of "personal care", but they had heard of nursing homes. When people realized that staying home with help was a better idea, they began advocating to make personal care mandatory, but the nursing home lobby fought them, and continues to successfully fight them today. Because of this, states don't have to offer personal care, and many don't. If NY suffers the major cuts projected due to the end of the Medicaid entitlement, the legislature and governor may face the real need to drop these programs.

If you are on Medicaid, you should care very much about the demise of the ACA, because it will mean the total restructuring of the Medicaid system, which is the same as saying we in NY will experience potentially draconian cuts. The Trump Administration and Congress say that their plan is more flexible and can help relieve states of regulatory requirements, but what they don't focus on is that the grants to states will be smaller. Once the money is gone, that's it. Under our current system, anyone who qualifies for Medicaid will get it, and NY gets a 50% match for each person enrolled. Under Congress's plan this will change dramatically. There will be no consistent match, and the guarantee of Medicaid coverage if you are very poor or disabled is gone.

Also, the ACA allowed states to expand the number of people eligible for Medicaid, providing insurance for millions of people. The bill that passed the House eliminates this expansion, forcing people out of Medicaid, with no options left for health insurance. What will end up happening, besides those people not being able to get needed medical coverage, is that they will begin using emergency rooms as their healthcare, knowing they won't be turned away. Why is this bad? Because the hospitals will have to shift the cost, by raising the fees they charge to private insurance plans. That will force those plans to raise their premiums—the thing the anti-ObamaCare politicians complain most about. That probably won't be enough to cover the cost, so states will have to raise taxes in order to subsidize hospitals serving poorer communities so they don't close. Finally, people using emergency rooms as their sole healthcare provider won't have the regular follow-up care of their own physician, nor will they be able to afford medication. If someone is diabetic, for example, this would be catastrophic.

The Trump Administration and Congress haven't taken the "human cost" into consideration. They are intent on repealing ObamaCare because it was a signature achievement of President Obama's administration. They ignore the fact that millions of people will lose Medicaid and other insurance, as stated by the Government Accounting Office, which is non-partisan and offers real facts, not the "alternate" facts that have become the hallmark of this administration.

The statistics show that the ACA can and does work if managed correctly and fairly. Are there issues that need fixing with the ACA? Of course there are, but let's fix them and not throw the baby out with the bath water. We need to preserve the current structure of Medicaid so that millions of elderly, disabled and poor people will be able to lead healthy lives in the community. If we can afford massive increases in defense spending, surely we can afford to care for the neediest Americans.

Have we become so obsessed with cutting taxes, Medicaid and other human services programs that we've lost sight of the humans behind the dollar signs? Have we become so mean-spirited as a people that we've simply stopped caring for anyone but ourselves? The Republicans consistently talk about "core values". I think the most essential of these values is to care for one another. By the looks of the AHCA Medicaid provisions and a glimpse at the President's proposed budget, that value is nonexistent in this administration.

O'Toole v Cuomo: A Conspiracy of Dunces

In March, the federal District Judge for the Eastern District of NY, Nicholas Garaufis, accused the Governor, the state's Attorney General, Department of Health (DOH), and Office of Mental Health (OMH), and an attorney representing several adult "homes," of conspiring to commit a "fraud upon the court" in a deliberate effort to overturn a four-year-old settlement requiring NY to move some 4500 people with mental illness out of adult "homes."

We've reported on this case many times, most recently as "*DAI v Cuomo*" (see *AccessAbility* Fall 2013); the case is now known as *O'Toole v Cuomo*.

Adult "homes" are large institutions, with anywhere from 80 to 250 or more "beds"; they resemble nursing "homes," but without most of the services or regulations. They don't exclusively house people with mental illness, but after psychiatric center closures in the 1980s and '90s, and the state's failure to provide real integrated community supports, they became warehouses for this population.

One of the requirements of the settlement, ordered by Garaufis, was for the state to issue regulations that effectively prohibit admitting any more people with serious mental illness to any of the large adult homes in the New York City area. The facility operators have chafed at this, of course, and they have filed a number of suits against the state to get the regulations removed.

Meanwhile, the state has been working to carry out the other terms of the settlement, which require that all residents of the facilities with "serious mental illness" be assessed and offered the opportunity to move out, either to "supported housing" or to OMH residential treatment programs. Progress has been slow and the state is behind schedule for various reasons (see page 10). Most of the people who have moved out report that they are satisfied, but to date, ten people have returned to the adult homes. This is technically in violation of the regulations, but DOH has granted exceptions when people say that they really can't make it "on the outside."

Thus it would seem to make no sense that a person with mental illness would need to sue the state to overturn the regulations, claiming that he was being denied the option of returning to an adult home. That, however, is just what happened in the case of *John Doe v Zucker* (Zucker is the Commissioner of DOH).

As it turns out, the case is largely a ruse. We don't know if the fictional name "John Doe" masks a real person or not. What we do know is that the attorney representing "him," Jeffrey Sherrin, also represents adult homes in other cases, and he is carrying out a deliberate strategy to attack the regulations by finding people who were unhappy after moving out of one of these facilities into supported housing, and getting them to file suit.

There may be more to it than the regulations, though. The settlement contains a clause ("Section O") that states that if a court decision invalidates any part of those regulations, the entire settlement is put in jeopardy; the parties must renegotiate it, and if they are unable to reach agreement in 120 days, the settlement is void and the case must go to trial. The ultimate outcome of the trial might be the same, but several years would pass during which NY would not have to build more supported housing, and adult homes would rake in more Medicaid funds.

As we have reported, both the Cuomo Administration and DOH have shown that they are not afraid of state or federal courts, because they cannot be forced to make restitution when they lose cases. Whether the goal is to reduce Medicaid spending by illegally cutting services, or to divert Medicaid dollars into the pockets of campaign contributors such as facility operators, the worst that can happen is that a court eventually orders them to stop. By then the damage is done.

The media focused on the fact that the NY State Attorney General (AG), Eric Schneiderman, asked Garaufis to be relieved of his duties to represent DOH and OMH in this matter due to an "impossible" conflict of interest. That is quite an unusual request, but what's really shocking is the reason he made it.

The AG's office has been defending the settlement and the regulations against Sherrin's suits in state court, and even got one of them moved into Garaufis' federal court (the amusingly named *Residents and Families United to Save Our Adult Homes v Zucker*; this alleged organization does not appear to have any independent presence on the web and it is only the first in a long list of plaintiffs, all of which are adult homes or associations representing them or assisted living or nursing facilities). However, an attorney named Michael Bass occupies a very strange position in the middle of all this; he is, according to an AG representative, "an in-house attorney [at the AG's office] who is the director of the Bureau of Litigation at DOH." On November 3, 2016, Bass got a letter from Sherrin concerning the *John Doe* case, in which Sherrin described his strategy to use people with mental illness as pawns to attack the adult home regulations and invited Bass to negotiate a settlement that would remove those regulations.

Bass agreed to negotiate on the basis that the adult home regulations would be removed. The AG's office has claimed that Bass was acting solely for DOH. In any event, a few days later, on November 8, Sherrin and DOH entered into a "tolling agreement," a common legal formality that gives parties to a lawsuit extra time to conduct research and negotiate, and an AG's office attorney signed off on it. At this point the AG was officially representing both sides of the case.

As the negotiations went on, Sherrin allegedly told Bass that they couldn't settle the *Residents and Families* case on the same basis because it had been moved into Garaufis' court, and he would block it. They also took their discussions off the record and began meeting in coffee shops and restaurants to negotiate. They apparently agreed to ask a state Supreme Court judge (despite the name, the lowest level of the state court system) in Albany for a preliminary injunction against the regulations in the *Doe* case instead. Sherrin filed the request with the state judge, Denise Hartman, on February 14, 2017 and the AG's office got a copy. According to Kent Stauffer, another AG staffer, that office was "surprised" by this action, even though it had signed the tolling agreement more than three months earlier. After a hurried discussion, the various AG attorneys agreed that they could not consent to an injunction, just minutes before the hearing began in Hartman's court. Since they didn't think they could withdraw as attorney for DOH and OMH at that late date, they decided to tell Hartman that they would "defer to their clients."

The hearing before Judge Hartman seems to have been pretty informal. No transcript of the proceedings was made. At some point the objective changed, from a preliminary injunction to a temporary restraining order (TRO). Ordinarily, to issue a preliminary injunction, a judge must conduct a formal proceeding where both sides submit evidence. This can take several months. TROs are typically only issued in extreme cases, where a plaintiff can provide some convincing evidence that any significant delay would result in irreparable harm, in which case the judge can issue the order without a formal process. As noted, there could be no imminent risk of irreparable harm in the *John Doe* case, since all "Doe" had to do was ask DOH for an exception to the regulations of the sort the agency had previously granted.

But Judge Hartman seems to have been ignorant of the federal settlement, and of what would happen to it if she issued the order. Neither Sherrin nor Bass seems to have informed her about it, as would have been their duty to do. So she signed the TRO.

None of the parties to this action formally notified Garaufis either, but he got wind of it, and at a pre-scheduled status hearing on the federal case, he demanded to know what was going on. Bass allegedly told him, "I do not think it was contemplated by any of the attorneys in [Hartman's courtroom] that this particular order on this very specific case was going to throw out this settlement." Garaufis then ordered Schneiderman to appear at a hearing scheduled for March 22 to explain "why the OAG took a position in Albany that appeared to conflict with positions it took in the Eastern District of New York, where it is currently defending the regulations."

On February 28 Stauffer submitted a formal request to Garaufis to have the AG removed as counsel for the state or its agencies in all of the federal cases related to this issue, and announced that he would also file to be removed in the related state cases, citing the conflict of interest.

By March 22, Garaufis was boiling. He'd heard from the lawyer representing the original *O'Toole* plaintiffs (the people with mental illness who wanted integrated supports instead of adult homes), Andrew Gordon, who now had copies of the email correspondence between Bass and Sherrin, and he asked Gordon to tell the assembled attorneys what he had learned. Gordon began by saying, "I don't even know how to catalog my outrage" over an apparent conspiracy to defraud Garaufis' court. He asked Garaufis to order an investigation to find out, if possible, what went on in the undocumented meetings between Sherrin and Bass, and to require the AG's and Governor's offices to provide any additional relevant correspondence or documents.

Schneiderman himself wasn't actually there; he was represented by yet another AG employee, Jason Brown. Garaufis said that Stauffer's February 28 memo was, "if nothing else, incomplete, as to the activity of the Attorney General's office in connection with these discussions with Mr. Sherrin, who represents—and has forever during this litigation—the nursing home operators, who are synonymous at least in the Court's mind with the adult home operators in their interests." He told Brown that the AG knew he had a conflict of interest in January or earlier, which he should have reported to Garaufis, and that he certainly should have told Hartman about the federal case. Brown claimed there was attorney-client privilege involved in the relationships with DOH and OMH, which neither he nor Stauffer could violate by revealing everything to Garaufis. Garaufis then threatened to haul them all before a federal grand jury. He also said, "it wouldn't have been a violation of the lawyer-client privilege to indicate [to Judge Hartman] that the State of New York is in a litigation in New York City before a federal court, with a settlement, so at least the state judge could ask questions about what was going on down here."

He then asked Zucker if "Doe" could get an exception to the adult home admissions regulations as others had. Zucker agreed, Garaufis ordered him to grant the exception, and he ordered Brown to go back and tell Judge Hartman that the Doe case was moot and she should lift the TRO. Zucker's attorney, Robert Begleiter, suggested that DOH or some other state authority might have a problem with that, but then said DOH was willing to go on record as agreeing to continue all of the other terms of the settlement, concerning assessing adult "home" residents and moving them to integrated settings.

Gordon and the attorney representing the US Department of Justice both told the judge that since DOH was so willing to continue implementing those terms, there should be no problem with resolving the current difficulty by removing Section O from the settlement agreement, so that any future court decisions on the admission regulations would not derail the process.

Begleiter suggested that the parties could work on this at an already-scheduled meeting that afternoon. Garaufis said, "I don't care that you are going to have a meeting. Meetings can be worthless, if there's bad faith. . . . [A]pparently there are people in the Attorney General's office and the Department of Health who like to have lunch to talk about my case and how to undermine it. So let them have their lunches in Albany, but they have to come down here and explain to me what's going on."

Garaufis ordered a period of "discovery" (sharing of information), and a new hearing on this issue to be scheduled for May 17. Presumably at that time they would decide whether a grand jury investigation was needed, whether the state was going to try to uphold the TRO and terminate the settlement or whether the parties would agree to remove Section O, and whether the already-scheduled new trial would go forward in July.

On the AG's conflict of interest, Garaufis had more to say. Apparently the Governor's office had proposed that Abrams & Fensterman, a New York City law firm that specializes in representing nursing facilities, according to its website, take over as counsel to represent the state and its agencies. Garaufis said, "I'm not going to allow the governor to decide who the lawyer is for the state of New York, where the lawyer he chose has a website that indicates that the firm represents 150 nursing homes. It doesn't pass the laugh test." He suggested that he would consider relieving the AG's office of its duty if they can find some lawyers to replace them who aren't also lobbying the legislature or the governor on behalf of the nursing home industry.

At press time no news on the May 17 hearing had been published. We'll update you next time.

Endrew F. v Douglas County School District: Be Careful What You Wish For...

On March 22, the US Supreme Court issued its decision in this case, on which we reported in our last issue. Endrew was an autistic child whose behavioral issues got worse during his primary school years, but his school refused to provide an Individualized Education Plan (IEP) that could effectively address his behavior and keep him progressing in his education. His parents gave up on the school and sent him to a private segregated program instead. When they tried to get the district to pay the tuition, the district refused and they went to court.

The Supremes ruled unanimously in favor of Endrew and his parents, and in doing so overturned a Circuit Court decision authored, in part, by the man who joined them just 19 days later—Neil Gorsuch.

The Supreme Court's opinion, authored by Chief Justice Roberts, confirmed our speculation that the Douglas County School District refused to provide adequate behavioral supports: "Endrew did much better at Firefly [the private school]. The school developed a 'behavioral intervention plan' that identified Endrew's most problematic behaviors and set out particular strategies for addressing them. Firefly also added heft to Endrew's academic goals. Within months, Endrew's behavior improved significantly, permitting him to make a degree of academic progress that had eluded him in public school. In November 2010, some six months after Endrew started classes at Firefly, his parents again met with representatives of the ... district. The district presented a new IEP. Endrew's parents considered the IEP no more adequate than the one proposed in April, and rejected it. They were particularly concerned that the stated plan for addressing Endrew's behavior did not differ meaningfully from the plan in his fourth grade IEP, despite the fact that his experience at Firefly suggested that he would benefit from a different approach."

The Circuit court, in ruling against Endrew's parents, relied on the 30-year-old Supreme Court *Rowley* decision, which included a statement that the Individuals with Disabilities Education Act (IDEA) requires schools to provide a "substantively adequate program of education" to eligible children, and that IEPs be designed to ensure that students make "some progress," but it does not guarantee a fully equal education. Roberts explained that the Court's decision deliberately didn't get into details due to the specifics of the case: Amy Rowley was a young child with hearing disabilities. The district offered her an FM listening device for her classes and weekly tutoring. Her parents wanted her to have a sign language interpreter. If they had been able to show that Amy wasn't learning without the interpreter, the *Rowley* decision, and 30 years of special education history, would have been different. But she was doing great in school—getting grades that were actually better than those of many of her hearing peers. The Supremes said that her level of progress was good enough, and the district wasn't required to do more.

That was the only intended meaning of that decision, Roberts wrote; its reasoning can't be applied to situations where the student is not actually doing well in school. He said that when a child with a disability can reasonably be expected to learn all of the same things as a non-disabled child in the same grade, then the IEP must lay out at least the same goals for that child. But, he added, "a child's IEP need not aim for grade-level advancement if that is not a reasonable prospect. But that child's educational program must be appropriately ambitious in light of his circumstances, just as advancement from grade to grade is appropriately ambitious for most children in the regular classroom."

Some disability rights advocates applauded the decision. A representative of Autism Speaks, an organization consisting of parents of people with autism and funded largely by pharmaceutical companies, said, "Clearly this is the most monumental IDEA case decided by the high court in over 30 years."

Other advocates complained that the new decision still doesn't set a clear standard for how much progress schools are required to ensure that students with disabilities make. We don't have details on precisely what Endrew's IEP goals were at the private school, or how much progress he made there. Although Roberts' words can be read to suggest that he didn't expect Endrew to do as well as a nondisabled child, it remains true that once his behavioral issues were properly addressed, he did make progress. The reason why the court took this case, the main reason why Roberts said what he said, was to craft a general ruling that could be applied in the future to students with a broad variety of disabilities and capabilities. The concept of "equal" progress is useless here. "Equal" to what? Equal to that of the nondisabled kid with a C-average who drops out as soon as s/he legally can? Equal to a kid with a B average? Equal to the A+ student who gets admitted to Harvard? Bear in mind that all of those outcomes are heavily influenced by factors over which the school has no control. Sure, you can look at a nondisabled student and make some reasonable predictions concerning how well s/he will do, but you can't guarantee that s/he will live up to those expectations. This decision is clearly an improvement over what was in place before, and it is probably about the best we can get, considering how vague IDEA itself is.

Yet we again caution advocates who are excited about this decision: This case was not about whether a public school is required to serve children with disabilities adequately. It was about whether a school district can be required to pay to send those children to segregated "special" schools ***INSTEAD OF*** serving them. It was the private school that delivered the appropriate IEP, enabling the appropriate behavioral and academic progress of this student, and in doing so, the law was satisfied as long as the school district "provided" that result by paying for it.

That can get expensive, so you may think this will be an incentive for schools to work seriously with these children in-house. But history has shown that schools will do almost anything to keep kids with significant disabilities out of classrooms where their presence would require teachers to treat students as individuals, and to avoid enabling real collaboration between "professional" and "non-professional" school employees, disabled and nondisabled students, and family members, in the interests of the child. We would bet that, in the wake of this decision, for a growing number of school districts, "almost anything" will now include paying private school tuition.

Access Living v Uber: Plus Plus Double Ungood Not-Transportation

We have been able to view some of the official documents in this case (see *AccessAbility* Winter 2016-17), which is now more important than ever given the NYS legislature's passage of Governor Cuomo's proposal to allow Uber to operate in upstate communities.

On December 6, 2016, Uber filed its response to Access Living's complaint with the court. In this document Uber took a "deny everything" approach. If you believe everything they said, you would conclude that Uber doesn't really do anything at all. (Page 2: "Defendants [Uber] deny that Uber offers access to travel services or travel services.") Not only that, but Uber's denials of fact contradict each other. For example, on page 7, we find "Defendants deny that Uber provides vehicles." Yet on page 9 there is "Defendants also deny that Uber lacks wheelchair accessible vehicles."

The less frivolous aspects of Uber's defense are these: The drivers who use the Uber app are "independent contractors" who are not subject to Uber's control, and people who install Uber's app and "sign up" for service are automatically bound to follow the company's arbitration procedures to resolve complaints and disputes, and therefore can't sue Uber in any court.

Case law has demonstrated that someone is not an "independent contractor" just because the organization that pays them says so, not even if that person signs a contract to that effect. If the organization that foots the bill has significant control over how the individual delivers whatever they are being paid to deliver, then that person is an employee. If it is true, as Access Living alleges, that Uber specifies the characteristics of vehicles that drivers must use to be eligible to participate in Uber's various service classifications, and Uber inspects those vehicles and directs drivers on how to provide the service, then the court may find that its drivers are not independent contractors at all. This would upend Uber's business model and could put it out of business, since Uber would then assume legal liability for riders' safety, among many other things.

The requirement that riders agree to arbitration looks like a "contract of adhesion"; that is, a "take it or leave it" contract whose terms can only be set by the seller. The buyer has no opportunity to negotiate or modify those terms. Courts are often unfriendly to such contracts and may void unfair provisions in them, so Uber's argument that its arbitration clause governs whether riders can sue could fail.

On the other hand, Access Living's complaint seems weak. It contains a lot of allegations that amount to "so-and-so heard from somebody else that Uber won't provide rides to people who use motorized wheelchairs, so they didn't bother to try to use Uber to get a ride." If that's all they've got, they won't be able to prove their case.

However, the court did not see fit to dismiss the case out of hand, and the deadline for motions was set for February 2018.

Uber is facing legal strictures and lawsuits for issues ranging from sexual harassment of its employees, to criminal evasion of inspection by transportation authorities, to problems with its self-driving vehicle development. The company's refusal to agree that anyone has the authority to regulate its activities has kept it from operating at all in many European countries. This is not a nice company, and the people who run it are not nice people. It is actually more likely that Uber's owners will simply pull their money out of the company and close it down than that they will ever require drivers to provide accessible vehicles. But stay tuned.

AMERICAN PSYCHO

Here's the latest in the ongoing psychodrama that is the Republican push to repeal ObamaCare and radically change Medicaid.

Actually, no, we're not going to recount the stomach-churning lurches and stumbles of the political process that has taken place the last several months. Suffice it to say that for politicians, it is one thing to spout off for one's limited fan base when one knows that no legislation is going to pass, and quite another to get something done in front of all of the voters in your district.

Instead, we'll try to shed light on some of the issues that have been discussed during this process.

Pre-Existing Conditions

One of the biggest things ObamaCare did was to make it illegal for insurance companies to refuse to cover "pre-existing conditions"; that is, any medical issue that you had before you enrolled in their insurance plan. This was not just a problem in the individual coverage market. Before ObamaCare, this was common even in employer-based plans.

With insurance companies being required to cover anybody who came in the door, without requiring them to pay a higher premium if they had chronic health problems, it became necessary to get a lot of very healthy people to buy plans, people who would be unlikely to use the insurance very much. This is why we have the "individual mandate," the requirement that if you don't have employer-based insurance, and you aren't eligible for Medicaid or Medicare, then you have to buy a plan on the insurance "exchange," or pay a penalty to the IRS at tax time.

Since a lot of those people can't afford to pay a lot for insurance, ObamaCare also pays subsidies, funded by your tax dollars, to the insurance companies to cover part of the premiums. The penalties collected by the IRS help pay for those subsidies.

Risk Pools

Pre-existing condition coverage is probably the most popular part of ObamaCare. Nearly everybody who voted for a Republican in 2016 because s/he promised to repeal ObamaCare did not want the pre-existing coverage to go away.

The insurance companies are claiming that there aren't enough healthy people signing up for coverage to pay for the increased cost of health care for the people with chronic health problems that they are required to cover. They are either raising their premiums or dropping out of the individual coverage market. Some people say that these companies are making hasty decisions; the ObamaCare system hasn't been around long enough for them to be able to accurately predict risks and costs in this new "pool" of customers.

But rising premiums and sellers dropping out, for whatever reason, is a real problem in some parts of the country. Of course, people who don't like the idea of government-funded health insurance aren't going to be friendly to increasing the subsidies. Instead, they are looking for ways to cut sicker people out of the market.

The bill passed by the US House of Representatives in May would eliminate the individual mandate, and replace the subsidies with refundable tax credits, but as best we can tell, it would not require many other changes to how ObamaCare works in the individual private insurance market. Instead, it would let states apply for waivers if they want to make those kinds of changes to address rising premiums or companies dropping out of the market.

A state could get a waiver to permit higher premiums for the first year of coverage for people with pre-existing conditions. Presumably, that would not come with a higher tax credit, so those people would have to pay more for coverage—perhaps more than they could afford.

A state could also get a waiver to dispense with the minimum requirements now in effect for a plan that could be sold on the exchanges, but only to people without pre-existing conditions. Insurance companies, theoretically, would charge lower premiums for skimpier plans.

States that applied for these waivers would be required to have some method for ensuring that people with pre-existing conditions would be covered. This would probably involve the state using its own money to subsidize premiums through a "risk pool." However, the proposed bill does not impose safeguards to ensure that these risk pools would be adequate to meet the need. The United States actually has a long history with these types of risk pools; they have always failed because they have always been underfunded. Some so-called "moderates" who were opposed to the earlier bills changed to "yes" votes when an $8 billion fund, to be paid over five years, was added to support state risk pools. Experts pointed out that this would cover a maximum of 700,000 people. It's pretty likely that a lot more people than that would be cut out of the market due to pre-existing conditions. And when the money runs out, if you haven't gotten coverage you go on a waiting list until more money flows into the pool—if it ever does.

It seems unlikely that NY would want such a waiver, and its market is doing well (see cover). So that doesn't seem terribly scary for New Yorkers. What does scare NY's Governor, though, is the special provision that some NY Republicans got inserted to force state government to take over paying the 25% match for federal Medicaid dollars that is now paid by counties. We think this is a good idea, because if we get counties out of having to pay for Medicaid, we can also get them out of causing delays and roadblocks in the eligibility determination process. The Republicans who got this provision added are happy because it should result in lower county property taxes. However, if NY is going to continue to provide the same level of Medicaid services, it will have to raise the state income tax by a hefty amount to recover those lost funds.

Also, along with repeal of ObamaCare, the Republicans want to end the "entitlement" status of Medicaid and impose tight limits on available funds. Since far more New Yorkers coming through the ObamaCare exchange end up on Medicaid than with private insurance, that's a much scarier proposition.

Medicaid Expansion

Along with a way to provide private medical insurance to more people, ObamaCare included ways to bring more Medicaid money into states to cover people with disabilities and/or very low incomes.

When most people talk about the "Medicaid expansion," they mean the provision that raised the income threshold for Medicaid eligibility for nondisabled childless adults. The House bill would end this part of the expansion. In New York that's a big deal because about two-thirds of the previously uninsured people who got insurance as a result of ObamaCare got Medicaid. Most of those people do not have disabilities, though.

But there are other expansions of Medicaid in ObamaCare. They include extra federal Medicaid funds for services provided through "health homes" (see page 9), and the "Community First Choice" program, about which we have written many times.

We don't think most of the proponents of repeal even understand what these programs are or know that a repeal will end them.

The End of the Entitlement

But the greatest threat to New Yorkers with disabilities in all this comes from the Republicans' determination to end the Medicaid "entitlement."

The "entitlement" means that anyone who meets the eligibility requirements for Medicaid is "entitled" to receive as much Medicaid-funded service as s/he needs. The state determines eligibility and provides a share of the funding; the feds are on the hook for the remaining cost for as many people as the state brings into the program. The state has considerable leeway to control spending because it can tweak the eligibility rules and the package of services it will provide. The feds have almost no control. This has always irritated federal lawmakers.

This aspect of Medicaid has nothing to do with ObamaCare. It predates ObamaCare by 45 years. But right-wingers have always hated Medicaid because they see it as free medicine for undeserving poor people. They do not care that almost all Medicaid money is used to provide services and supports to people with disabilities, even though people with disabilities get counted among "the deserving poor" by just about everybody. And they do not really understand the details of how Medicaid is used for this purpose. They just want to destroy it so some allegedly lazy "welfare queen" can't get free birth control. That's as far as they go in their analyses.

It is a measure of how far right the government has drifted that now, for the first time in 50 years, there may be enough votes in Congress to pass a bill to destroy the Medicaid entitlement and hand it to a President who will surely sign it.

Various versions of the bill contained two ways to do this: block grants and per capita spending caps. The bill passed by the House contained the per capita cap.

"Per capita" is Latin for "by the head"; instead of a license to draw down as much federal money as necessary to meet the needs of every person a state declares eligible, each state would be allocated a fixed amount of Medicaid money per year for each head attached to the body of a Medicaid recipient. When that amount has been spent, there would be no more that year for that person. This is how "fully capitated" managed care operates.

A formula to determine the cap for each state would presumably be based on conditions in that state. Many states today get a much higher federal Medicaid matching-dollar rate than NY does; our rate for most purposes is 50%. But under capitation, that matching rate would no longer be a fixed percentage of the total costs. Instead of having to pay no more than 50% of the cost to meet a person’s needs, NY might end up paying 60% or 70% or more. This could very quickly lead NY to stop providing Medicaid services that are “optional,” such as prescription drug coverage and “Level I” homecare. “Level II”—medically-oriented “home health aide” service—is not optional, but not every person with a disability who needs an attendant qualifies for it. Level I personal care includes help with bathing, dressing, using the toilet, getting into and out of bed, and similar things. Without these, lots of people would be forced into nursing facilities, because nursing facility coverage is also not optional.

It is also possible that as compensation for ending the entitlement, the feds might also remove the “medical necessity” rule.

Current federal law requires states that opt to offer a Medicaid service to provide as much of that service as is necessary to meet the individual’s documented medical needs. When it does so, it is guaranteed, in NY’s case, to get 50% of the cost, whatever it is, back from the feds. Of course, NY must still pay 50% out of its own pocket, which is why it often resists obeying the medical necessity rule. But if the state doesn’t have to follow that rule, it can impose all kinds of arbitrary caps on hours of service, numbers of appointments, or even the medical conditions that will be covered. One of the first things to go would likely be the non-medical services, such as service coordination, supported employment, habilitation, and assistive technology, that are covered by Medicaid waivers.

Based on past history, we don’t think that a majority of NY state politicians would want to make these kinds of cuts. We are less sure that a majority would be willing to raise taxes enough to make up the difference. So if a tight cap on the federal share of Medicaid is imposed, we are likely to have a very rough ride indeed.

That is still a pretty big “if.” The US Senate must first pass its own bill (they are starting from scratch, not trying to pass the House version). Then the House and Senate must agree on a compromise version before it goes to the President. It remains to be seen whether there actually are enough members of Congress who will, when push comes to shove, pull the trigger on such a bill. But the right-wingers will certainly keep trying until the voters responsible for this situation realize what they have set in motion and take steps to stop it.

Interesting Conflicts and Other Stories

In May, the federal Centers for Medicare and Medicaid Services (CMS) announced that it is postponing the start date for compliance with the new Home and Community Based Settings (HCBS) regulations for three years, to March 17, 2022. This affects New York’s Statewide HCBS Transition Plan (see *AccessAbility* Fall 2016). To date state agencies have made no announcements as to how, or whether, this will change what they are doing.

However, the new federal conflict-of-interest rules aren’t part of this; they, and the new person-centered planning regulations, are already in effect. And for New York’s Medicaid waivers, the big issue continues to be compliance with the conflict-of-interest rules.

State officials say they have “approval” from CMS to establish new kinds of “health homes” that will take over the service coordination role for all of the waivers. We aren’t sure how final this approval is.

Health homes are a form of case management aimed at people with significant disabilities and certain chronic health issues who are at risk of repeated hospitalization. For example, people who have both serious mental illness and diabetes are eligible for health home service. The idea is to provide some amount of follow-along to ensure people keep their medical appointments and comply with their treatment plans. Under the Affordable Care Act (ObamaCare), states get a higher federal matching rate for Medicaid funds spent for health homes.

New York is understandably eager to get its hands on that money. It is also facing a problem as it tries to move people with developmental disabilities into managed care: this group has higher needs for “case management” than any other group that is under managed care today, which makes the cost of serving them much higher. So having health homes do the service coordination may generate enough extra revenue to cover those costs.

OPWDD is evolving a plan to address the conflict-of-interest rules that will involve moving all current OPWDD service coordinators over to these special health homes, which will be called "Care Coordination Organizations" (CCOs). The agency believes this will let everyone keep their current service coordinator. But those service coordinators will no longer work for their current agency. STIC's service coordinators will no longer work for STIC; ACHIEVE's service coordinators will no longer work for ACHIEVE. If those people want to keep being service coordinators, they'll have to work for a CCO. Since CCOs will cover broad regions of the state, OPWDD believes the service coordinators will need to work "remotely," most likely out of the same offices they occupy now; agencies like STIC would lease that office space to the CCO.

The CCOs will be required to have expertise and experience in delivering a range of services to people with developmental disabilities. The best way to do that is to have agencies with that expertise form and govern the CCOs. STIC is in the process of deciding how we will participate.

We emphasize: We don't like this. We don't think the federal conflict-of-interest regulation requires a solution that results in our service coordinators no longer working for us. But the alternative would be to mandate that individuals who get service coordination from us can no longer also get other OPWDD services from us, and vice versa. We hope that if we participate in governing a CCO, we can influence how it does service coordination to make sure you continue to get the high quality service you have received from us. We also hope that we will be able to ensure that the CCO continues to provide good salaries and benefits to the service coordinators.

OPWDD is talking about taking a year to transition the service coordinators from their current employers to the CCOs once this process begins. OPWDD is supposed to issue a "Request for Information" to service providers in May as a first step in the application process for organizations that want to form CCOs. The agency has a timeline for the entire process but we don't think it's worth reporting here; OPWDD has not met any of its self-imposed deadlines for anything since it began its service reform process in 2010.

Meanwhile, the state must submit a waiver amendment to CMS to get formal approval for this. That amendment will be subject to public comment, and you can be sure that we will respond.

We've heard that CMS has told the NYS Department of Health (DOH) that the TBI and NHTD waivers must begin following the conflict-of-interest rules by January 1, 2018. We've also heard that the same health home/CCO concept will eventually be applied to those waivers. It seems unlikely that any CCOs could be up and running by that date. However, there is a "geographic scarcity" exception for the conflict-of-interest rules; people can get both service coordination and direct services from the same agency if there is only one agency in the "geographic area" that can meet their needs for both of those things. The OPWDD environment is very service rich; it is unlikely that such a scarcity situation would arise for it except, perhaps, in the North Country. But the TBI and NHTD system has a severe shortage of service coordinators and service coordinator agencies. For most participants, at least in upstate NY, there is only one choice of service agency, and there are a lot of people on waiting lists for those waivers because they can't find service coordinators. So about all DOH needs to do in the near term is issue a formal plan to CMS explaining this situation and requesting approval for the "geographic scarcity" exception.

We don't believe that should let them off the hook for beefing up the service system to meet federal requirements for network capacity when those waivers are moved into managed care. However, the deadline for that move has been extended again, to January 2019.

Too Little, Too Late

On April 3, Clarence Sundram, the former state disability services oversight "czar" whom federal District Court Judge Garaufis appointed to monitor the *O'Toole v Cuomo* adult home settlement, issued another periodic report that was highly critical of the settlement agreement's process to move people with mental health disabilities out of adult "homes."

The Department of Health (DOH), which oversees adult homes, and the NYS Office of Mental Health (OMH), which oversees services for people with mental illness, are facing some tight deadlines. The four-year mark, by which the state is supposed to have assessed and moved 2500 people, is coming up in July. But as of the end of March, only 1891 people had been assessed, and only 491 had moved. Ten of those have since returned to adult homes.

In a previous report Sundram cited the use of multiple contractors to perform assessments, and their inconsistent procedures, as a cause of problems. The state then went to a single contractor, after which the assessment process slowed down considerably, and the number of people found appropriate for the most integrated setting, "supported housing," dropped, while the number of referrals to more structured OMH residential treatment programs increased. The transition support services are only available to people who are assessed as having a "serious mental illness," but the number of people found not to be eligible has "sharply" increased. Also, due to the delays, adult home residents are growing discouraged with the process and are dropping out.

There are many lessons to be learned from Sundram's 99-page report, but all of it is now under a cloud created by the revelation of a possible conspiracy between New York State officials and the adult homes to derail the settlement entirely (see page 3). As a result of that news, it is possible to view many of the reported problems as the result of deliberate efforts to minimize the number of people who are moved out, depriving facility operators of income, until the settlement can be terminated entirely.

More details are likely forthcoming. For now we can summarize the situation as follows:

Almost everyone who moves from an adult home to “supported housing” via this process experiences a successful transition and is happy with the results. Only ten (2%) of those who have made that move have decided to return to an adult home. In at least some of those cases, people returned because they had expected to be able to live with close friends from those facilities in their new homes, but those friends did not move.

The meaning of “supported housing” varies with the providers and the residents; at a minimum it means the resident gets help to pay the rent and some assurance they will not be evicted without a good-faith effort by the housing provider to resolve problems. Beyond that it may mean that staff visit the resident on some schedule, to make sure they’re doing okay, to answer questions, and to refer them to other services, such as help with training, employment, transportation, or health care. In some cases it can include scheduled in-home staff support (home health aides or personal care attendants), though in many cases involving people in the settlement, such services, when provided, are arranged separately through Medicaid managed care just as they are for people with other types of disabilities. The amount of service is supposed to vary with the needs of the individual, but the extent to which that promise is kept also varies with the experience, training, and interests of the service providers. It seems that some people with significant behavioral issues do not get enough services to prevent serious problems. Sometimes these situations get fixed by intervening care coordinators who either get the providers to improve their service or arrange for different providers to come in. In other situations no amount of intermittent support seems to be adequate; these people genuinely do need a more structured setting, at least temporarily while better management of their medications and behavior can be established.

As for whether the people being assessed actually have a “serious mental illness”: That has always been a gaping loophole in the agreement. For sure, just about everybody living in adult homes has some form of non-physical disability that makes it difficult for them to have a home of their own. But substance abuse, traumatic head injury, “organic brain syndrome,” dementia, intellectual disability, and “serious and persistent mental illness” are all common conditions among the residents; many of them have more than one. The terms of the settlement raise a red flag about “significant dementia” in particular; if that’s present, the person is ineligible even if they also have a mental illness, and lots of these people are elderly. Beyond that, having received any OMH services in the 24 months prior to the date of the settlement is supposed to be enough to establish a “serious mental illness.”

However, what the general public, lawyers, or judges think is “mental illness” is not always what psychiatrists and OMH mean by that term. An ordinary person who goes into a noisy, crowded, cluttered adult home “day room” may be excused for believing that everybody there is mentally ill; certainly nearly all of them would be better off elsewhere. But that’s not what the settlement is about. The settlement requires people to be “assessed,” and no matter how scientific the authors of any assessment system claim their product is, in the end, the results amount to an opinion formed by an assessor, the quality of which depends on the assessor’s training and experience, personal prejudices and beliefs, and on the instructions they have been given by their employers. There are arguable reasons in many cases to conclude that a person’s problem is not “serious mental illness.” There has always been pressure to limit the number of people found eligible to move, and that pressure may have grown recently as the Cuomo Administration has gone from increasing to cutting funds for housing, and has adopted the position that potential future action by the Trump Administration justifies cutting Medicaid spending now.

The take-away from Sundram’s report is that the process, when done right, gets excellent results, but that even under the best of circumstances, not everyone in an adult home is going to be fully integrated into the community, and the fact that this happens for a few people is no reason to stop trying.

STIC PRESENTS

ADVOCATING FOR DIFFERENT ABILITIES

A Fun-Filled Day of Activities and Refreshments

Join STIC as we celebrate advocacy, different abilities, and the 27th. anniversary of the Americans with Disabilities Act

When: July 26, 2017

10:00 am to 4:00 pm

Where: Southern Tier Independence Center rear entrance

135 East Frederick St, Binghamton

- Dedication of our brand new Sensory Room
- Zoo Mobile
- Face painting
- Adapted bicycles and Go Baby Go
- Assistive technology demonstrations
- Voter registration and accessible voting machine
- American Sign Language story telling
- Wheelchair basketball (see if you can make a basket using a wheelchair!)
- Wheelchair obstacle course (navigate the course using a wheelchair)
- Many displays and activities for all ages and abilities

Don’t miss the fun!

Fudgy Budget Nuggets

At this writing there is still a month or so remaining in the current legislative session, so it is possible that there will be some additional results that fall into the distinctively broad category that is "state budget" in New York. Here is what we know now:

The big win (though we don't know how big it actually is) came on the issue of coping with minimum wage hikes. The final budget contains language that will appropriate funds to give direct care/direct support professionals who work in programs funded by OPWDD, OMH and OASAS a 3.25% raise on January 1, 2018, and another 3.25% increase on April 1 of that year. There also seems to be language to give a raise to "clinical staff" in those programs on April 1, 2018, though we don't have a percentage rate.

It's important to remember that making money available for those raises on those dates does not necessarily mean that organizations like STIC will get that additional money beginning on those dates. The rates the state pays for these programs get adjusted on a two-year cycle. The state has sometimes issued special "add-ons" that take effect immediately, but we don't know if that's being planned for these funds. Stay tuned.

We are also told that there was $240 million in a separate "pot" for wage increases for "home care." We don't know if this is the same pot that, in Cuomo's original budget proposal, contained $225 million for low-wage "health care workers", which included hospital and nursing facility employees as well as home health aides, personal care aides, and CDPA workers. We also don't know what this amounts to in terms of a wage increase.

The Governor did not get the "prescriber prevails" rule removed for Medicaid prescription drugs, but there was agreement to impose a cap on what the state will pay for certain medications. It is unclear what effect this will have on people with disabilities. If this measure starts preventing people from getting drugs they need, then under current law a legal challenge might be possible, because there are no exceptions to the federal Medicaid "medical necessity" rule: If a state opts to provide a Medicaid benefit (such as prescription drug coverage), then it must provide as much of that benefit as is medically necessary to each eligible person; there can be no arbitrary caps. Of course, if Congress enacts a different Medicaid regime, all bets are off.

The usual attempt to eliminate "spousal refusal" for Medicaid eligibility was beaten back again.

Waivers of state special education rules for school districts, proposed by Cuomo and the Senate, were rejected for the third year in a row.

For reasons that we don't understand, the legislature partially caved in on Cuomo's attempted fiscal power-grab. They agreed that Cuomo could demand a mid-fiscal-year (September) budget adjustment and give the legislature 90 days to pass it; if they don't pass it then Cuomo can slash spending himself. Perhaps they believe the federal government won't be able to enact anything that would immediately affect NY's federal funding. If so, they are likely to be right. Perhaps they also think that even if Trump and Congress somehow manage to get it together to enact measures that will immediately cut funds to NY, they'll be able to agree on a budget themselves within 90 days. That is probably wishful thinking, considering how long it took them this spring. Beyond that, we don't have more details. Are there any limits on the reasons for which Cuomo can demand a budget adjustment? Does there have to be a passed and signed federal measure that cuts NY's funds immediately, or would mere paranoia about the future suffice? We don't know. What if the legislature passes an adjusted budget that Cuomo doesn't like? Can he reject it and cut whatever he wants then? We don't know. We think the legislature made a serious mistake.

Despite assurances from both houses that there was agreement to increase the annual general operating appropriation for Centers for Independent Living like STIC, in the end there was no such increase. Oh well. It's not like we ever get one anyway.

The general-purpose Access to Home program was again level-funded at $1 million. So for another year, that program will run out of money before filling all requests for assistance, while the much larger pot allocated for veterans will sit mostly unused.

The Visitabilty tax credit didn't pass. We don't know if the disability employment tax credit did.

Cuomo dropped his attempt to "carve out" Medicaid transportation from Medicaid managed long-term care and force people in those programs to use the Transportation Manager companies instead.

However, Uber and other "transportation network companies" (actually, Uber claims not to be a "transportation" company at all; see page 6) are authorized to operate upstate this summer. There is a "task force" to study the need for wheelchair-accessible service but no requirement that these companies provide it. Lyft, a similar company that does not have Uber's reputation for being pigheaded, announced an agreement with the National Federation of the Blind to require its drivers to accommodate service animals, on penalty of being dropped from the service. That’s good news for people who use service animals, and it may also have interesting legal ramifications for the industry, since that is the sort of thing that leads auditors to conclude that the drivers are not, in fact, independent contractors.

Cuomo had proposed extra funds for the OPWDD START program for downstate, but there was no mention of the roll-out for our region, which had been promised for this past January. We learned from Broome Developmental Services that roll-out is to begin this fall with some focus groups for stakeholders. We’ll let you know if we get invited to the party.

YOU’RE CURED!

The 21st. Century Cures Act was passed by Congress and signed by President Obama in December. Although known primarily for its provisions to speed up the federal approval process for new drugs, it also contains some of the mental health measures that were debated over the past year (see *AccessAbility* Spring, Summer, and Fall 2016).

The final law contains a section to clarify the HIPAA provisions regarding disclosing information about people with mental illness: practitioners can give information to people who they believe might be able to keep someone from harming themselves or others even if that person doesn’t agree to the disclosure. They are not required to give information to family members merely because they are family members.

States would have to use at least 10% of their community mental health block grants for early intervention programs to address psychosis, including school services, family support, and medical treatment.

There’s a $5 million grant program to support Assertive Community Treatment (a tiny figure for the nation as a whole, but any additional funding for this highly successful service is welcome). There is also money for community policing programs, including training for first responders in how to work with people in crisis, and the federal Department of Justice is required to introduce at least one pilot program for drug or mental-health “courts” (judicial diversion that gets people into treatment instead of jail). There is also more money for “assisted outpatient treatment” (court-ordered treatment like New York’s Kendra’s Law), but no requirement that states use it.

The bill creates a new Assistant Secretary for Mental Health and Substance Use position in the Department of Health and Human Services.

There is better enforcement of the federal mental health insurance parity law, including more frequent audits of insurance companies by federal monitors, and a report to Congress on loopholes in the law that these companies exploit.

There are no restrictions on federal Protection & Advocacy programs regarding helping people with mental health disabilities avoid forced treatment or contest information disclosures.

The provisions in earlier bills to increase funding for temporary intensive inpatient crisis stabilization services seem to be gone.

This is an altogether weaker, more limited measure than advocates had hoped for. On the other hand, it is remarkable that the post-election lame-duck Congress passed it at all to give outgoing President Obama a final win.

STIC NEWS

NY Connects Comes to STIC

by Maria Dibble

STIC is pleased to announce a new program, in conjunction with the local Offices for Aging in Broome, Chenango and Tioga Counties. Funded through the NY State Office for Aging (NYSOFA), STIC is a subcontractor of the Resource Center for Independent Living (RCIL) in Utica, partnering with NY Connects in each of the above three counties. The goal is to expand the resources of NY Connects to serve more people with disabilities as well as older individuals.

What is NY Connects? It is an expanded information, referral and assistance service that includes the following: Referrals to all agencies, including for-profit businesses and programs; screening for financial services; person-centered “options counseling”, which presents the options available in response to the consumer’s question, as well as assistance in understanding the choices so they can make an informed decision; public benefits and application assistance; direct coordination between agencies for services; and more. They can be a one-stop referral source to answer questions spanning an extremely wide variety of topics.

STIC has hired one full-time person to work with NY Connects in Broome, and one full-time person to rotate between Chenango and Tioga Counties. In addition to answering people’s questions over the phone, they will make home visits when appropriate, follow up to ensure people got what they needed, outreach to the community to publicize the program and more.

If you need assistance, use the phone number for your county:

Statewide: (800) 342-9871

Broome: (607) 778-2278

Chenango: (607) 337-1600

Tioga: (607) 687-4222 Ext. 331

SELF HELP

Brenda Sprung from Bridgewater!

by Dacia Legge

Brenda—4 years in Bridgewater Nursing Home—moved into her own apartment in Tioga County in April 2017!

Brenda is a 55 year old woman with a diagnosis of multiple sclerosis that gradually incapacitated her until she was admitted into the Bridgewater Center for Nursing and Rehabilitation. Even though she was treated well by staff, she loathed being in an institutional setting and just wanted to move back into the community with appropriate services to support her. Brenda would cry and cry over the lack of choice, dignity and independence one experiences when “stuck” in a nursing home. Many of the staff felt she was “safer” in the facility, but Brenda begged for freedom.

Brenda was proud to share that she was a waitress for over 30 years at the Skylark Diner in Vestal, and was always a fast-paced and hard worker. She had lived in Apalachin, NY for many years and had been a home owner there, but was unable to return there. She missed having her pets and her loved ones nearby.

In November of 2015, Brenda made a self-referral to STIC’s Open Doors program, and at that time the only options to get out of nursing facilities were by using either the Nursing Home Transition and Diversion waiver (NHTD) or the Traumatic Brain Injury waiver (TBI). Open Doors staff submitted a formal NHTD referral on Brenda’s behalf in December of 2015.

Unfortunately, the Southern Tier has an enormous shortage of service coordinators to pick up cases for both NHTD and TBI. Brenda waited and waited for a service coordinator. Both NHTD and TBI services can’t be used until there is a service coordinator to write an individualized service plan and to set up the aide services and any other necessary programs/supports.

Open Doors also made a peer referral on Brenda’s behalf and that gave her someone else to visit with her regularly. The peer is someone who has also experienced nursing home/institutional stays and they work to help brainstorm and strategize with the individual.

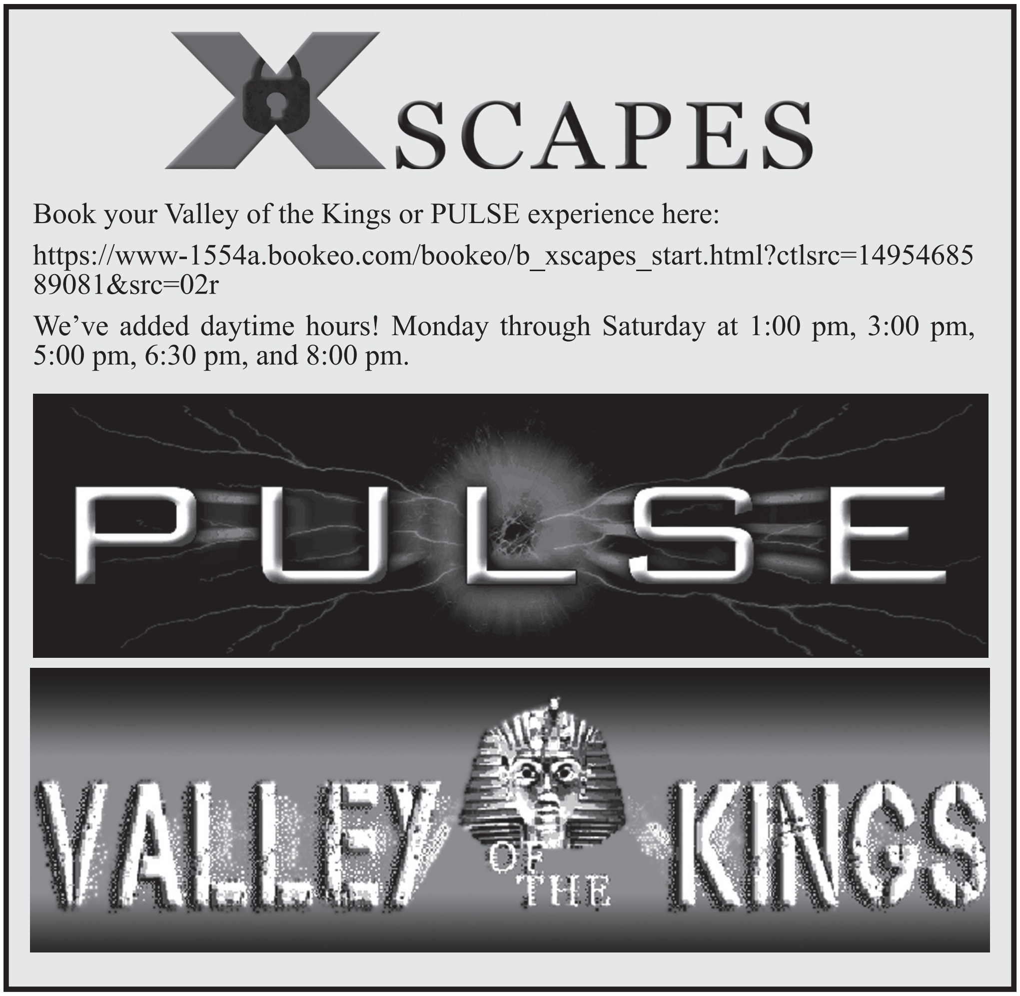
After eight months, Open Doors connected Brenda with STIC’s housing coordinator, who helped her apply for a HUD “mobility impaired unit”. These apartments are income-based and accessible. Brenda still did not have a service coordinator, but the hope was that she would have one by the time her name came to the top of the housing list.

After a year and two months of waiting for a service coordinator, Open Doors re-strategized with Brenda. She decided to go forward with Medicaid managed long-term care (MLTC) for services. To do this, Brenda signed a letter to be removed from the NHTD referral process. Also, her name was at the top of the list for the apartment, and we needed to find a way to use this opportunity to get her out. Brenda was assessed and deemed eligible for services through Fidelis MLTC on May 1!

Brenda will be using CDPA (Consumer Directed Personal Assistance) staffing for 5 hours per day, seven days a week and will have physical therapy, occupational therapy, and nursing services, as needed. Her apartment is accessible and affordable, and she has made friends with many of her neighbors. Another great benefit is that Brenda’s family lives nearby and is more involved with her than ever!

We are so happy for you, Brenda!

The Open Doors program is here to assist individuals, by supporting their wishes to return to their community, with the supports they want, after a stay in nursing homes, rehabilitation or developmental centers. Often people have to battle a



Brenda flashes keys to her own home!

medical-model mentality and other attitudinal barriers that suggest most people leaving a facility need 24/7 services or supervision. However, this mind-set ignores the fact that people have the right to self-determination, the dignity of risk and to be in the least restrictive setting they choose. Open Doors staff will advocate alongside you or your loved one, to provide a voice for what individuals want for their supports and how they want to live their lives.

If you would like more information on the Open Doors Program, please reach out to:

Dacia Legge, LMSW

Open Doors Regional Lead Coordinator

Southern Tier Independence Center

dacial@stic-cil.org

(607) 724-2111 x 329 (phone)

(607) 772-3606 Attn: Dacia (fax)

COMMUNITY PROGRAMS

A Self-Advocate's Guide to Medicaid

(from ASAN)

The Autistic Self-Advocacy Network (ASAN) is proud to announce the release of our plain language toolkit, A Self-Advocate's Guide to Medicaid.

Medicaid is the biggest health care program in the country. It's an important part of the United States healthcare system. But a lot of the information out there about Medicaid and attempts to change it can be difficult to understand and navigate. That's why we've partnered with the Autism Services, Education, Resources and Training Collaborative (ASERT) and the Special Hope Foundation to develop this plain-language toolkit.

This toolkit is the third in a series of accessible policy and advocacy resources that ASAN is releasing this year, following our ACA toolkit and our toolkit for getting through to your elected officials. These resources equip self-advocates to participate in important conversations about our lives and the services we rely on. A Self-Advocate's Guide to Medicaid explains in plain language:

- Who can get Medicaid
- What Medicaid pays for
- What Medicaid waivers are
- What Home- and Community-Based Services (HCBS) are
- How Medicaid is funded, and
- What would happen if the government makes changes to how Medicaid is funded

ASAN
AUTISTIC SELF ADVOCACY NETWORK

ASERT
bringing autism resources together.

The Special Hope Foundation

The toolkit is available in both Easy Read and Plain Text versions. The Easy Read version uses pictures along with text, and has more white space. Both are written in easy-to-understand language and are screenreader-friendly.

We hope that you'll use this toolkit to understand and participate in these important conversations over the next year. We encourage you to share it widely so that we can give as many self-advocates as possible the tools we need to tell lawmakers: ***Nothing about us without us!***

To check out the toolkit, visit:

https://autisticadvocacy.org/policy/toolkits/medicaid/

UNCLASSIFIEDS

For Sale: Walk-In Whirlpool & Air Bathtub - American Standard 48” long x 28” wide x 37” high with built-in seat, grab bar and extension kit to fit 60” opening. Purchased new, never installed - $2,750.
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MAIL TO: **Southern Tier Independence Center, Inc.**
135 E. Frederick St.
Binghamton, NY 13904

Name ____

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City ___________________________ **State** ___ **Zip**_______

Phone ____

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

THANK YOU!

Southern Tier Independence Center

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