

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

AccessAbility

Fall 2019
Number 136

MASS SHOOTINGS AND MENTAL HEALTH: The Real Story



by Ken Dibble

In the wake of the most recent mass shootings and the ongoing drama of people on the far right and the far left baiting each other over immigration, President Trump made statements that characterized mass shootings as a “mental health problem” and suggested that forced institutionalization might be one of the solutions. He’s actually right on the first point, but he’s dead wrong on the second.

Although Trump clearly does deliberately bait the left on the immigration issue in order to provoke hysterical reactions from progressives to entertain and encourage his far-right base, we don’t think he knows enough, or cares enough, about mental health to try to play these games with that issue. He was likely just repeating a common theme that he’s heard elsewhere.

However, lots of disability rights activists took him seriously and issued various statements in opposition. Just about all of these statements made three main points:

1. People with mental health disabilities are more likely to be victims of crimes than to commit them.
2. The percentage of people whose mental illnesses induce violent behavior toward others is vanishingly small.
3. Racial and religious hatred are not mental illnesses, they are just evil.

Some statements also made another point:

4. Forced institutionalization would not be necessary if the community-based mental health system worked the way it’s supposed to.

All of those things are true. And people with disabilities have very good reasons to fear a swing of the pendulum back in favor of institutions. The nursing facility lobby has considerable power, and it has lately shown that it can even get to alleged “progressives” like Governor Cuomo, who has been trying to destroy the CDPA program while telling the feds that the state has lots of empty nursing facility beds ready for people who lose their homecare (see page 7). He also came out swinging against Trump’s remarks and blamed guns instead of his own insistence on keeping Medicaid spending capped well below what’s necessary to make reliable and effective mental health services available.

But now it’s time to make sure that the truth doesn’t get buried under the propaganda. Why? Because something needs to be done about shootings, and there are, sadly, only a few realistic options. A few days after he made his initial remarks, Trump’s underlings issued orders to various federal health-related departments not to make statements contradicting him. Fortunately, *AccessAbility* isn’t subject to orders from

INSIDE

The Domino Effect of CDPA Cuts	4
Cuomo Signalling Medicaid Cuts: Follow the Money	5
Disabilities Behind Bars	6
CDPA Goes to Court	7
And the Beatdown Goes On: OPWDD Fails to Stop Abuse	8
No More Non-Medical Vaccine Exemptions	9
Courts Watch	10
Medicaid Managed Care Unmasked	11
She’s in the Hall!	12
Xscape with Us	13
Support Your Local DSP!	14
End Abuse!	14
Join us for a TRUNK Or TREAT	14

elected officials, campaigning politicians, or social activists of any stripe. Our mission is to report truth and oppose falsehood concerning disability matters, regardless of the source.

Most of the people who claim that “mental illness” is involved in only a small percentage of mass shootings (a common estimate is about 25%) are only talking about the “big three” biochemical diseases: schizophrenia, bipolar disorder, and major depression. And they often further limit the numbers by referring to “diagnosed” mental illness.

This is a narrow, medical-model view. The Independent Living movement has a broader take on this. We consider things like post-traumatic stress disorder, and other forms of trauma-related severe emotional disturbance, as well as alcohol and substance abuse, to be mental health disabilities. And while not “mental” disabili-

AccessAbility

September 2019

EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

AccessAbility is published seasonally (Spring, Summer, Fall, Winter) by Southern Tier Independence Center. Letters, information, articles and ads are always welcome. Deadlines are February 15, May 15, August 15 and November 15.

Our address is:

AccessAbility

Southern Tier Independence Center
135 E. Frederick Street
Binghamton, NY 13904

Subscriptions

Subscriptions are \$10 per year (4 issues). Subscriptions are voluntary, but very much needed to help cover newsletter production costs. Use the form on the back to subscribe.

Advertisements

AccessAbility prints unclassified ads free for disabled consumers, unless they promote a for-profit business. For-profit businesses can advertise in *AccessAbility*, in Un-classifieds or a display ad, at our regular rates. Ask the editor for information.

Reprints

Any *non-copyrighted* information originating in this newsletter may be reprinted without permission. If you want to reprint an article or opinion piece, please credit *AccessAbility* and the author.

Authorship

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

ties as we understand them, traumatic brain injury and intellectual disability can also be implicated in violent behavior. As we said, President Trump likely doesn't know the difference, but disability rights activists surely should.

Moreover, just because a condition has not been "diagnosed" doesn't mean it doesn't exist. People often don't get diagnosed until after they've done something disruptive. If we had a community mental health system that actually effectively screened people, we would likely find that the percentage of mass shootings in which some sort of behavioral disability was involved is a lot higher than 25%.

It is quite true that the relative ease with which people can get rapid-fire long guns is the best predictor of whether mass shootings will occur in a particular country. Some mass shooters do spend a lot of time planning and preparing for their attacks. Many others, though, act on a sudden impulse, often because their disability-related inability to cope with emotional stress has failed more spectacularly than usual. If these people, especially, could not easily get a gun, they would likely regain control and never shoot anyone.

People who don't like gun regulations often claim that they only keep law-abiding people from getting guns; they don't have any effect on the criminals who are most likely to use them to shoot people. That argument is flat-out bogus. If it were true, then the rate of gun violence in countries that have strong gun control laws in place would be about the same as that in the USA. But it's not. The truth is that all of the guns used by American criminals are first purchased legally by someone; they are then often stolen, but because gun-registration and waiting period laws are deliberately so poorly enforced, there are plenty of criminals who buy guns openly from licensed dealers. In countries where it is very difficult for law-abiding people to buy hand guns and rapid-fire long guns, it is even more difficult for criminals to get them, and that is a big reason why gun-related crimes are so rare in most other developed countries.

However, we aren't going to solve this problem by calling for strong gun control even though that solution is very likely to be effective. The US Supreme Court has made it quite clear that it's not going to accept more than a certain amount of gun

regulation. New York has probably already gone about as far as it's possible to go on that. Other states could do more, but those with governments in the hands of right-wingers and libertarians will not. And as long as they don't, it will be easy to move guns from less-regulated states into more regulated states. Nor can we expect that if Democrats sweep the elections in 2020, they will enact strong federal gun control. Although some very leftist Democrats have been making a lot of noise lately, national opinion polls indicate that most Democratic and independent voters do not support their most radical views. Most Democrats in the House of Representatives today are moderates, not progressives. The majority of Democrats elected in 2020, if they win the presidency and the Senate, will also be moderates. The NRA, though undergoing some difficulties due to scandals recently, is still quite able not only to pull campaign funds from people who support gun control, but also to run pro-gun candidates in primaries to defeat those people. Nor will even all progressives buck the NRA; Bernie Sanders, for example, has historically opposed strong gun control, because his Vermont constituents don't like it.

It's not just about mass shootings either; the most common form of gun-related death in the United States is suicide. In nearly all cases, just about everybody agrees that suicide is a behavior that is caused by mental illness. People with mental illness aren't very likely to shoot other people, but a lot of them are quite likely to shoot themselves if they can get a gun—and getting a gun is going to remain easy to do in the US for well into the future.

Ideological explanations of seriously aberrant behavior are highly suspect, whether they come from the right ("he did it because he didn't have a traditional nuclear family that inculcated strong Christian values") or from the left ("he did it to express rage as a white Christian male who had lost his privileged status").

Emotional disturbance as a result of physical, sexual, or psychological abuse offers really good explanations for sudden violent behavior, but they are only of value if applied even-handedly. There are no moral excuses for ever losing control and doing something evil, whether one claims abuse by a father as a reason for targeting men or a mother's neglect as a reason to target women. But early detection and appropri-

www.stic-cil.org

ate responses to such issues can prevent more tragedies.

Very few people with significant untreated behavioral health issues really have the insight to understand their own motivations. People who have what are usually called “severe and persistent mental illnesses” often pluck current events out of the news and mix them into their irrational thinking. And many people who have uncontrollable severe feelings of anxiety, anger and fear see patterns, conspiracies and enemies where there are none, and will, when asked, blame virtually every person or event in their lives for those feelings. The fact that a person with serious behavioral issues of any type says he shot a bunch of people because he hates immigrants or Muslims does not necessarily mean that such hatred had anything to do with what led him to that act. Not to mention that not all mass shooters even give hatred against other social groups as their reason.

Most of these events end in the shooter being killed, often because the shooter intended it that way. They either shoot themselves or commit “suicide by cop”. Because of this it’s not always possible to gain a clear understanding of the mental state of shooters at the time they commit the act.

But let’s look at the relationship of homelessness to mental illness for a clue. It’s certainly true that there are some places in this country where housing is so scarce and costly that there are people who are not mentally ill living in cars or hopping from one friend’s home to the next because they have no permanent place to live. Many of these people even have full-time jobs. (It’s probably fair to question their judgment; why would you choose to live like that rather than moving to a less-expensive, less congested place? But poor judgment is not a mental illness.) But there are also people living out under freeway overpasses and in public parks in communities where housing is not scarce or super-expensive, who will tell you that they aren’t mentally ill, they “just want to be free” or they can’t stand being “cooped up” or committed to one place. If you spend more than a few minutes talking to these people, you’ll quickly understand that they can’t in fact organize their thinking well enough to do what it takes to keep a roof over their heads. That *is* mental illness, substance abuse, brain injury, and/or intellectual disability.

If we could actually “debrief” these dead shooters after the fact, we would likely find that many of their claims of some sort of ideology, whether racist, religious, sexist or what have you, as motivation, were just part of their delusions, whether induced momentarily by overwhelming stress in combination with a history of psychological trauma, or as a result of an ongoing degenerative organic or biochemical brain disease.

That’s actually good news, because it means that even though we can’t get adequate gun control, if we could beef up the community mental health system we could prevent many of these shootings. I emphasize, we need better **community-based** mental health services, not institutions (see page 6). This might be an opportunity to actually get something meaningful done about that, and it should not be squandered for the sake of political correctness.

We’ll repeat, it is true that only a tiny percentage of people with mental health disabilities behave violently towards others. We don’t want you to think we believe otherwise. It is also true that although mass shootings have become more frequent recently, only a tiny number of people are killed that way every year. And yet it is still true that a much larger percentage of those shootings than some people would like to believe are carried out by people who have a significant behavioral health disability, and a very large number of people with those disabilities kill themselves with guns even if they never point them at anyone else. This is not about blaming victims or demonizing anyone, it’s about honestly identifying real problems and potential so-

lutions. Most of these horrific events could be prevented by ensuring that everybody who needs help with a mental, behavioral, or emotional issue can get it promptly, and continue to get it as long as they need it, while remaining in their own homes and keeping their jobs and relationships with friends and family.

As usual, it’s about the money. So-called “red flag” laws are a good idea, but only if they are enforced. It does no good to have a law that allows a judge to confiscate the guns of somebody who appears to be mentally disordered if the judge never hears about that person, or if the case goes on a waiting list to be heard, or if the person can get another gun because nobody is monitoring them. All of those things have happened in places where “red flag” laws are in effect. It takes money to make those laws work. It takes money to do effective mental health screening. And especially, it takes money to ensure that people don’t get dropped from mental health services the minute they show a little improvement (see *AccessAbility* Summer 2019 for a discussion of how both private and government health insurance programs do this).

It will take less money to adequately fund community services than it would to reopen institutions, but it will take considerably more money than we’re spending now. Getting that money appropriated will take all the creative energy that disability rights advocates can muster. Giving truthful information to responsible elected officials who would like to do something about this is where that energy should be directed—and not to lunging at bait in the media.



The Domino Effect of CDPA Cuts



by Sue Hoyt

There has been all kinds of news and articles in regard to the state Department of Health (DOH) and its devastating proposal to make deep cuts to the CDPA program. It is important to expand on these and get into the “meat” of things, breaking down the impact to show the domino effect these cuts could have.

The first impact will be to the Fiscal Intermediaries (FIs), as it is their administrative costs that are being slashed. Without the proper funding for administration of the program, there is the potential for FIs to have to close. The DOH makes it sound like this will have no impact, as consumers can transition to other FIs. This isn't as simple as they make it seem; consumers could end up with an FI that is hours away, making communication and assistance more difficult for the consumer and the personal assistant, which affects the ability to properly administer the program, the end result being the consumer not getting proper services.

This result is the same for the FIs that have to close down: consumers unable to transition to other FIs are left without their personal assistants and possibly forcing them into institutions. This is literally part of the DOH's whole plan. The DOH says NY has “*excess bed capacity for both hospitals and nursing homes*”! That is their exact wording in documentation provided about the cuts!

Even if this wasn't completely discriminatory, derogatory, and unethical, it is also completely FALSE!

There are no beds! The state cut funding to nursing homes, they cut the amount of Medicaid beds available. And there is currently a NATIONWIDE NURSING SHORTAGE which affects both hospitals and nursing

homes, and it is predicted to get worse:

*“All states will suffer a **shortage** of registered **nurses** through a combination of an aging Baby Boomer population, the retirement of 25% of RNs working today and a lack of **nursing** faculty to train more qualified **nurses**. The **nursing shortage** in the United States is expected to be particularly severe between 2020 and 2030.”* <https://geriatricnursing.org>

There have also been suggestions of consumers being able to switch to licensed home care services. This is also FALSE! There is also a statewide shortage of certified homecare givers, which prevents consumers from being able to switch over to a licensed PCA or HHA provider. As HomeHealthCareNews.com reported in January of this year:

“Caregiver Shortage Could Mean 7.8 Million Unfilled Jobs By 2026: The nationwide shortage of caregivers continues to be one of the biggest industry-wide problems for home health and home care agencies, with no end in sight. And in the future, the employment

crunch could become even worse than previously expected.”

<https://homehealthcarenews.com/2019/01/caregiver-shortage-could-mean-7-8-million-unfilled-jobs-by-2026>

So now we have FIs closing, all employees of the FIs are on unemployment, consumers have no personal assistants or homecare providers and nowhere to go due to shortages in institutions. All of the personal assistants are out of jobs, family members are quitting their jobs to stay home and care for loved ones due to no other means of care.

The dominoes are falling, and the end result is devastating!

100,000+ without care + 100,000+ jobless = human and economic deaths.

[Editor's Note: Sue Hoyt coordinates our CDPA program. See page 7 for our story on the lawsuit to stop this from happening. There is some hope that we can win the legal battle, but if not, we'll let you know how you can help.]

BAD WEATHER?

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

Cuomo Signalling Medicaid Cuts: Follow the Money

The first quarterly report on the current (2019-20) New York State budget contains a warning that Medicaid spending is increasing much faster than projected and that big Medicaid cuts may be coming next year. This announcement comes in the wake of Governor Cuomo's recent rate increase for nursing facilities and hospitals, at a time when the governor is trying to cut administrative rates for the CDPA program to a level well below actual cost while telling federal regulators that there are lots of empty beds in those facilities for CDPA consumers.

Governor Cuomo has made much of his efforts to limit the growth of the New York State budget. He has followed a policy of capping total budget growth at 2% per year, and Medicaid spending increases at the 10-year average US medical inflation rate (currently about 3%).

Medicaid pays for virtually all long-term care services that New Yorkers with disabilities use, such as homecare (including Consumer Directed Personal Assistance—CDPA); Medicaid waiver services for people with developmental and other disabilities, including most costs for group “homes”; nursing facilities (for people in long-term placements); as well as ordinary medical services and prescriptions.

Medicaid also pays for medical services for many nondisabled people who do not work or whose employers do not provide health insurance. While the majority of Medicaid recipients in New York do not have significant disabilities, the bulk of the actual spending benefits people who do. And the fastest growth rates are mostly for long-term care items, in large part because the population is aging, and older people use more long-term care.

A moderately deep dive into the budget report reveals that, while Medicaid spending is expected to grow faster than 3%, total spending is still on track to stay under 2%. The 2% total spending number is the only one that really affects New York's solvency or ordinary taxpayers. But Cuomo is treating Medicaid as a special case that has to be targeted for big cuts regardless.

What's behind this?

The governor granted a significant Medicaid rate increase to nursing facilities (the most

expensive form of long-term care for people with disabilities) and hospitals (the most expensive form of acute care for all people) in October of 2018. That change will increase the state's Medicaid spending by about \$500 million over three years. Meanwhile, he refuses to permit wages for homecare workers outside New York City to rise to the level of those for fast-food workers. Homecare is a far less expensive substitute for nursing facility services, between 33% and 80% less than serving the same person in a nursing facility. And now he's trying to wipe out most providers of the least-expensive form of homecare, the CDPA program (see page 7).

Now we get into the weeds, but bear with us, because there's a big pirate treasure chest hidden out there.

The Cuomo Administration said the extra money for hospitals and nursing facilities came from the state's conversion settlement with the Fidelis/Centene managed care insurance company. Centene, one of the nation's largest such companies, purchased Fidelis, a not-for-profit agency, from the Catholic Church. The Church used the proceeds to set up the Mother Cabrini Health Foundation to serve “needy” New Yorkers. The state taxed the sale and expected to collect \$2 billion from Centene over four years.

The state's share goes into a “Health Care Transformation Fund,” and Cuomo is allowed to spend it on any “health related” purpose he wants, without approval from the state legislature.

As Cuomo was mulling over what to do with that money last year, the Greater New York Hospital Association (GNYHA), a trade association that represents, and lobbies for, both hospitals and nursing facilities, along with SEIU 1199, the big New York City healthcare workers union, lobbied him heavily to increase Medicaid rates for

hospitals and nursing facilities. In addition to the typical ongoing behind-the-scenes lobbying activity, both organizations had previously collaborated on a \$6 million ad campaign to oppose Cuomo's Medicaid cuts during the winter 2018 budget battles.

Later in 2018, GNYHA's “Management Group” made donations to the NYS Democratic Committee totaling about \$1.25 million. That amount was greater than the total of all contributions GNYHA had made to the Committee across the previous 12 years. All but about \$100,000 of the 2018 donations came during August and October. The rate increases, whose total cost of \$500 million exactly equals the first-year receipts from the Fidelis sale, were announced in late October.

The Committee is effectively under control of Governor Cuomo, and most of its funds are used to support his election campaigns. GNYHA's money went to the organization's “housekeeping” account. That account is supposed to be used for “party building” activities and not political campaigns, but the rules are easily and commonly evaded.



Some people have speculated that the Cuomo Administration's attack on the CDPA program is intended to force the hundreds of small service providers out of business, making way for establishment of one or two huge centralized operators (see page 7). A few people who claim to have an inside track on New York City healthcare politics have suggested that one of those

operators might be 1199. We have been unable to verify that contention.

On the other hand, it is true, and documented in official government records, that Cuomo's health department told federal regulatory authorities that if CDPA participants lost servic-

es, empty beds in nursing facilities and hospitals were waiting to take up the slack.

It's also true that increasing Medicaid rates for the oldest, least integrated, and most expensive forms of both long-term and short-term care cannot possibly be considered "health care transformation."

Of course, Cuomo will claim it's all just a coincidence and that the Health Care Transformation Fund is not a political slush fund. He may also say that "pay for play" is illegal, and that if anybody ever asked him to give them something in return for a campaign donation, which nobody ever has, he would knock him down (as he said recently in a different context).

As for the implications for next year's budget: It would seem that Cuomo wants to appear to keep his promise to cap Medicaid spending, and so having increased that spending to benefit certain groups that support his political campaigns, he now needs to find ways to cut it elsewhere. You may hear that he wants an "across the board" Medicaid cut, but don't be misled. While most people might think that means equal cuts across all Medicaid programs, what it has historically meant to New York State government is an average cut across all programs, meaning some programs get hacked deeply, and others don't get cut at all. You can probably guess which programs won't be cut in that scenario. Meanwhile, we'll be monitoring the airwaves to see if there's another big GNYHA/1199 ad campaign against Medicaid cuts.

We'd like to thank the Empire Center for Public Policy and its NY Torch blog, and Crain's New York Business, for bringing this information to light. You can get more details here:

<https://www.empirecenter.org/publications/following-the-money/>

Disabilities Behind Bars

Here's a simple fact from the Bureau of Justice Statistics: "People behind bars in state and federal prisons are nearly three times as likely to report having a disability as the nonincarcerated population, those in jails are more than four times as likely."

Does that mean that people with disabilities are more likely to be intentional evildoers? No, it does not. It means that the needs of people with disabilities are more likely to be misunderstood, or neglected, or ignored, or exploited by real evildoers, leading them unwillingly into situations that eventually get handled by law enforcement.

Here's more: "Cognitive disabilities—such as Down syndrome, autism, dementia, intellectual disabilities, and learning disorders—are among the most commonly reported: Prison inmates are four times as likely and jail inmates more than six times as likely to report a cognitive disability than the general population. People with mental health conditions comprise a large proportion of those behind bars, as well. The Bureau of Justice Statistics reports that fully 1 in 5 prison inmates have a serious mental illness."

These quotes come from a 2016 report from the Center for American Progress: *Disabled behind Bars: The Mass Incarceration of People with Disabilities in America's Jails and Prisons*.

We actually can't say it any better than they did, so we'll let the report speak for itself:

"Mass incarceration of people with disabilities is unjust, unethical, and cruel. But it is also penny-wise and pound-foolish, as community-based treatment and prevention services cost far less than housing an individual behind bars. According to a 2014 study of Los Angeles County, the average cost of jailing an individual with serious mental illness exceeds \$48,500 per year. By comparison, the price tag for providing Assertive Community Treatment, or ACT, and supportive housing—one of the most intensive, comprehensive, and successful intervention models in use today—amounts to less than \$20,500 annually, just two-fifths the cost of jail."

Housing people in non-penal segregated congregate institutional settings is even more expensive than jail or prison. People with dementia often end up in nursing facilities; for them the cost today is around \$100,000 a year. There are still a couple of institutions in NY for people with developmental disabilities, and several for people with mental illness, but placements are mostly temporary while people receive intensive rehabilitation services prior to returning to the community. But for the "back to the institutions" crowd: When year-long stays in those places used to be common, the cost, in today's dollars, was roughly \$350,000 per person.

Although you'll hear larger numbers from those trying to get more money for a particular pet disability project, a reasonable estimate for the percentage of Americans who have disabilities that affect their ability to do important things is about 15%. This number is rising because Americans are growing older and disability tends to go with aging. Still, it's notable that somewhere between 25% and 50% of the people who are shot to death by police in the

United States have disabilities. (The number varies so much because different reporters define "disability" differently.)

If you spend much time in a jail or prison, your disabilities will probably get worse. And if you went in without a mental health disability, prison, all by itself, can give you one. Most people with disabilities who get involved with law enforcement are people whose disabilities cause behavioral issues. If that's you and you're in the hoosegow, your behavior is likely to land you in solitary confinement. As the report notes: "A growing array of research reveals that even short stays in solitary confinement can have severe and long-lasting consequences for people with disabilities, and particularly those with mental health conditions. Furthermore, many individuals who had not previously lived with mental health conditions experience significant psychological distress following solitary confinement. The tragic but all-too-common case of Kalief Browder brought this to light [in 2015]. Browder died by suicide after nearly two years in solitary confinement in Rikers Island on charges, later dismissed, that he had stolen a backpack."

The reason this is happening is because community services for people with behavioral disabilities other than the developmental kind are woefully inadequate. When those services are readily available and consistently maintained, they do as good a job of keeping people out of the hands of law enforcement as institutions ever did, and at a significantly lower cost (roughly between one-third and four-fifths less than the cost of keeping the same person in an institution).

Why are community services so inadequate? Because as vocal civil rights advocates with mental health disabilities began to get noticed beginning in the 1950s and 1960s, cynical politicians saw an opportunity to cut spending on services by closing institutions, and instead of transferring all of that money into community mental health systems, they put it back into the pockets of the wealthy taxpayers who paid for their election campaigns.

There certainly are lots of people with behavioral disabilities who get good treatment and support services, and whose conditions respond well to treatment. Those folks rarely get in trouble with the police or end up in jail, because their behavior does not attract that kind of attention. But for people who don't have good services or who are more difficult to treat and whose behavior will probably always be at least somewhat out of the ordinary, this is a very serious issue.

Re-opening institutions is *not* the solution. Not only are they nearly as inhumane and abu-

sive as prisons, they are far more expensive than necessary to address the problem. The solution is to take the money back out of the pockets of wealthy taxpayers—where it never should have gone—and use it to provide a truly effective community mental health system.

The report has lots of specific recommendations for how to do that. You can read it here:

<https://cdn.americanprogress.org/wp-content/uploads/2016/07/15103130/CriminalJustice-Disability-report.pdf>.

But here's the executive summary: Put the money that was stolen from mental health services back.

The jail abolition movement scored a big victory along those lines on August 13, 2019, when the Los Angeles County Board of Supervisors voted to cancel a \$2.2 billion contract to build a huge mental health institution to replace its Men's Jail. How did that happen? A coalition of mental health and anti-jail advocates organized to develop a serious plan, detailing how putting the money into a much-improved community mental health system could divert up to 5000 people "with significant mental health needs" from jail and into appropriate support services. The plan proposes a shift "from a punitive criminal justice response to a public health, trauma-informed approach to crisis" — "Care first, and jail only as a last resort." The Board will now consider ways to implement the plan.

It can happen here too, if we want it enough.

CDPA Goes to Court

As we've reported (*AccessAbility* Spring 2019, Summer 2019), the Cuomo Administration has been trying to gut the Consumer Directed Personal Assistance (CDPA) program, which allows people with disabilities to hire, train, schedule, and supervise their own personal attendants; those attendants can do anything a traditional Personal Care Aide can do, as well as anything a more expensive Certified Home Health Aide can do, and many things that an even more expensive Visiting Nurse can do.

The plan was to replace payments to Fiscal Intermediaries (FIs) that run the program that are based on a percentage of hours of service each participant receives with a flat per-person-per-month (PMPM) administrative rate. This would cut the administrative funding for FIs by an average of 65%, making it virtually impossible to run the program in a way that is responsive to participants' needs and that also complies with various New York State laws governing employment and financial accounting. Regardless, Cuomo's Department of Health (DOH) insisted that CDPA services

would not be affected and participants would not be harmed.

We had reported that it seemed that DOH officials were genuinely confused about how CDPA works and were issuing mixed signals on whether they were open to negotiating with FIs. DOH met with FIs, some of whom prepared an alternative PMPM rate structure that would save nearly as much money but would also, by considering the greater needs of people who use higher amounts of CDPA services, allow FIs to continue to operate. After DOH received that proposal they clammed up and refused to discuss the matter further. Some people speculated that Cuomo had darker motives, but there was no hard evidence to support those beliefs.

But over the summer the smoke cleared and the truly ugly nature of Cuomo's plan emerged. We now know that the intention is to wipe out all, or nearly all, of the several hundred FIs in the state and replace them with a small number of other organizations. We also know that DOH fully understands this will end CDPA services for many people, and that they just don't care.

After DOH cut off negotiations, disability activists staged protests in Albany, disrupting meetings of a new "advisory council" that was enacted in the 2019-20 state budget to develop best-practice policies and procedures for CDPA programs. The goal was to deliver a message to the DOH officials who were present at those meetings. These events generated media coverage, and DOH consistently told reporters that this was only about cutting excess administrative costs for payroll processing and no people with disabilities would lose any services or be harmed.

On July 1, 2019 DOH issued an instructional document explaining that the PMPM rate would take effect on September 1, 2019. Most of the document was about requirements for how FIs that planned to close should manage that process and ensure that CDPA participants could be moved to other FIs. The policy required FIs to give participants 45 days notice of a closure, using a "template" letter that DOH planned to provide. DOH did not actually issue the template in time for FIs that planned to close on September 1 to be able to comply.

Since this is a change to NY's Medicaid state plan, it must be approved by the federal Centers for Medicare and Medicaid Services (CMS). In its application to CMS, DOH said that no one will go without services as a result of FI closures because New York has "excess bed capacity for both hospitals and nursing homes." In other words, DOH knew

this would not only put FIs out of business, it would also disrupt vital homecare services for people with disabilities. They had deliberately lied to the media about that.

Several Centers for Independent Living (CIL) that are also FIs (including STIC), along with three organizations representing CILs and other FIs, sued DOH in NYS Supreme Court in Albany. The complaint argued that DOH's changes to the program were "rules changes" that required the state to follow a process of obtaining and analyzing public comment, which DOH had not done. They pointed out that relying on institutional settings to serve people who could no longer receive less expensive CDPA services at home was a clear violation of the Americans with Disabilities Act *Olmstead* Supreme Court ruling, which requires states to serve people in the most integrated settings.

DOH's response to the suit was weak. They claimed that a rate change is not a "rule," and that they were just carrying out changes approved by the state legislature and signed by the governor for the 2019-20 budget. In fact, there was nothing about a PMPM system in that budget, and DOH could not produce any evidence that there was. Also, while a mere rate change (say, cutting an hourly rate for a particular service by a dollar) may not be a rule that requires public comment, changing the entire mechanism by which FIs are reimbursed for their administrative work, including separating it from the rate they receive to pay wages to homecare workers, is definitely a rule change. DOH also claimed that their July 1 policy memo was only about a new re-application procedure for FIs seeking approval to operate that *was* in the budget and is set to take effect on January 1, 2020. But the July memo clearly stated that the PMPM system, and the procedures for transferring people to other FIs, will take effect on September 1, 2019.

The case was argued before a judge on August 16. The judge asked the lawyer representing DOH who would do the work if the FIs closed. The lawyer said there were "other" FIs waiting to take it on. The judge asked the lawyer to name one. The lawyer refused. That raises a big question. Early on, some people speculated that Cuomo wanted to create one or two centralized FIs, similar to the Medicaid transportation managers that he set up a few years ago—which led to a loss of public transit services in smaller communities across the state and made getting a ride somewhere more difficult for people with disabilities. Ominously, all of the FIs in New York City refused to sign on to the lawsuit. Has DOH been dangling a big contract in front of them?

The FIs asked for a temporary injunction to block these changes before they take effect. On August 23, the judge refused to grant the injunction. A temporary injunction requires that the FIs would suffer irreparable harm before the court would have time to fully decide the case. Although the FIs submitted affidavits stating that the PMPM rate system was well below their operating costs, and would inevitably and quickly lead to their closure, none of the affidavits stated that they would close on September 1 when the new rates take effect. Further, the judge noted, if DOH is found to be in the wrong, they would simply be ordered to retroactively reimburse FIs at the old rate. The judge did seem to think that DOH had a lot of explaining to do, so she ordered them to provide more information. The FIs will get to file a brief in response to that, and they'll be in court again on September 13. That will be after this newsletter goes to press, but we'll let you know what happened as soon as possible.

And the Beatdown Goes On: OPWDD Fails to Stop Abuse

On June 9, 2019, the New York *Times* reported that state employee unions are still protecting serious abusers who work in OPWDD group homes, and that the agency has been unable to fire them.

The *Times* collected disciplinary records from 2015 to 2017 which showed that over a third of employees who "committed abuse-related offenses" in OPWDD facilities were returned to work after the cases were investigated. Despite OPWDD's claims to be "changing the culture" in its facilities following an abuse scandal that erupted nearly ten years ago, and despite the alleged successes of the state's Justice Center for the Protection of People with Special Needs, the situation may be worse now than it was eight years ago, prior to the Justice Center's creation. At that time, a *Times* review of disciplinary cases found that only a quarter of workers who committed substantiated abuse (including sexual assault) were transferred to other facilities instead of being fired.

OPWDD's union contract with its workers requires that in most cases where the agency wants to fire someone, the employee can take the issue to arbitration. In many of those cases, the arbitrator refuses to allow the firing.

In May 2016 events at an OPWDD group home nicknamed "The Bronx Zoo" by its employees came to light when families of several residents sued the state for failing to protect their relatives from abuse for over a decade. Among the incidents recounted:

A nonverbal female resident of the facility tested positive for a sexually transmitted disease in 2004 even though she was unable to consent to sexual activity.

A female worker gave "lap dances" to a male resident, encouraging him to fondle her breasts, while other workers laughed and cheered.

Residents were beaten by staff, resulting in black eyes, deep skin sores, lacerations requiring stitches, head trauma and more.

A "whistleblower" complaint filed by a worker at the facility in 2014 was apparently ignored. The whistleblower said that she reported every incident she witnessed to her superiors but was told "not to listen to what I was taught in training class because it would label me as a snitch and that I should keep my mouth shut." Two workers at the facility were so frightened of testifying in the civil lawsuit that the judge took the extraordinary step of having them arrested and brought into court to file depositions. A former employee told state investigators that he had his car window broken after reporting on another worker.

The Justice Center was able to substantiate abuse charges against 13 employees of the facility, but arbitrators refused to fire any of them.

These events were not isolated to the Bronx.

A woman who lived at a group home in Rochester in 2017 made a 911 call pleading for help to get out of the facility because she was sure she was going to be killed there. Later that year she indeed was killed by two workers who pinned her to the floor, probably suffocating her. One of those workers was allegedly "very close to being fired" prior to the incident after being repeatedly disciplined, and eventually demoted, for a variety of rules violations.

In 2016, a worker in a Finger Lakes facility pulled a resident's hoodie up and over his head and then whacked him several times. He was returned to work after the investigation.

Other employees in other locations around the state who engaged in various forms of neglect and abuse such as repeated pinching, pushing residents to the ground, throwing a shoe at a resident, and sleeping on the job were allowed to continue to work for OPWDD.

OPWDD's spokesperson, Jennifer O'Sullivan, told the *Times* "that abuse of people in the agency's care 'is completely unacceptable' and that the Bronx workers were disciplined and retrained."

Really? What sort of retraining did they receive?

Did they need to learn that they should not give lap dances to residents because that was

not completely obvious before? How about a lecture on how it's frowned upon to rape non-verbal women? Or any woman. Perhaps they clarified that the acceptable procedures for working with group home residents do not actually include punching them in the face and slamming their heads into the walls. Did they advise the staff not to answer the phone with "Good morning, Bronx Zoo," as a family member was greeted a month after the lawsuit was filed?

Were similar trainings provided to workers in other locations? Did they instruct that Finger Lakes worker that he should not have pulled the resident's hoodie up over his head before he beat him? Hey, maybe an employee of a group home might not know that he should not throw shoes at the residents before he was "retrained."

It should go without saying that it's impossible to "retrain" thugs and rapists to become kind, caring human service workers. It should, but apparently it doesn't. So we're saying it: People who abuse people with disabilities cannot be "retrained." They must be fired. All of them.

It's true that OPWDD is hamstrung by the union contract, but the governor and the legislature are not. The problem with the arbitration clause is several decades old, and after the last big public airing of these issues during the creation of the Justice Center, the contract was re-negotiated and re-signed. State officials knew they could have insisted on ending arbitration for employees accused of abuse and neglect in the new contract, but they refused to do so. The legislature, including some members who have recently ranted self-righteously about the ineffectiveness of the Justice Center, understood these issues well, yet they deliberately weakened the already-weak provisions concerning employee discipline and firing in the Justice Center law.

In June the *Times* reported:

"Mark Kotzin, a CSEA [union] spokesman, declined to comment on specific cases. He said the employees have 'some of the hardest work imaginable,' and when they hear of abuse or neglect, 'they get upset and want the abusers gone.'"

While many employees are compassionate, some boil over, case files reveal.

"I will pop you like a zit. I [expletive] hate you," one worker said to a resident. "Why do you act like such a crazy person?" another worker asked a resident. A third proclaimed that she "did not give a [expletive] about the consumers."

The *Times* missed the mark. This is not a case of people “boiling over,” as though they were merely overstressed and letting off steam. They are the words of callous, vicious abusers, and they cannot be excused under any circumstances.

Neither can the jokes that are OPWDD’s “new culture” and the Justice Center’s “protection of people with special needs.”

No More Non-Medical Vaccine Exemptions

On June 12, 2019 Governor Cuomo signed a bill ending non-medical exemptions from requirements for children attending public school to be vaccinated.

Media reports emphasized that the law would end “religion-based” exemptions, after it became widely known that a large number of recently-reported cases of measles occurred in Orthodox Jewish communities in New York where families have a history of obtaining such exemptions. It should be noted that Jewish religious experts have said that there is nothing in the tenets of Orthodox Judaism that requires or justifies refusing to vaccinate children.

In fact, the new law outlaws all exemptions based on anything other than medical reasons. Exemptions can only be granted when a physician certifies that a vaccination would endanger the health of the child. The New York State Department of Health (DOH) quickly issued regulations requiring doctors to fill out detailed forms to clearly state valid medical reasons why specific vaccines should not be given to a specific child. Prior to the issuance of those rules, physicians were allowed to sign simple general statements saying a child should not be vaccinated for medical reasons. State officials believe that the DOH regulations will make it much harder for doctors sympathetic to the unjustified beliefs of some parents to issue bogus exemptions.

This issue is, of course, important to the disability community because of a small but vocal movement of activists who began claiming several years ago that childhood vaccinations cause autism. They do not.

The origins of this false belief can be traced to two sources:

Wakefield’s studies

British researcher Andrew Wakefield published two studies linking measles/mumps/rubella (MMR) vaccines to autism. The first study was determined to be entirely fraudulent and was retracted by the publisher. The

second study had serious methodological flaws that made it useless. Wakefield was subsequently judged to be unethical and dishonest and his license to practice was revoked. It was later revealed that he was paid about £400,000 (over \$500,000 US) by some families of children who were suing a vaccine manufacturer to issue research findings to support their claims.

Robert F. Kennedy Jr. and Thimerosol

The Kennedy family is historically linked to advocacy for children with developmental disabilities, which lends an aura of respectability to Kennedy’s claims. He has publicized a long-refuted theory that a chemical called Thimerosol in childhood vaccines causes autism. Thimerosol contains mercury, and mercury is certainly poisonous. There is confusion about the difference between two compounds that contain mercury—ethylmercury and methylmercury. Methylmercury is highly poisonous, and as best we can tell, it was never used in vaccines. Thimerosol is a brand name for ethylmercury. Ethylmercury is broken down quickly in the human body and excreted; small amounts of it are not harmful. Prior to 1999, some childhood vaccines contained Thimerosol—ethylmercury—as a preservative. Although there was no evidence that it was harmful, in order to address concerns, it was removed from all typical childhood vaccines, including MMR vaccines. Members of Kennedy’s own family, as well as a raft of medical experts, have repudiated Kennedy’s claims.

To summarize: Childhood vaccines administered today **do not** contain Thimerosol or mercury, and vaccines of any kind **do not** cause autism.

There’s a famous quote (attributed to Daniel Patrick Moynihan): “Everyone is entitled to their own opinions, but they are not entitled to their own facts.”

A fundamental failure to accept that is what has led us to today’s world, in which everything except what **you** want to believe is “fake news,” and conspiracy theories abound. People who find that upsetting, and who would like to do something about it, should begin by carefully examining their own beliefs and attitudes toward information that they do not like.

It’s certainly true that sometimes people conspire to do bad things in order to benefit themselves. But evil conspiracies to do awful things merely to amuse some deranged villain only happen in James Bond movies. And

it is extremely unlikely that any evil conspiracy involving large numbers of people and continuing over decades could be kept secret from everyone except a select few who have the “inside track.” Those who believe there is a conspiracy to deliberately cause autism should ask themselves, why? Why on earth would anybody do that? There’s no big money to be made; the difference in cost between a vaccine that contains Thimerosol and one that doesn’t won’t begin to pay for the fines and jail time that would surely be imposed as soon as somebody conducted a chemical analysis on a vial of MMR vaccine and found mercury in it. Which, by the way, no one has found since 1999.

Very little that is important in this world is simple. There are no quick solutions for complex problems, no easy explanations for upsetting events.

Not all of the causes of autism are known, but heredity is probably the most important one (families that have one autistic child are more likely to have another one than families that don’t). There is some evidence that it may also be caused by spontaneous mutations that occur in human eggs or sperm, or that an embryo in the womb can be damaged by infectious or autoimmune diseases in ways that cause autistic symptoms. Although symptoms of autism usually do not appear immediately in babies, there is no credible evidence that anything that happens to a child after it is born can cause autism. Part of the problem is that, while the “autism spectrum” describes a collection of observed behaviors that people with that diagnosis have in common, it is growing increasingly clear that there are actually several different neurological conditions that can cause those behaviors. It’s also likely that, due to a media focus on the condition, and increasing funding for services for it, more people are being misdiagnosed as autistic today than a couple of decades ago.

Human beings are social animals, and they only can truly be safe, comfortable, and healthy when they accept their social responsibilities. One of those responsibilities is to get your children vaccinated. Measles is easily transmitted in societies that do not establish effective “herd immunity” against it. Herd immunity is known to have broken down in the communities that experienced measles outbreaks this year, due to a growing number of families that did not vaccinate their children. Measles can kill people; autism cannot. Refusal to vaccinate needlessly puts other people’s children at risk. Now **that’s** evil.

courts watch

Matter of Mental Hygiene Legal Services v Delaney: No Solutions

Olivia CC is a teenage girl with diagnoses of intellectual disability, disruptive mood dysregulation disorder, intermittent explosive disorder, attention deficit disorder, and “a chromosomal syndrome” who was stuck in a hospital emergency room for several months due to New York’s failure to provide her more appropriate services. We cannot find the original complaint and are left with news reports and a judge’s decision to understand what happened.

“Disruptive mood dysregulation disorder” means Olivia was usually irritable and frequently had temper outbursts. “Intermittent explosive disorder” means that the temper outbursts were violent and could involve attacking people or damaging property. The experts are not very confident about the causes of these things. They could be related to biochemical or physical abnormalities in the brain, or to psychological trauma, or both. (There is some evidence that repeated emotional trauma inflicted on young children actually causes permanent brain abnormalities.)

The girl was reported to have become “uncontrollable” at school, and she was taken to a hospital emergency room in Plattsburgh. The people there said she didn’t need any medical or psychiatric treatment, and wanted to release her. Her mother reportedly was afraid she would harm another of her children and refused to take her home. So she spent several months in the emergency room while various people tried to find a residential placement for her.

The hospital reported the mother to the county Department of Social Services (DSS) for child abandonment. DSS, however, agreed with the mother that she could not take Olivia home.

The school district said Olivia needed a residential school, but could not find one to take her even after applying to 27 such schools.

OPWDD tried to get her a temporary place-

ment in a group home, whether operated by OPWDD or one of its contractors, but could find no openings.

The child had been enrolled in the OPWDD Home and Community Based Services (HCBS) Medicaid waiver, but we have no information on what services, if any, she had been getting. Failing to place Olivia outside the home, OPWDD agreed to increase funding for her waiver services to provide more help in the home, but no “qualified provider” could be found to serve her. The mother asked OPWDD to send its own employees into the home to help but OPWDD responded that it could not do that.

After much delay, Mental Hygiene Legal Services (MHLS) sued OPWDD (whose Commissioner was then Kerry Delaney) on behalf of Olivia and her mother in state Supreme Court. They lost there, so they appealed to the Appellant Division, where they lost again.

Eventually a placement was found, and the judge could have dropped the case at that point. But she was so disturbed by the situation and others like it that she issued a decision anyway. The suit raised multiple issues, and the resolutions are pretty technical, but here are the important points:

It’s legal for the state to designate school districts as primarily responsible for finding services, including residential services, for school-age children with disabilities.

The judge did not think that a situation that results in a child living in a hospital emergency room for several months violates the Americans with Disabilities Act (ADA)’s prohibition on discrimination on the basis of disability, or the US Supreme Court’s *Olmstead* decision,

which requires states to provide services to people with disabilities in the most integrated settings appropriate to their needs. The judge pointed out that OPWDD could not compel its subcontractors to modify their procedures to provide services to a specific person. She also cited another federal court decision, *Rodriguez v*

City of New York (Remember that one? We do! See *AccessAbility* Winter 1999-2000), to support her belief that asking OPWDD to send its own employees into Olivia’s home would be asking the agency to create an entirely new program, a “fundamental alteration” that the *Rodriguez* judge said the ADA and *Olmstead* do not require.

Although one might argue that under federal Medicaid law, the state was legally obligated to provide all medically necessary services to Olivia “with reasonable promptness,” the judge dredged up *Armstrong v Exceptional Child Center, Inc.* (*AccessAbility* Spring 2015 and Summer 2015) in which the US Supreme Court found that federal Medicaid law does not give service recipients the right to sue for enforcement. The only way to enforce Medicaid laws, according to that decision, would be to demand that the federal Department of Health and Human Services (HHS) cut off the state’s funding for failure to comply; if HHS refused to do that, then Olivia’s mother could sue *them*.

The judge concluded that the state has created a service gap for children who need “temporary” residential placement outside the home and that it should do something about it—but there was no legal way to compel any particular solution.

There might be one way, actually: If *DRNY v New York State, Cuomo & Delaney* (*AccessAbility* Spring 2018) is decided properly, OPWDD will be required to begin discharge planning for students in residential schools much sooner, which will mean they won’t be kept in those institutions after reaching adulthood, which would make more “beds” available in them for actual children like Olivia. So far, though, there’s no decision in that case.

We can debate the wisdom of using out-of-home placements for children as an escape valve for frustrated parents, and point out that getting intensive services into the home at a very young age can prevent kids from becoming uncontrollably violent teenagers. But without knowing the specific facts about Olivia and her family, it would be inappropriate to make judgments here.

We can only agree that these situations are a crisis of the state’s own making, a product of the Governor’s practice of capping Medicaid spending for services not promoted by wealthy campaign contributors at unworkably



low levels, and again point out that intensive in-home early intervention services, and small-scale temporary respite and crisis residential programs, are less expensive than large institutions like residential schools.

Woods Services v DRNY: Oops...

In October 2017, New York's protection and advocacy watchdog, Disability Rights New York (DRNY) published a scathing report on Woods Services, a large institution for people with developmental disabilities in Pennsylvania (*AccessAbility* Winter 2017-18). Among the programs at Woods Services is a "residential school" for school-age children with developmental disabilities. The report alleged ongoing, frequent incidents of serious abuse and neglect in the residential school that were systematically being covered up by Woods Services administrators.

Such children are sometimes referred to those institutions by school districts that are unable or unwilling to "handle" them, usually due to behavioral issues. In nearly all cases, local public schools could have done a better job of providing behavioral supports to those children to avoid sending them away. However, instead of following best practices, school districts fail to show progress on the students' Individualized Education Plan goals and stonewall parents about it until those parents agree to the residential placements. There may not be available "beds" at residential schools in New York (due, in part, to OPWDD's failure to transition people out of those schools once they become adults), so they are sent out of state. DRNY has a statutory responsibility to monitor and oversee such programs when they serve New York citizens.

DRNY, like STIC and other Centers for Independent Living, and nearly all disability rights organizations, are opposed to unnecessary segregation, and believe that nearly all segregation is unnecessary. DRNY's report clearly illustrated that bias.

When the report was published, Woods Services posted a response on its website that just as clearly indicated that the facility was contemptuous of the whole idea of community integration for people with developmental disabilities. The response also accused DRNY of deliberately, and with malice, lying about conditions and events at the Woods residential school, and Woods subsequently filed a lawsuit for defamation against DRNY. DRNY countersued.

Eventually, both sides agreed to a settlement, and DRNY issued a joint statement in June 2019. The statement said, in part:

"Having now had further opportunity to review records and other evidence and with the benefit of hindsight, DRNY and Woods feel that the Report and the Response to the Report could have been more cooperative and collaborative, and have agreed that going forward that will be the case. DRNY regrets not giving Woods a meaningful opportunity to either respond to or provide relevant information concerning the assertions in the Report before DRNY published it.

Both parties have concluded that rather than engage in further litigation concerning these matters, the public interest which they both serve would be furthered by a settlement, the terms of which provide (1) that the Report and the Response are permanently withdrawn, and will be removed from the websites of DRNY and Woods respectively, will not be further disseminated, and should not be used or relied upon by any third parties for any purpose; (2) for procedures and policies that will govern and help ensure that future interactions between DRNY and Woods will be cooperative and cordial; and (3) certain other terms which shall remain confidential."

Medicaid Managed Care Unmasked

In April 2019 US Senator Bob Casey (D-PA) wrote to the Inspector General of the federal Department of Health and Human Services to request a national investigation of Medicaid managed care programs. He wrote, "Reports from across the country have surfaced alleging that some Medicaid managed care companies (MCOs) continuously deny care to patients sorely in need of care. In some cases, patients have experienced entirely preventable life-altering harms." He also asked for a review of whether the federal Centers for Medicare and Medicaid Services (CMS), responsible for authorizing managed care programs, provides adequate oversight.

We can definitely say that CMS does not provide adequate oversight. They farm that responsibility out to the states, and many state governments barely monitor MCOs at all. Several years can pass before CMS audits state health departments and finds something, as happened when New York's Department of Health (DOH) was discovered to have allowed crooked MCOs in New York City to collect millions of dollars in fraudulent claims for providing alleged "Social Day Care" services to senior citizens who weren't eligible for them.

Casey's letter cited several news reports of MCOs illegally delaying or denying appropri-

ate services to Medicaid recipients, including long-term care recipients who were elderly and/or had developmental disabilities. The reports mostly covered events in California, Texas (though the Texas story featured Centene, the national company that took over Fidelis in NY), and Iowa. The stories are here:

<https://www.dallasnews.com/news/medicaid-managed-care/collection/pain-profit-investigating-medicaid-managed-care-texas>

<https://khn.org/news/whistleblower-medic-aid-managed-care-firm-improperly-denied-care-to-thousands/>

<http://features.desmoinesregister.com/news/medicaid-denials/>

Additional information, including newspaper articles chronicling Iowa's dismal experience with managed long-term care for people with developmental disabilities, is here:

<https://theddnewsblog.blogspot.com/2018/05/iowa-managed-care-and-privatization-of.html>

As a result of events recounted in stories like these, OPWDD's new Commissioner, Dr. Theodore Kastner, has said that the state needs to slow down the process of moving OPWDD services into managed care. Kastner began his career as a Direct Support Professional. He's been an effective advocate for deinstitutionalization, and has conducted research in the role of managed care in developmental disability services. We hope that Dr. Kastner is not eaten alive by the OPWDD/DOH bureaucracy and their allies in the insurance and service provider industries as previous progressive OPWDD Commissioners were. And we will keep an eye out for any results of an Inspector General investigation of Medicaid managed care.





STIC NEWS



She's in the Hall!

We are proud to report that STIC's Executive Director, Maria Dibble, was inducted into the New York State Disability Rights Hall of Fame on June 13, 2019. Maria and four other inductees were honored with a gala dinner at the Rivers Casino in Albany.

This was only the second year of Hall of Fame inductions. Maria now joins an elite list of celebrated New York luminaries such as Bruce Darling, Marilyn Saviola and Patricio "Pat" Figueroa. Douglas J. Usiak, a 2018 inductee and Chairperson of the New York State Independent Living Council (NYSILC), made introductory remarks. The awards were presented by NYSILC Executive Director Brad Williams.

Maria Dibble entered the disability rights arena in the early 1980s, a time when "accessibility" was little more than a word in the dictionary for those outside the disability

community. In New York's Southern Tier, that began to change when Maria, newly graduated from college, rejected suggestions that she seek employment in a sheltered workshop and co-founded the Southern Tier Independence Center (STIC). For the first time, area residents with disabilities had a local resource and voice to bring their concerns to policymakers and the public.

As STIC has grown, so has Maria's career as a savvy leader and a seasoned advocate for the rights of individuals with disabilities. She was on the front lines in Washington during the battle for passage of the Americans with Disabilities Act (ADA). Maria and her fellow advocates' tireless work came to fruition when President George H.W. Bush signed the ADA into law in 1990. Maria took momentum from the ADA's passage and used it to advance key components of the Independent Living mission, including deinstitutionalization, supported employment, and Consumer Directed Personal Assistance (CDPA). She was a leader in the Association on Independent Living, one of the entities leading the charge for a state-

wide CDPA Program. And she continues to defend CDPA against attacks from legislators, budget hawks, and the profit-seeking medical-industrial complex.

Maria was appointed to the New York State Independent Living Council (NYSILC) board of directors and served as chair in the early 2000s, when the SILC and state plan were moving in new directions.

Maria realized there was lack of services for people who have both mental health and developmental disabilities. Existing services for each group treated people as if they belonged in one category, and those with dual diagnoses were shuttled from provider to provider, never getting the care they needed. She recognized that children were especially vulnerable, as many mental health care providers are reluctant to treat them.

In 2004, Maria mobilized the resources of STIC to create the Children's Mental Health Task Force and address this gap in services by fostering collaboration among voluntary and government agencies, schools, and care providers. Under Maria's leadership, the task force created action steps for the near and long-term future, and generated a dozen detailed recommendations to address the issue. Among Maria's many accomplishments, this one stands out because it demonstrates the reach of her efforts, illustrates her willingness to tackle complex and challenging issues, and proves her ability to bring a diverse group together for a common purpose.

Not only has Maria brought about change both locally and globally, she has also inspired and mentored several generations of advocates. Each of these advocates has gone on to work for change and inspired others to do the same. This ripple effect ensures that individuals with disabilities in Broome County and beyond will feel the impact of Maria's work for generations to come.





XSCAPES

SOUTHERN TIER'S PREMIER ESCAPE ROOMS

Xscape with Us

by Maria Dibble

Have you been pining for an adventure? Looking for a distraction? Yearning to search for clues and solve puzzles similar to quests in computer games?

Well, do we have a treat for you!

It is Binghamton's own Xscapes rooms, with original designs, extreme creativity, beautiful detailed décor and cunning puzzles. Many attendees have told us that

our rooms are the best they've ever seen, and some people go all over the country to find them.

Gather a group of six to eight players and go to www.xscapes-stic.com to register for one of our rooms. All proceeds benefit Southern Tier Independence Center and the people with disabilities we serve. With so many looming cuts, we could use your

help while you have some fun.

We have four choices of themed rooms:

Valley of the Kings: An ancient Egyptian theme.

Pulse: Disarm the bomb before it explodes

Twilight Zone, The Rod Serling Experience: We pay homage to his life and his works

And

Wizard and Dragon: Try your magic to appease the dragon

The first two rooms are each an hour, and the last two are 90 minutes, costing \$20.00 and \$25.00 per person respectively.

The ultimate goal is of course to have fun, as you try to find the clues to solve all the puzzles before your time runs out.

Our venues are so exciting and engrossing that many people come back to try every single one.

On one occasion, a man asked his fiancé to marry him by having us hide the engagement ring in one of the puzzles. She was quite surprised and she did say "yes".

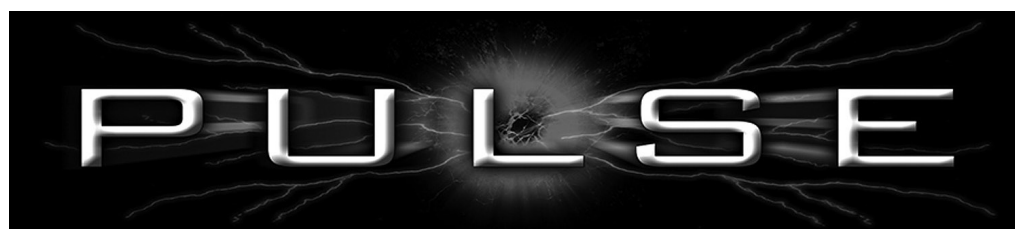
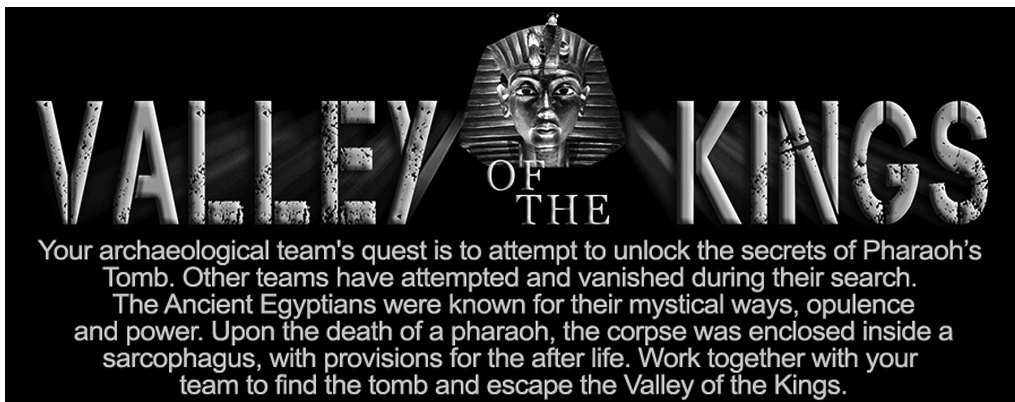
Many businesses and organizations have found our rooms a valuable venue for team building.

In addition to the exciting rooms at STIC, we have portable rooms—a 13 by 13 tent that groups can rent for a party, or other event.

Coming in a few months, we will have a tent designed for either children or adults called, "The Wizard Academy"—great for birthday parties and the like. Watch these pages for future updates.

Are you and your group up to the challenge? Are you clever enough to "beat the clock" and "Xscape" from the room? Come check us out. You won't regret it.

Go to www.xscapes-stic.com to learn all about us, and the availability of games and times.



SELF HELP

End Abuse!

(from the NYS Developmental
Disabilities Planning Council)

Check out this new website designed to prevent abuse of people with disabilities:

With the many forms of abuse, it can happen to anyone. Funded by the New York State Developmental Disabilities Planning Council, endAbuse of People with Disabilities is a new website that provides a repository of accurate and reliable resources about the abuse of people with disabilities. Users of end-abuse.org can access multimedia content that offers information about the forms of abuse, targets of abuse, peer-to-peer support, and advocacy. Additionally, those in need have the ability to get immediate assistance from the "Get Help Now" section which includes a "quick escape" browsing option. Please share this website and use the hashtag #endAbuse to join the conversation on social media. Together we can prevent the abuse of people with disabilities!

<http://end-abuse.org/>

Support Your Local DSP!

by Lucretia Hesco

National Direct Support Professionals Week (September 9 – 15) gave us the opportunity to show appreciation for the dedication and commitment that our STIC direct support professionals provide to people with disabilities.

DSPs provide a broad range of services, which must be individualized and tailored to meet each person's needs. DSPs are a critical component in the lives of the people we serve, enabling those with intellectual and developmental disabilities to learn new skills and become more independent.

We were proud to recognize the magnitude of their contributions during Direct Support Professionals Week. If you see any of our DSP team members, please be sure to express your gratitude for all of the incredible work they do every day!



Join us for a **TRUNK Or TREAT**

**Saturday
October 26, 2019
5pm—7pm**

**@ STIC
135 E. Frederick St.
Binghamton, NY
13904**





NOW HIRING DIRECT SUPPORT PROFESSIONALS!

Join the Habilitation Team at the
Southern Tier Independence Center
to provide support to people with disabilities.
Must have flexible hours and a valid driver's license.
Please email your resume to **apply@stic-cil.org**.

Please join us on
Wednesday, October 2, 2019,
from 9am – 11 am or 3 pm – 5 pm
for walk-in interviews at our office at
135 E. Frederick St. Binghamton, NY 13904.



This newsletter is also available in large print, on cassette, and online, at:
www.stic-cil.org

NON-PROFIT ORGANIZATION
 U.S. POSTAGE
PAID
 BINGHAMTON, NEW YORK
 PERMIT NO. 126

135 E. Frederick St.
 Binghamton, NY 13904
 (607) 724-2111 (voice/TTY)
 Toll Free (877) 722-9150
 email: stic@stic-cil.org
 RETURN SERVICE REQUESTED

Free Access Is Not Free

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

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

- | | |
|--|--|
| <input type="checkbox"/> Individual \$5 | <input type="checkbox"/> Contributing \$100 |
| <input type="checkbox"/> Supporting \$25 | <input type="checkbox"/> Complimentary \$_____ |
| <input type="checkbox"/> Patron \$50 | <input type="checkbox"/> Newsletter Subscription \$10/year |
| <input type="checkbox"/> Make Me A Member | |

MAIL TO: Southern Tier Independence Center, Inc.
 135 E. Frederick St.
 Binghamton, NY 13904

Name _____
 Address _____
 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

EXECUTIVE DIRECTOR

Maria Dibble

ASSISTANT DIRECTOR

Jennifer Watson

ACCESSIBILITY SERVICES: Frank Pennisi

ADA SERVICES: Frank Pennisi

BEHAVIORAL CONSULTING:

Veronica Wallen Rachel Schwartz
 Yasmin Van

DEAF SERVICES: Heather Shaffer

DEVELOPMENT: Bill Bartlow

EC-FACE: Karen Lawrence Beth Kurkoski

EDUCATION SERVICES: Stephanie Quick

HABILITATION SERVICES: Kim Kappler

Daniel Schwartz Corine James
 Hannah Hickox Catherine McNulty
 Cathy Sostre Brittany Lynady
 Lucretia Hesco Julia Massaro
 Kathleen Scanlon Katie Trainor-Leounis

HEALTH EXCHANGE NAVIGATORS:

Christy Sodan Joy Stalker Michelle O'Hare
 Theresa Askew Loretta Sayles
 Chad Eldred Theresa Kircher Patricia Lanzo
 Brittany Pritchard Brittaney Carey

HOUSING SERVICES: Grace Eggers

INTERPRETER SERVICES: Stacy Seachrist

MONEY FOLLOWS THE PERSON:

Peg Schadt Krystal Pierre Millien
 Marcy Donahue

NHTD RESOURCE CENTER:

Ellen Rury Daena Scharfenstein
 Belynda Raminger Laura O'Hara
 Pamela Lounsberry

NY CONNECTS:

Amy Friot Eileen O'Brien

PEER COUNSELING: Jane Long

Danny Cullen Robert Deemie
 Richard Farruggio Susan Link

PERSONAL ASSISTANCE SERVICES:

Susan Hoyt Tess Savage Tyasia Jewell
 Katina Ruffo Alicia Riehle

PSYCHOTHERAPY:

Charlie Kramer Jane Long

SA-FACE: Shannon Smith Tara Ayres

SUPPORTED EMPLOYMENT: Brian Roth

Kandi Stevens Michelle Dunda
 Rachel Barton Crystal Musshafen

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER:

Belinda Turck
 Ellen Rury Courtney Medovich
 Lori Wilmot Valerie Soderstrom

TECHNOLOGY SERVICES:

Jessica Kendricks Decker Ayers