

AccessAbility

Spring 2018
Number 130

Broken Promises May Lead to Broken Lives, *Especially If We Let Them*

by
Maria Dibble

How many times can Governor Cuomo ignore people with disabilities, break his promises, or introduce detrimental policies and cuts? Let me count the ways!

1. Revival of sheltered workshops.

The state made a formal agreement with federal regulators in 2014 to close sheltered workshops. In 2015 the Governor's Employment First Commission took plenty of credit for OPWDD's closure plan and called integrated employment for competitive wages the "preferred alternative" to sheltered workshops. Since then we've found, from the people we've helped to leave segregated work and living circumstances, that all of them are happier.

But OPWDD's December 2017 "emergency" regulations allowing payment of sub-minimum wage for "prevocational services" in segregated work settings for unlimited periods of time restores this outdated and unnecessary model of services and provides money that backward-looking agencies can use to get their workshops up and running again (see page 9).

A few former OPWDD employees and family members (ignoring that their own children say things are better now) have complained to politicians about the closures, but that doesn't justify breaking this promise. Remember that line, "life, liberty and the pursuit of happi-

ness"? Well, disabled people want that too, if only we bothered asking **THEM**—not their parents—directly.

2. Refusing to provide a path to a competitive wage for homecare attendants.

The Governor seems to be playing favorites, raising wages a bit for workers serving people with mental health and developmental disabilities in specialized programs but ignoring the rest. I don't begrudge them the increase, I applaud it, but why are some workers more important than others? Are the people who take disabled folks to community locations to do volunteer work or learn how to manage money really more valuable than those who come into their homes, help them shower, use the toilet, get dressed, and eat their breakfast? These homecare workers can work for Burger King and eventually earn \$15.00 an hour, but if they keep assisting people with disabilities to remain in the community, the most they can aspire to is \$12.50 an hour (in upstate regions) in a few years. There you have it, burgers are more important than people.

There is already a steady drain of homecare attendants to other jobs where they can make more money, and people with disabilities and the elderly are the ones that suffer.

Oh, the Governor offered money in the proposed budget to "conduct a study" of "rural

INSIDE	
Feds Ding NY Medicaid	
Managed Care	3
Budget Bickering Begins	3
Courts Watch.....	5
CCO Update: A New Home	7
Letting the CHIPs Fall	8
OPWDD's Bogus	
Prevoc "Emergency"	9
Employment First	
Goes Sideways	10
NYAIL 2018 Legislative and	
Disability Rights Agenda	10
Getting DSRIpped.....	13
New Medicare Cards	
Coming this Spring.....	13
ASAC Thanks You!.....	14
Xscapes	14
Community Health Survey	15
Sound the Alarm, Save a Life.....	15

areas" (really, he means "anything north of Westchester County"), to determine the extent of the shortages. Governor, I'm in Broome County, an urban area with 200,000 people, and there is a great shortage here. I can say with total confidence that it's even worse in real rural communities.

The attendant shortage, driven by low wages, is a well-known problem nationally, and it's been going on for years (see page 4). This is just a case of ignorance, of a Governor who only listens to a few state agency commissioners and members of his inner circle instead of paying attention to the wider world. We don't need any more studies because we already know the answers!

3. Promising a fair, less expensive and more patient-centered new model of service delivery that we now know as managed care and managed long-term care.

We have totally upset the service system in NY in the last few years, forcing a move to managed care under the guidance of Medicaid

AccessAbility

March 2018

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.

Director Jason Helgerson, and the Medicaid Redesign Team (MRT), with promises of large savings and better care. Have you felt better cared for? If you are in managed care, do you know who your Care Manager is (see page 3)? I'll bet not!

So what is better? And has it saved money?

I remember the MRT and others promising us that our doctors would come together to ensure that each one was informed about our treatment. Though advances in technology allow physicians and others to share information about us, they have to *read* that information for the technology to help. Have your doctors done that? Mine haven't. They're too busy typing to read it. Sometimes they don't even look at us, too busy at their computers to give us the attention we need and deserve.

And as time goes on and New York ramps up its "Value-Based Payment" system, our doctors may be faulted if we don't achieve certain goals, such as lowering our A1C or losing those pounds they hound us about. It will now be their fault if we don't behave like perfect patients.

This is what Managed Care forced on us—patients and medical personnel alike. It was a bad deal from the beginning and it continues to spread like a cancer through the entire medical system.

The architect of this failing system is Jason Helgerson, whom Governor Cuomo bragged about "seducing" to come work for him. Helgerson left Wisconsin after introducing a similar managed care approach, which many say is a failure. He made many promises, broke most of them, and now he's moving on "to greener pastures," leaving behind pastures that are brown and dying.

4. Increasing the base score on the Universal Assessment System tool from five to nine, making it harder to qualify for Medicaid Managed Long Term Care (MLTC) (see page 11).

Helgerson says that too many people are entering Medicaid managed care. Of course they are! He and the Governor forced them to with the great plan foisted upon us by the MRT.

5. Forcing people with disabilities to stay in the MLTC plan they initially select for a full year.

Currently they can switch at any time. Preventing this switch is harmful because if someone's condition changes, their MLTC might not offer what they need and they'll be stuck for a year.

6. Kicking people out of MLTC if they are in a nursing home for more than six months.

As Assemblyman Richard Gottfried, Chair of the Assembly Health Committee, said at a recent budget hearing, "That gives a managed long-term care plan an enormous incentive to unload high-cost home-care patients into nursing homes, knowing that in a few months that person who is now institutionalized will be off their books. That seems not only cruel to people who want to be in their homes but contrary to what we have said is our policy in New York for many years."

Helgerson's response—"If at any point they decide to relocate to the community, we'll create an opportunity to re-enroll in a managed long-term care plan"—ignores the fact that people often "decide" to go into a nursing facility as a last-ditch effort to stay alive, because they can't get enough services in their homes. Gottfried snapped back, "They'll have no home to go home to."

7. Restricting the number of homecare agencies to ten in every managed care plan.

Helgerson says there are too many small agencies; they need to consolidate.

For years, policy "experts" who work for big health care providers and insurance companies have been pushing the idea that "consolidation" of small providers into big companies—say, by having the companies they work for buy up the little ones—is somehow better. If you can't see why they would think that way, there's a bridge in Brooklyn I'd like to sell you.

Just read about the aide shortages described above to see why this is a horrible idea. There aren't enough agencies now, which is pushing some folks into nursing homes. Perhaps that's what the Governor wants. What other conclusion can be drawn from the available evidence?

8. Leaving Independent Living Centers like STIC at level funding, making it 12 out of 13 years without an increase, while health insurance and other costs have skyrocketed out of control.

This while we help people to avoid nursing home and other institutional placements, which are far more expensive and dehumanizing than remaining at home.

Which finally brings me back to the Governor and his consistent practice of ignoring the needs, wishes, and survival of people with disabilities, including those who are elderly, and breaking one promise after another. At least he's consistent.

We supposedly have a large budget deficit of about \$4 billion, but what is beyond my comprehension is that we can afford to build airports, renovate stadiums and the like, but we

can't take care of the people of our state, especially those who are disabled and elderly.

The administration thinks of people with disabilities and/or the elderly as "throw away people." To them, we simply don't matter, and

we likely never will. I've written letters, made phone calls, rallied in front of the Governor's office and more, but to no avail.

The only viable path is to fight back by voting and by participating in STIC's many advocacy

efforts. Contact Sue Ruff at (607) 724-2111 if you want to learn more about our advocacy work. We are not "throw-away people"! And if we unite we can throw out those who think we are.

Feds Ding NY Medicaid Managed Care

In a report issued in September 2017, the federal Medicaid Inspector General (MIG) heavily criticized the New York State Department of Health (DOH) for failing to oversee the state's Medicaid Managed Long-Term Care (MLTC) program. As a result, MLTC plans overbilled, failed to provide services, and did not provide real person-centered planning. The report confirms what STIC and other advocates have been saying about managed care for several years.

A few years ago (see *AccessAbility* Summer 2013), some managed care companies in the New York City area committed wholesale fraud by recruiting elderly people to attend Medicaid-funded day programs with offers of free food and recreation. They enrolled hundreds of them in Adult Day Health Care (ADHC) services. ADHC is a congregate program that provides recreation, meals, and health monitoring, supervision, and services, and it is supposed to only be available to people who have significant disabilities. Most of the enrollees were quite healthy and didn't need the service, and many were not eligible for the Medicaid-funded program based on their income, or because they also had Medicare. After these crimes were discovered, it occurred to the MIG that other MLTC plans might be doing similar things.

So MIG auditors took a random sample of 100 monthly capitation payments that were made to 29 MLTC plans between April 1, 2013 and March 31, 2014, for recipients of ADHC services. In 36% of the payments, the state requested federal reimbursement even though the plans did not fully comply with contractual requirements. 71% of the payments were made even though the plans did not provide adequate person-centered planning.

Among the contractual requirements, 10% of the payments were made even though the plans did not provide any long-term services and supports during that month. Half of those payments were made to plans that didn't provide services for nearly an entire year. 19% of payments were made to plans that either did not conduct, or did not document, the partici-

pant's eligibility assessment prior to the payment being made—sometimes delaying the assessments by half a year or more. 14% of the payments were made for people who didn't have a written service plan.

On the person-centered planning front: 65% of payments were made for people whose service plans contained generic language and were not individualized, or whose plans only addressed a small number of very basic needs and ignored psychosocial concerns. 8% of plans did not address post-hospitalization safety or support issues for individuals who had those needs. 5% of plans did not address participants' diagnosed mental health or cognitive issues, including failing to provide for psychiatric evaluation. 3% of plans did not address the needs of people who were at risk of falling in their homes. 60% of plans did not even provide basic referral or coordination for strictly medical services—which should have been their strong point.

Finally, the contracts in place between the state and the MLTC plans at the time did not allow the state to recover payments when plans didn't comply with the contracts.

The MIG says that its random sampling method is statistically valid so it can apply these percentages across the state's entire MLTC system, and on that basis concluded that the state made \$1.4 billion in overpayments to MLTC plans during FY 2013-14. The MIG said that these failures occurred because "the State agency did not adequately monitor MLTC plans for compliance with Federal and State requirements."

New York's response was predictable: We didn't do anything wrong, and we won't do it any more. Specifically, the state says it established a new "unit" to survey and monitor MLTC plan compliance in 2015. It did not explain why no such unit existed when it started paying the plans in 2012. The state also said it was working on an improved contract for MLTC plans that will be more specific about person-centered planning and other requirements. But New York disputed the MIG's

claim that the state could have saved \$1.4 billion; state officials said it couldn't have done that because the feds didn't require them to have a pay-back provision in the contracts.

As OPWDD and DOH pointed out in a recent Response to Comment on their managed care transition plans, New York has 30 years of experience with Medicaid managed care in some form. And for 30 years, advocates have complained, and sued the state, repeatedly, because DOH failed to adequately monitor managed care companies and require them to comply with the regulations. Come on! Nobody who isn't a complete idiot, or an "inside man" working for the insurance industry at DOH, would sign a contract that doesn't require the vendor to pay the state back if it doesn't carry out the terms of the contract, whether the feds told them to or not.

But when confronted with the ADHC fraud scandal five years ago, New York's Medicaid Director, Jason Helgeson, said that he preferred to let managed care companies police themselves. In February 2018, Helgeson announced that he will be leaving state government effective April 6.

Budget Bickering Begins

As the annual debate on the state budget began, pressure on several fronts seemed to be creating cracks in the Cuomo Administration's "Managed Care for All" program.

An un-named senior health care official in the administration told a meeting of Independent Living advocates early in 2018 that Medicaid managed care doesn't seem to be working as well as expected, and that the administration is seeking alternatives.

As part of his budget proposal, Cuomo suggested that if a managed care participant goes into a nursing facility and stays longer than 180 days, this alleged "permanent" nursing facility placement will be "carved out" of managed care. Assembly Health Committee Chair Richard Gottfried (D-New York City),

responded to that proposal at a joint NYS Senate/Assembly hearing on health care in February, calling it “not only cruel to people who want to be in their homes but contrary to what we have said is our policy in New York for many years.”

New York Medicaid Director Jason Helgerson says that “elder care” is now the most expensive portion of New York’s Medicaid long-term care budget. The fact that the state allegedly overpaid Medicaid Managed Long-Term Care (MLTC) insurance plans by \$1.4 billion a few years ago, mostly for senior adult day care services that were never delivered, might have something to do with that (see page 3).

Cuomo proposed a change to the state’s Universal Assessment System (UAS) “scoring” process that would make it much harder for people to qualify for MLTC services. Advocates who say that the UAS excluded people even without the proposed change seem to have an ally in Gottfried, who is said to be favoring permanently carving out the TBI and NHTD Medicaid waiver programs from managed care.

Senate Health Committee Chair Kemp Hanon (R-Hempstead), who does not always support the disability community, blasted Helgerson and DOH Commissioner Howard Zucker at the hearing. He said they claimed the UAS was going to be a tool to improve care, but now it’s going to be a “fiscal tool.” He accused the officials of having “no idea what the bureaucracy does to actual care” and demanded to know where the accountability was in the system.

At another meeting that included disability advocates, Helgerson bragged about New York’s new Medicaid “Value Based Payment” system, known as the Delivery System Reform Incentive Payment program (DSRIP). He said the system, which has been under attack for funneling a lot of new money to hospitals without showing results, was actually working well. He cited an example of a person with significant disabilities who was living in his own home but had a lot of hospitalizations. DSRIP, Helgerson said, solved this problem: it had the person placed in a nursing facility. When the advocates in the room expressed outrage, Helgerson said that DSRIP doesn’t exist to increase community integration; it exists to reduce hospital admissions.

Also at the joint hearing, other politicians demanded to know why the Cuomo Administration’s promises that managed long-term care would save money haven’t come true.

We have some answers. First, Helgerson’s approach in New York is the same as it was in Wisconsin: appear to create “savings” for New York taxpayers by maximizing the amount of federal Medicaid dollars used to pay for services. When fully realized this will shift, but not cut, service costs. It hasn’t been fully realized because New York’s process has been so riddled with inept mistakes that the feds have refused to approve many of the state’s inadequate plans. So while a significant number of people with less costly needs have moved into managed care, those with the most expensive needs, including people with developmental or mental health disabilities, brain injuries, and people under age 65 with chronic progressive diseases, have not.

Second, some managed care companies do enroll people with high needs and then cut their services, but perhaps even more have simply refused to enroll them. Many managed care companies have dropped out of the program completely, claiming they can’t afford to operate on what the state pays them, and leaving lots of people suddenly without services. All of these people eventually fall back on the fee-for-service system, with no changes in spending.

Third, a lot of the people in managed care are in the New York City area, which has unionized attendants, and all homecare workers in that area must be paid the “prevailing” (union) wage whether they are union members or not, thanks to those very same legislators who are now questioning the costs. People in New York City are also more likely to get a full schedule of 24-7 service if they need it than people elsewhere, in part because it’s easier to recruit and schedule workers in a big city with good public transit systems and reasonable wages, and in part because the city has a very organized (unions, again) personal care advocacy community. So New York City is bending the cost curve—not that there’s anything wrong with that. If things worked the way they are supposed to upstate, we’d be spending more up here too.

And finally, the demographics. America is aging, and with age comes disabilities. Over time the percentage of people who need long-term care services increases. Even if the amount of services provided is reduced, medical inflation barrels merrily along at a much higher rate than the Consumer Price Index, and the total cost of serving more people will be higher. Politicians who keep looking only at the annual bottom line and wondering why it doesn’t get smaller are deluding themselves. It is never going to get smaller. At best, it can only get bigger more slowly.

Backup Watch

Another big issue this year is the attendant shortage. As we’ve reported, the problem with availability of homecare in New York isn’t so much getting approved to receive it as it is getting all of your approved hours covered, especially outside of the two largest cities. You may be able to establish a theoretical schedule of coverage, but the minute one of those attendants calls in sick, or their car breaks down, or they need a vacation or find a better job, you are scrambling for backup. That’s why we say the real problem with New York’s homecare system isn’t a need for new or different services, it’s the need to guarantee backup.

There are three basic reasons why there’s no backup upstate. First, these are small communities where the pool of available workers is limited. Second, public transportation is extremely sparse, with many bus routes running only once every hour or two—and many areas aren’t served by buses at all. Attendants are among the poorest of the working poor; they typically don’t have their own vehicles, or they drive clunkers. So when a car breaks down or the person your aide relies on to give them a ride to work doesn’t show up, even if a backup worker can be found, chances are she can’t get to you anytime soon. (At the budget hearing described above, Helgerson said transportation cuts were necessary and save \$90 million a year, while Commissioner Zucker chimed in, saying we need more telemedicine—using video cameras and microphones to communicate across the internet—so people can live at home without attendants. We at STIC wondered how a videophone is going to give people showers and get them in and out of bed.) Third, attendants are among the poorest of the working poor because they mostly make minimum wage, and thanks to the Cuomo Administration, the minimum wage upstate for fast-food workers has now climbed past the minimum wage for other kinds of workers. (The upstate fast-food minimum wage is \$11.75/hr, while for homecare workers it’s \$10.40/hr.) The best attendants constantly leave as soon as they can get a better job.

This isn’t just happening in New York; it is a common problem across the western world that has been getting growing media attention for nearly two decades now. Here are just a few examples:

American Journal of Nursing, January 2002: “Nursing care providers in home care: a shortage of nonprofessional, direct care staff: A Pennsylvania report documents the problem.”

Nursing Times (United Kingdom), June 25, 2013: “As the number of older people in the UK soars there is a clear shortage of carers, as councils [local governments] are unable to find providers to cover requested care.”

New York Times, February 26, 2014: “Topping the list of occupations expected to grow between 2012 and 2022 are personal care aides, in the No. 1 slot (580,800 new positions); home health aides, No. 4 (424,200 jobs); and nursing assistants, No. 6 (312,200 jobs). ... There isn’t going to be a big increase in the work force that typically fills these jobs—poorly educated, low income, usually minority women—over the next 10 years.”

Huffington Post, February 6, 2017: “Here are eight signs that the shortage in direct care workers has become a crisis...”

Reuters, August 3, 2017: “The United States is headed toward a severe shortage of caregivers—paid and unpaid—in the decades ahead, according to human resources expert Paul Osterman. A professor of human resources and management at the Massachusetts Institute of Technology ..., Osterman is the author of a new book, *Who Will Care for Us: Long-term Care and the Long-Term Workforce*, which examines trends in the labor force market for caregivers. His conclusion? ‘It’s an absolute train wreck waiting to happen.’”

Time Magazine, October 25, 2017: “as the industry has grown, the hospice care people

expect—and sign up for—sometimes disappears when they need it most. Families across the country ... have called for help in times of crisis and been met with delays, no-shows and unanswered calls... A Kaiser Health News investigation ... analyzed 20,000 government inspection records, revealing that missed visits and neglect are common for patients dying at home. Families or caregivers have filed over 3,200 complaints with state officials in the past five years. Those complaints led government inspectors to find problems in 759 hospices, with more than half cited for missing visits or other services they had promised to provide at the end of life.”

Bloomberg News, February 9, 2018: “Some 80 million people will be seniors by 2050. Our national home-care infrastructure isn’t close to ready.”

Some of our leaders have been paying attention. At the budget hearing, Assemblyman Gottfried was livid as he pointed out that we have a “greying” population and we will never be able to cut Medicaid spending for seniors, and Senator Liz Krueger (D-Manhattan) sparred with Helgerson about this. Helgerson, noting that the cost of long-term care in New York is increasing at \$1 billion a year, wondered whether all of the people getting those services really need them. He said we have to cut the amount of services people get to control costs. Krueger pointed out that we’ve created a successful program, and now people are living longer so we are going

to cut their services to save money. She said, “I need a better answer.” Helgerson talked about expanding telemedicine, and again, we wondered how a video camera was going to feed people and wipe their butts.

The Governor’s budget plan displays startling ignorance of what everybody else has known for decades. There are pay-raises above 3% in his proposal for “direct service providers” (DSPs) who work in programs funded by OP-WDD, OMH, and OASAS. That’s good, but that’s not homecare. For homecare workers, there are projected spending increases to keep pace with the state’s rising minimum wage—which, as we’ve said, will not rise as high upstate as in New York City. There’s no recognition that homecare workers will actually have to make more than McDonald’s burger-slingers, will have to make as much as OP-WDD DSPs, in fact, to address this problem effectively. For folks upstate, Cuomo is only offering to “study” so-called “rural” homecare availability to find out if there really is a problem. There are about 6 million New Yorkers living outside New York City, Buffalo, and their suburbs. This is not just a problem for a handful of “hicks.”

So that’s the big excitement in the governor’s budget proposal this year. Most of the rest is the usual stuff, and you can read more about it in the NYAIL Disability Rights Agenda on page 10.

courts watch

A.T. v Harder: Harder to Ignore

We first reported this case last fall (see *Access-Ability* Fall 2017). A. T. and other teenagers are being held in the Broome County Jail by Sheriff Harder, and despite their mental and/or developmental disabilities, have been subjected to solitary confinement for extended periods that has led to deterioration in their mental health. Some of these children are merely awaiting trial and unable to post bail; they have not been convicted of any crime.

As we’ve reported, there is almost unanimous agreement among mental health professionals and experts in prison administration that solitary confinement is harmful to people with mental or developmental disabilities or who have experienced psychological trauma.

There is also considerable agreement that use of solitary confinement is counterproductive to the goal of keeping prisoners from “acting out.” In fact, it increases the likelihood that prisoners will behave badly, because the damage done by solitary reduces their ability to control their own behavior.

We were able to review the plaintiffs’ “memorandum of law” in this case, which provides details on how the jail’s conduct violates the federal Constitution’s Eighth (“cruel and unusual punishment”) and Fourteenth (“due process”) Amendments, as well as the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). We also read the statement of a clinical psychologist hired by the plaintiffs to investigate and form an opinion on the jail’s treatment of children.

The psychologist, Andrea Weisman, Ph.D., has over 30 years’ experience in working with incarcerated children with disabilities in jails, prisons, and youth facilities. She observed that children in solitary in the Broome County Jail have nothing to do except read a Bible or, for up to an hour a day, get “recreation” in a bare concrete enclosure—often while shackled so severely that they can’t do meaningful exercises. She wrote, “The conditions of solitary confinement at the Broome County Jail are some of the most severe and restrictive I have ever encountered in my over 30 years of professional experiences. These deprivations of human contact and environmental stimuli would be substantial for anyone, but for juveniles they are devastating. Even at the Federal Bureau of Prisons’ ADX Florence facility, one of the most secure super max facilities in the

country [where everybody is in solitary confinement all the time], inmates have access to writing materials, art supplies, educational materials, closed circuit TVs providing access to programming, personal items and both individual and group mental health treatment.”

Then she provided several pages of evidence that solitary confinement harms people, followed by several pages documenting incompetence and neglect by the two full-time social workers, one full-time drug/alcohol counselor, and one part-time psychiatrist that make up the entire mental health services staff for a facility that houses over 400 people. Nationally, on average over 60% of the people in any jail or prison have a “major mental illness”, and up to 90% of incarcerated children have experienced trauma, such as physical or sexual abuse, but one of the social workers didn’t think there were many inmates with mental health issues in the jail.

There have been some related developments outside the courtroom. New York’s “Raise the Age” law was signed by Governor Cuomo in April of 2017. As of October 1, 2018, children under the age of 16, and beginning October 1, 2019, those under the age of 17, cannot be held in adult prisons in NY. This means the teenagers in the BC Jail will have to be moved to the Children’s Home of Wyoming Conference boarding facility if there’s a vacancy, or to a similar facility elsewhere. But that doesn’t solve the problem for those facing several more months of mistreatment in the jail right now, so we hope there is an early decision in the *Harder* case.

The NYS Commission of Corrections recently proposed new regulations on “Inmate Confinement and Deprivation.” The state’s protection & advocacy agency, Disability Rights New York (DRNY), responded in January with comments stating that the regulations do not go far enough to protect juveniles and

people with disabilities. They said the regulations should prohibit solitary confinement for juveniles and disabled inmates unless there is a “clear danger to others,” as other states have done, and that such confinement should involve “heightened monitoring,” including frequent face-to-face visits from mental health professionals. They also said that decisions to impose solitary confinement must never be made solely by a prison administrator; a mental health specialist should always be consulted before making the decision.

We would prefer children facing minor charges simply to be released to their families. But we have to be honest: sometimes kids with mental health or developmental disabilities end up in jail because their families want them out of the house, because they can’t cope with their needs. It is essential that there be effective early screening, pro-active behavioral supports, and rapidly available crisis intervention services for these children if we really want to do the right thing, not just the expedient thing. When children begin to show a potential for emotional disturbance or serious behavioral issues, which they can do well before they reach school age or become capable of really hurting someone, the community must immediately respond with a high level of in-home and out-of-home support. Counseling for family members, positive behavioral support plans, attendant services, respite involving meaningful community activities, and, in some cases, frequent home visits from social workers to make sure that necessary things are being done, are all needed. If we provide those things reliably, most of these kids will never get to the point where they become unmanageable.

In other words, when people ask for help, we should act immediately. Too often, though, families ask for help early on but are refused service until crisis is imminent.

So, having ended up with kids in jail, some people ask, how are we supposed to deal with their behavior if we can’t use solitary confinement? Well the state of Ohio, which, like New York has two major cities and several smaller ones, and a population of about 11.5 million people (NY’s is about 19.8 million), found that after it completely eliminated “disciplinary isolation” for juveniles, violent incidents in its youth facilities dropped by 22%. This is really easy to explain. Children’s ability to understand their emotions and control their impulses is not as good as adults’. By definition, mental and developmental disabilities make that an even tougher problem. Solitary confinement leads to paranoia and rage. So

when the authorities respond by isolating you instead of helping to defuse those feelings, when you are finally released from “the box” you are even more likely to “go off” on other people than before you went in there.

DRNY v New York State, Cuomo & Delaney: Nasty Discharges

This case was filed by DRNY in federal district court for the Eastern District of NY on November 30 2017. As we’ve reported, local school districts are supposed to serve all children with disabilities, and most of them could do a much better job of it, but they prefer not to be inconvenienced. So some kids get sent to “special” private day schools, and others end up in residential schools, which are like developmental centers with classrooms.

New York State law and regulations require people to be discharged from residential schools when they reach the age of 21. It’s OPWDD’s responsibility to plan and arrange for these discharges. According to DRNY, OPWDD has a pattern and practice of failing to do this promptly. At least 97 adults are still in residential schools outside of New York state. All of them are deemed by OPWDD “ready for discharge to a community setting” and do not oppose such a discharge, but 92 of them have been stuck in the schools for at least a year after turning 21. OPWDD begins discharge planning for such students at age 19, which DRNY considers too late.

DRNY alleges that this not only violates state law, but federal laws. Specifically, it violates those laws’ prohibition against unnecessary institutionalization as clarified by the US Supreme Court’s *Olmstead* decision, which cites Title II of the Americans with Disabilities Act (ADA) governing public entities (OPWDD is a public entity) and by extension also references Section 504 of the federal Rehabilitation Act governing recipients of federal funds (OPWDD, again). Residential schools are specifically defined as institutional settings by federal Medicaid law and regulation.

DRNY wants injunctive relief, requiring OPWDD to immediately implement discharge plans for all adults awaiting discharge, and to begin planning discharge at age 16 for all remaining residential school students.

This case relates to the findings of DRNY’s investigation of Woods Services, a dangerously deficient residential school in Pennsylvania that houses over 100 New Yorkers, several of whom are adults who have “aged out” of school (see *AccessAbility* Winter ‘17-



'18). Woods Services posted a response to the investigation on its website alleging that DRNY's report was "filled with allegations that are untrue, exaggerated, missing critical facts, and defamatory" and was the result of DRNY's alleged "extremist ideology" that "trumps truth and reason." In January Woods Services sued DRNY in federal court for "defamation." *AccessAbility* requested comment from DRNY on Woods Services' response in December 2017 but received no reply.

DRNY v Unified Court System: Abstain from Abstaining

This case (see *AccessAbility* Winter '16-'17) challenges the federal constitutionality of New York's Article 17A guardianship procedures, which apply only to people with developmental disabilities, do not require a court hearing or presentation of any evidence of incapacity, and do not require that the candidate for guardianship be provided legal representation or even be notified of an opportunity to oppose the guardianship. The suit was filed by DRNY in federal District Court for the Southern District of New York in 2016. The Court told them to take it to a State court instead in August 2017. DRNY appealed to the 2nd federal Circuit in December.

DRNY alleges that the state's Article 17A guardianship provisions violate the due process clauses of the 5th and 14th Amendments of the US Constitution, as well as the federal Americans with Disabilities Act's prohibition on discrimination on the basis of disability. Also, the lawsuit is specifically directed against the state court system; it seeks to stop the courts from granting 17A guardianships. So because the suit alleges violation of federal law, and because letting the defendant (the state court system) decide the case would be an obvious conflict of interest, DRNY says this is a federal matter to be decided in federal court.

Lots of US Supreme Court precedents say that federal courts should not defer to the states when a matter related to federal law is brought before them, but there are some exceptions to that rule, referred to collectively as the *Younger* case. Under *Younger* and later cases, federal judges have found that a federal court can "abstain" from deciding a case involving federal issues if the case or a similar case is currently also being considered by a state court, or if a concurrent case would affect how state courts enforce compliance with their orders. All of those exceptions require that the same or similar case must be currently under consideration by a state court.

Neither this case nor any similar cases are before New York State courts. It seems that the District Court abstained because DRNY's complaint asked for state courts to be ordered to inform people currently under Article 17A guardianship that they can apply to have those guardianships removed or modified under New York's Article 81 process, which requires presentation of clear and convincing evidence to a judge. DRNY says this decision is wrong, first because that request doesn't actually affect procedures used by courts to enforce their orders, and second because there are no similar cases pending before state courts.

CCO Update: A New Home

OPWDD has been moving forward with surprising speed on the transfer of Medicaid Service Coordination to regional "Care Coordination Organizations" (CCOs). This is likely to begin to affect at least some of you starting this July. For the last three months or so, service coordinators have been getting lots of training on what it means to be a Care Coordinator and on how to answer your questions. If they haven't discussed these changes with you yet, they will soon.

STIC is one of the owners of a CCO called Prime Care Coordination (PCC or "Prime Care"). Prime Care was officially designated by OPWDD as a CCO in January. STIC will serve as Prime Care's "hub" (regional headquarters) for the Southern Tier region, covering Broome, Chenango, Cortland, Delaware, Otsego, Tioga and Tompkins Counties. Service coordinators now employed by STIC, Catholic Charities of Broome County, the Family Enrichment Network, and possibly some other agencies, will work for Prime Care and operate out of this hub.

Prime Care is taking advantage of the option to transition service coordinators over the course of a full year, so while STIC's and the other agencies' service coordinators will become Care Coordinators around the beginning of July 2018, with expanded duties, they will not become Prime Care employees before July 2019. It's also not clear when our hub will formally open; it may not make sense to do that while the service coordinators still work for the separate agencies.

Prime Care is expected to offer all of the agency service coordinators the opportunity to work as Care Coordinators, and we think most of them will accept that offer, so most of you will be able to keep your current service coordinators.

When this happens, Prime Care Coordination will employ and supervise the former service coordinators, now known as Care Coordinators, though most of them will have offices in STIC's building on East Frederick St. in Binghamton. As a hub, we will provide office space and infrastructure only; we won't be "in charge of," or responsible for, the Care Coordinators.

We've received some more clarification on some of the issues we've reported on previously.

The OPWDD/DOH Transition Plan for Medicaid Managed Care says pretty clearly that Care Coordination will only be provided by CCOs—that is, organizations that are owned and controlled by experienced not-for-profit providers of a range of developmental disabilities services. When managed care begins, the CCOs will either become managed care insurance companies, or contract with managed care companies to provide the Care Coordination. It's still too soon to talk about real managed care locally; at the earliest, it won't arrive here until the early 2020s (and recent developments may delay it further, see page 3). But at this stage Prime Care is looking to affiliate with iCircle, a Medicaid managed care company that was founded by some of the same people and organizations that started Prime Care. STIC's Executive Director, Maria Dibble, is a founding member of the Boards of Directors of both organizations.

So there should be no case of an inexperienced generic managed care company doing care coordination for people with developmental disabilities. That's very good news.

On the issue of the Health Home benefit versus ordinary service coordination, we have more news, but we aren't sure it's so good.

As we've explained, "health home" is not a place, it's a form of service coordination that includes not only long-term supports and services for people with disabilities, but also management of ordinary medical services. People are supposed to benefit by having the same person who helps them do things like find a place to live or get habilitation services also be involved in making their medical appointments and referrals, especially people who might not follow through on medical treatment without such help.

Health Home is part of the Affordable Care Act ("ObamaCare," which is still in effect; see page 8). That law was written largely by people who weren't familiar with Medicaid service coordination; that's why they thought

it was something new and different. What's really new and different is that New York will get a much bigger share of Medicaid funds for people who choose the Health Home benefit than it gets now to provide service coordination. So the state is going to push you very hard to accept Health Home.

We had hoped that you would have a genuine choice between Health Home and old-style Medicaid service coordination, but that's not going to happen. A few of you don't have full service coordination; you've chosen "Plan of Care Services and Supports" (PCSS) instead. In PCSS, you have a service coordinator whose only job is to hold ISP meetings and

file the paperwork; you can't (or aren't supposed to) get ongoing help to solve problems from that person. When you move over to the CCO, OPWDD will change the name of PCSS to "Basic HCBS Plan Support," but it will still only be a paperwork function. If you want real service coordination you'll have to sign up for Health Home Care Coordination.

Most of the people involved in this believe that moving from Medicaid service coordination to Health Home won't really change what you get from your "coordinator" at all. We hope that's true, but we are skeptical. There is a regulatory requirement for Care Coordinators to try to convince you to take active measures

to improve your health, whether you have any health issues that you consider important or not. Coordinators may start out acting one way, but may change how they behave when program auditors get involved later. OPWDD has clarified that an "inability" to comply with medical treatment recommendations won't cause you to lose your other services, and it has acknowledged that many people think Health Homes could be coercive, but it has refused to say that Care Coordinators won't be permitted to pester you about things that you don't care about. At this point, we can only advise you to be assertive, and make sure you set limits with your Care Coordinators that you can be comfortable with.



Letting the CHIPs Fall

Actually, although they were dangling for a good long time, the CHIPs (Children's Health Insurance Programs; known in New York as Child Health Plus) did not fall at all. Instead, as part of its January stop-gap spending bill, Congress extended the program for six years.

As predicted, Congress retroactively funded CHIP back to its expiration date of October 1, 2017. However, Congress also kept some parts of the CHIP expansion that were in the Affordable Care Act (ACA, or "ObamaCare"). That we did not expect.

Like all health insurance, CHIP is complicated, but here's a (fairly) simple explanation of where we are now:

ObamaCare required states to offer CHIP to families with incomes up to 133% of the federal poverty level (FPL), but it allowed states to choose to increase that eligibility threshold up to 400% of FPL. There was also a "maintenance of effort" (MOE) clause in ObamaCare that required states to continue the program at whatever eligibility level they chose until Oc-

tober 2019. In January Congress actually extended the MOE to October 2023, but allowed states that set eligibility above 300% of FPL to roll it back to 300% in October 2020.

ObamaCare also increased the percentage of matching federal funds for CHIP by 23 percentage points (we don't know what the resulting match was for NY but it's at least 88%). That increase will now decrease to 11.5 points in October 2020, and to zero in October 2021, when NY's match will again be what it was before ObamaCare was enacted.

In New York, all children are qualified for Child Health Plus if they don't have other insurance coverage, but their families will pay the full premium charged by the insurance company if their incomes are above 400% of FPL. For families with incomes between 300% and 400%, there's a sliding scale premium. Families below 300% pay no premium. New York must continue this until October 2020, after which it may choose to require a full premium for incomes above 300%, and in 2023 the entire CHIP program expires and must be

renewed, possibly with different rules. As of now we don't think New York is planning to cut the benefit when it becomes able to, but losing the increased match will be an incentive to do that, so stay tuned.

Why did the right-wing ObamaCare-hating Congress do this? Because in their December tax-cut bill, the Congressional ObamaCare haters repealed the ACA's penalty for failing to purchase health insurance. As a result, the non-partisan Congressional Budget Office (CBO) concluded that so many people will decide not to buy insurance that the government's costs for subsidizing those purchases will drop, reducing the total Medicaid bottom line. That bottom line would be cut even more as the federal match for CHIP declines, making CHIP cheaper than forcing kids onto regular Medicaid. In essence, expanding CHIP for six years won't increase spending nearly as much as people thought it would.

By the way, ObamaCare has *not* been repealed, despite the claims of some members of the Trump Administration. If you don't have

Medicaid, Medicare, or employer-based health insurance, you are still legally required to buy insurance yourself. What's changed is that the IRS will no longer add a penalty to your income tax bill if you don't buy it. Also, the federal government is barred from subsidizing insurance premiums with direct payments to insurance companies, but it will still subsidize your premium payments with refunds if you qualify. Just about everything else that came with ObamaCare is still in effect, although the feds will now consider issuing rules that will let insurance companies try to trick you into buying poor-quality insurance that won't cover much and will leave you with huge deductibles and co-pays. Beware!

Meanwhile, in February Congress agreed on a spending plan that actually increases the federal budget for healthcare for this year and next year. This allowed for continuation of the ObamaCare Community Health Centers, among other things. But Trump is already calling for deep cuts beginning in October 2019, including killing the ObamaCare Medicaid expansion and ending the Medicaid entitlement. This fall's elections will largely determine whether he has any chance of succeeding, so please get involved, and especially, get out and vote.

OPWDD's Bogus Prevoc "Emergency"

Effective December 5, 2017, OPWDD put in place "emergency" regulations that allow service providers to keep people with developmental disabilities "working" for sub-minimum wages in completely segregated settings indefinitely. In other words, with one stroke of its regulatory pen, the agency has revived sheltered workshops.

Following multiple scandals involving neglect and abuse of people with disabilities, and misappropriation of funds, by OPWDD and its subcontractors, the federal government required the agency to agree to completely stop using state funds to support sheltered workshops, and to reduce its use of other segregated "day programs." At around the same time, the feds, through the Centers for Medicare and Medicaid Services (CMS), issued new regulations that had the potential to ensure that nearly all non-residential supports and services would have to be provided in ordinary integrated settings.

Most people with developmental disabilities and their families applauded these changes. They had been campaigning for real jobs and real wages, real homes, and the ability to

choose their own activities in ordinary community places, and associate with people of their choice, for many years. In short, they wanted "real lives," as OPWDD publications put it.

"Prevocational services" is an old idea. Historically it was used to partially fund the operations of sheltered workshops, most of which don't earn enough from selling the things they manufacture to fully cover their costs, even when they don't pay minimum wage to the workers.

As part of its reforms, OPWDD issued regulations in 2014 that clarified that prevocational services are intended to teach people skills that will be used in real jobs. Those regulations also established "community prevocational services" separate from "site-based" services; the community version was to be provided in ordinary places in the community rather than in special segregated facilities. Finally, those regs prohibited enrolling any new people in site-based prevoc programs provided in sheltered workshops or "day training" programs after July 1, 2015. Since, at the time, there were almost no site-based prevoc programs not in such places, this ended new enrollments in segregated prevoc almost completely.

Along with these changes, there were incentives to get more people into supported employment, which requires competitive wages, and to allow people of retirement age or who were really not capable of doing work that's worth paying for, to do something more natural, such as participating in volunteer or recreational activities in ordinary community locations, using community habilitation services.

When any beneficial reform comes about, there are always a few people who oppose it, out of fear, ignorance, or deliberate malice. When these reforms were announced, there was a concerted effort by a small group of well-connected OPWDD employees and family members to enlist state-level politicians to get them stopped. We emphasize that this was, and still is, a very small group of very loud people. They have been effective not because they represent the disability community, but because they have certain influential politicians in their pockets, and because historically there are two kinds of OPWDD leaders: those who have a strong commitment to integration but no staying power, so they resign when faced with political pressure to do the wrong thing instead of defending reforms, and those who have staying power but no strong beliefs, so they cheerfully do the wrong thing when a politician tells them to.

The first evidence that the anti-reformers were going to succeed came when OPWDD issued its "guidance" for sheltered workshops to "convert" to so-called "integrated employment settings." Those workshops had to submit conversion plans to be approved by OPWDD. Approval would be granted for sites where up to 75% of the workers were receiving OPWDD services, and nearly all of the other workers could be other people with developmental disabilities who didn't get OPWDD services, or people with other kinds of disabilities. In other words, the new "integrated employment settings" could be nearly 100% segregated.

However, at the time the media had been reporting multiple instances of fraud by sheltered workshops—cases where people were being paid less than minimum wage even though their disabilities did not prevent them from producing as much as nondisabled workers, or where workers were crowded into tumble-down barracks, malnourished and ill-clothed, and marched daily to work in dismal and dangerous factories for pittance wages, most of which were withheld to pay "expenses." New federal vocational rehabilitation laws made it harder for schools and voc rehab agencies to simply dump kids into workshops when they "aged out" of school. And there was growing support in Congress for outlawing the use of sub-minimum wage entirely. As a result, workshop operators were finding it harder to get contracts to make things, and referrals were drying up. We thought it was only a matter of time until they all went out of business. Indeed, they all have gone out of business in our region.

But this tiny group of disgruntled former state employees and offended parents could not let it lie, and they continued to push their pet politicians to do something about it. Every time the issue was raised in the media, even when the focus of the story was on how successful supported employment and community habilitation programs were, the reporters would find a few of these people to provide quotes about how closing sheltered workshops "upset" their children who no longer got a "paycheck" (for a few dollars a week) and could not spend time at "work" with their friends, and who were allegedly unsafe in settings where they had to be treated like adults.

Meanwhile, a new federal administration took over, and it soon became clear that Trump's CMS was a very different animal. The agency's officials signaled that they would be taking a "hands-off" approach to a lot of things, including compliance with integration requirements. And immediately, things began to change at OPWDD.

In 2017 the agency was supposed to begin submitting hundreds of segregated residential and day program sites for “heightened scrutiny” to see if CMS would allow them to stay open. Nothing has been done on that score. Also, the OPWDD Managed Care Transition Plan will force providers of integrated residential supports, including some forms of habilitation and respite services, to face rate renegotiations 90 days after managed care capitation (monthly payment caps) begins, while allowing operators of segregated group homes to lock in current rates for each resident for as long as the resident lives there. We pointed out this obvious bias in our comments. In response, OPWDD flat-out lied and said there was no such bias in the plan.

And then, in December, we were told that failure to allow people to be paid sub-minimum wage while receiving prevocational services in fully segregated settings was an “emergency” that threatened their health and welfare, so OPWDD had to put those regulations in place first and ask questions later. (Lest you think that the inability to collect sub-minimum wages actually does affect people’s welfare: don’t. Nobody making sub-minimum wages in sheltered workshops depends on that money for anything more than buying coffee, snacks, or trinkets. Those workers are entirely reliant on their families or government checks for their existence.)

There’s more detail to those regulations than we’re reporting here, but basically, they allow site-based prevoc to be provided in settings that comply with the workshop conversion guidance (that is, nearly 100% segregated), and people can now be paid sub-minimum wage while receiving those services. The agency that provides the service has to “assess” each person annually to determine if they still need the service. That means the agency that gets paid to provide the service gets to decide, each year, if they still want to get paid. Guess what they’ll decide. And, agencies that operate “enclave” supported employment programs, which are segregated rooms in larger job sites where only people with disabilities work, but which must pay minimum wage, will now be able to pay some of those workers in those segregated rooms less than minimum wage and call it prevoc services instead. Essentially, workshops that were about to go under due to a lack of funding from contracts will get a new lease on life from prevoc service fees. And in some places members of the pro-workshop crowd may be able to resurrect closed workshops.

We hope that doesn’t happen here. We can tell you that when the local workshops closed,

without providing much advance notice or any transition support for the people affected, STIC stepped in and helped many of those people get real jobs through supported employment. Many others went to another agency that provides real community prevocational services in integrated settings. We can report that all of those people, after a naturally somewhat stressful period of transition, are very satisfied with their situations. They—the people with disabilities themselves—uniformly report that they are happier now than they were in the workshop. And despite that, some of their families *still* complain to the media and politicians about it. Something other than genuine concern for the feelings of their children is going on here.

We hope those families will start listening to their children and rejoice in their new-found happiness and sense of self-worth, and we hope those politicians will face the fact that they’ve been misled about the entire issue and get off OPWDD’s back.

Employment First Goes Sideways

Although almost nothing has been done to carry out the original recommendations of Governor Cuomo’s Employment First Commission, we were surprised to learn that the Commission seems to have taken a different direction that might actually be better.

In the last year the state has gone from one to four staff dedicated to the Employment First initiative.

They are asking all 254,000 state vendors to hire one person with a disability. The first mailing, including a “Disability Employment Toolkit”, has gone out to 57,000 of them. Employment First will electronically track whether the vendors opened the email or attachment and will follow up with them. They are considering strongly urging vendors to hire people during the first year of the project, and then perhaps making it mandatory if they don’t hire people.

The Commission has started a campaign to dispel the myth that if you get a job, you lose your benefits. Beginning in February 2018, every person with a disability who has an email address in the NY Employment Services System database (NYESS) will be automatically told about any benefits they still qualify for while working, such as 1619b, the Medicaid Buy-In, Earned Income Tax Credit, Student Earned Income Exclusion, Impairment-Related Work Expenses (IRWE), ABLE accounts

and PASS plans. They will be directed to the nearest certified Benefits Advisor for more detailed information and follow-up. Any service provider working with the person (job coach, MSC, etc.) will get the same notification so they can help them with the process. This is the first program of its kind in the nation. They are aware that not everybody in NYESS has access to a computer, but they are starting with those who do and will work on how to include others later.

New York State has special provisions for hiring people with disabilities (section 55-c for veterans and 55-b for others) through its civil service system. They are using artificial intelligence to match applications with appropriate job openings. Beginning in April 2018, applicants will be notified of openings, and state hiring managers will be given a list of 55-b or c applicants who are qualified for their openings. This is a big change. Up to now there has never been a top-down method to hook qualified people up to these civil service jobs; managers had to know about the program and ask how to use it, something they almost never did.

NYAIL 2018 Legislative and Disability Rights Agenda (abridged)

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL is dedicated to removing barriers to full community integration and safeguarding the civil rights of people with disabilities. This year marks five years since Governor Cuomo issued the State’s *Olmstead* Plan, which outlines how the State would advance its community integration efforts for people with disabilities. But Cuomo’s Executive Budget proposal does little to achieve these goals. Cuts to Medicaid and level funding for chronically underfunded programs like ILCs, Access to Home, and the Long-Term Care Ombudsman Program demonstrate no commitment to *Olmstead*. People with disabilities in New York are struggling with a high rate of poverty; low employment and wages; low median household income; high homelessness; high rent burdens and lack of home ownership; and lack of accessible transportation. NYAIL’s 2018 legislative priorities address these disparities. Now more than ever, with dramatic policy changes being advanced at the federal level, it is imperative that New York enact laws to protect the civil rights and programs that allow people with

disabilities to live independent, integrated lives in their communities.

INDEPENDENT LIVING PRIORITIES

- **Increase base funding for ILCs to \$18 million in SFY 2018-19 as recommended by the State Education Department and Board of Regents, with the ultimate goal of increasing the State appropriation to \$25 million.**

ILCs provide critical services to people with disabilities, designed to assist them in navigating the ever-changing service system in order to live independent, fully integrated lives in the community. As the state continues to re-design health care, ILCs play a crucial role.

ILCs have been severely underfunded for the past 13 years while the cost of providing services and demand has increased dramatically, creating a crisis for centers and the people with disabilities they serve. In 2016/2017, the state's network of ILCs served over 100,000 people with disabilities, family members and others; an increase of more than 20,000 in just five years. To address this, the Board of Regents recommended a \$5 million increase to the network of ILCs. But for the second year in a row, these increases disappeared from the final budget and ILCs received no increase. The need for a funding increase in 2018-19 budget is critical.

Investment into ILCs actually saves the state money. Data from ACCES-VR show that the work of ILCs to transition and divert people with disabilities from costly institutional placements saved more than \$2.3 billion since 2001. ILC transition and diversion activities save the state more than \$9 in institutionalization costs for every state dollar invested in ILCs.

- **Provide a necessary voice for people with disabilities in state government by reactivating the duties of the State Office for the Advocate for Persons with Disabilities.**

Governor Mario Cuomo originally established this Office to advocate for people with disabilities in state government. This office was responsible for advising and assisting the Governor in developing policies to help meet the needs of people with disabilities and coordinating the implementation of Section 504 of the Federal Rehabilitation Act of 1973. But when the Justice Center reorganized itself, it did so without any advocacy function.

The disability community desperately needs a voice in state government. Reinstating the Office for the Advocate for Persons with Disabilities is a critical first step.

HEALTH/MEDICAID

- **NYAIL strongly urges the state to create a high needs community rate cell.** The establishment of a high needs community rate cell would provide MLTC plans with sufficient funding to support those with the greatest needs to live in the community. The current capitation rates do not provide for this. Last year's budget included a commitment to explore a high needs community rate cell with CMS. The state must move forward with this to ensure that people with the most significant needs can get the care they require to live at home.

- **Address the home care crisis by providing a living wage to home care workers.** People with disabilities who require home care are having a harder time getting the care they require to remain in their homes and out of costly institutions. Particularly upstate, people are unable to get care at home because too few people want these low paying jobs. The state has a legal obligation under *Olmstead* to ensure people have access to appropriate care in the most integrated setting, their home communities. The state needs to provide a living wage to home care workers to attract people to work in that field. The proposed budget includes a \$3 million appropriation to assess the home care crisis in rural parts of the state and to increase wages only in fee-for-service personal care and waiver programs, but this does not go far enough.

Home care workers must be paid equivalent rates to those of providers under OPWDD. By increasing rates for home care up to the funding levels of OPWDD providers, the state will truly help address the current home care crisis by offering essential home care workers a living wage.

- **Increase the state's share of funding for the Long-Term Care Ombudsman (LTCOP) program to \$3 million.** The LTCOP serves as an advocate and resource for people living in nursing facilities and other institutions. The program is intended to promote and protect residents' rights as well as their health and safety by investigating and resolving complaints made by or on behalf of residents. The LTCOP receives federal funding, but it is insufficient to provide adequate services, and New York's match is one of the lowest compared to other states. NYAIL urges the state to increase its share of funding to \$3 million to ensure the population of people in long-term care facilities are adequately served.

- **Fully fund New York's No Wrong Door system, including an \$8 million annual ap-**

propriation for ILCs. The state expanded its No Wrong Door system to bring together the federally funded Area Agencies on Aging (AAAs) and ILC networks to create a true single-point-of-entry system for accessing long-term services and supports. Ensuring access to comprehensive, accurate, and unbiased information about long-term service and support options is essential as New York implements systemic reforms to its Medicaid system and the way long term care is delivered. This past year, AAAs and ILCs have successfully worked together to expand the program, with numbers served continuing to increase. Despite this, the Executive Budget proposes a two-year allocation that is not sufficient to maintain the system.

New York must keep the No Wrong Door system whole by fully funding the program. The funding allocation must include an \$8 million annual appropriation for ILCs.

- **NYAIL strongly opposes requiring a UAS score of 9 to qualify for MLTC.** The state's managed care for all campaign has transitioned many people who need LTSS into MLTC plans and other managed care models. Confusingly, the Executive Budget now seeks to limit enrollment in MLTC by changing eligibility and mandating people who are at or above the nursing facility level of care (NFLOC) into fee-for-service (FFS). The NFLOC requires a Uniform Assessment System (UAS) score of 5 or greater. Directing new applicants with a UAS score of 5-8 to FFS will result in a huge influx of Medicaid participants at the local Departments of Social Services, which no longer have the infrastructure to handle these cases.

Further, only under MLTC can family members claim spousal impoverishment, which allows people to get on Medicaid without putting their spouse in poverty. This will significantly impact many elderly spouses who live on fixed incomes and could result in unwanted and unnecessary institutionalization. The state must keep the requirement for MLTC participation at a UAS of 5.

- **NYAIL strongly opposes carving nursing facilities out of MLTC.** Carving nursing facilities out of MLTC will incentivize plans to push those with the most significant (read: expensive) needs into nursing facilities. In the Governor's *Olmstead* Plan, he prioritized reducing the long-term stay nursing facility population in NYS. This proposal would make it more difficult for those with the most significant needs to get care in the community. NYAIL calls on the legislature to reject the proposal to carve nursing facilities out of MLTC.

● **NYAIL strongly opposes requiring MLTC enrollees to remain in a plan for twelve months.** An individual's ability to change plans is one of the few protections they have in MLTC and must be preserved. Once individuals are locked into their plans, there is nothing to prevent plans from cutting hours or services they need to remain safe in the community. Also, if a person's provider leaves the plan, s/he loses the ability to receive services from the provider they know and trust.

● **NYAIL strongly opposes limiting spousal refusal to MLTC members and decreasing the spousal impoverishment resource allowance to the federal minimum.** The Executive Budget proposes eliminating spousal refusal for those receiving services outside of MLTC. Spousal refusal is a longstanding provision of state law ensuring an individual's access to the Medicaid-funded services and supports they need to live in the community when their spouses "refuse" to spend down their resources to support them. The alternatives are to force couples to divorce, become totally impoverished, or to institutionalize their loved ones purely for financial reasons.

The proposal to decrease the spousal impoverishment allowance to the federal minimum of \$24,000 would force individuals to choose between living in poverty and ensuring his/her spouse can access necessary Medicaid-funded services and supports. The proposal would force many "well" spouses onto Medicaid, who could otherwise avoid it. These proposals would have a disproportionate impact on low-income New Yorkers.

HOUSING

There is a housing crisis in New York State for people with disabilities due to the lack of affordable and accessible housing. People with disabilities who are on fixed incomes, or who have low wage jobs, are unable to afford to rent without a subsidy. More than a third of people with disabilities are severely rent burdened, spending more than 50% of their income on housing. A modest one bedroom costs an average of 133% of a person's SSI in New York State. Avoiding institutionalization or homelessness depends on having a housing rental subsidy. Yet landlords turn down prospective tenants who have rental subsidies. This results in a situation where even with a subsidy, people with disabilities are often unable to find housing. NYAIL's policy recommendations address the housing crisis by making housing more accessible and affordable.

● **Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law.** A.5431 (Weprin) and S.1898 (Comrie) or S.7003 (Krueger).

● **Incorporate inclusive home design/visitability features in new residential housing that receives financial assistance for construction from federal, state, county or local governments.** A.1023 (Simon) and S.3315 (Krueger).

● **Increase funding for Access to Home to \$10 million.** Access to Home is an important program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow individuals with disabilities and older New Yorkers to stay in their homes and out of institutions. For many people, the addition of a ramp to their front door makes the difference between being able to leave the house and being homebound. Access to Home has been funded at a mere \$1 million statewide, leaving many parts of the state without the program and resulting in years-long waiting lists. The state has invested in programs designed to help people leave nursing facilities, but without funding for home modifications, many people still can't leave the nursing facility. While the state allocated \$19.6 million over three years to the program, those funds were limited to veterans with disabilities. Much of these funds have gone unspent and could be used to help fund Access to Home for everyone, while still giving veterans a preference. The State must increase funding for Access to Home to \$10 million to help people to leave institutions and move back into the community.

● **Create a Visitability tax credit to help homeowners retrofit their homes to make them more accessible, or to incentivize for visitable features at the time of construction.** Governor Cuomo has consistently indicated his support, but again failed to include this tax credit in his proposed executive budget. This is a priority for the disability community, as a tax credit would help keep people in their homes and out of institutions by assisting people with the costs associated with making their homes more accessible. NYAIL urges the legislature to include the \$1 million pilot program as proposed in A.5950A/S.2411A of 2017 in the state budget.

VOTING

Ensure early voting is fully accessible. NYAIL supports expanding access to voters by implementing early voting that adheres to the same standards available on Election Day.

There seem to be no provisions ensuring that universally designed and accessible Ballot Marking Devices (BMDs) will be available at all polling sites during early voting. It is critical that the State ensure full access to the polls during early voting by mandating that all polling sites are physically accessible and have a BMD available during early voting as required by federal law.

People with disabilities are still fighting for our right to a private, independent vote. The Help America Vote Act (HAVA) mandated all polling sites to have accessible, universally designed voting machines for all state and federal elections. But local elections, which are not held to the same standard, are often administered using paper ballots only, which are inaccessible to many people with disabilities. Moving these elections to coincide with state and federal elections will ensure they will be held in an accessible manner.

● **Change local, village, county, and City of New York elections to coincide with the dates of state and federal elections.** S.382 (Carlucci).

EMPLOYMENT

Working-age New Yorkers with disabilities have a 32% employment rate, resulting in a 41% gap between people with and without disabilities. The poverty rate for New Yorkers with disabilities is 17% higher than for nondisabled New Yorkers. Such high levels of unemployment and poverty affect all areas of life, including overall health. Governor Cuomo made New York an Employment First State when he issued Executive Order #136, which makes competitive, integrated employment with appropriate supports and services the first option. The priorities below will help achieve some of the most substantial results.

● **Establish a small business tax credit for employing people with disabilities.** A.1369 (Cusick) and S.3688 (Addabbo).

● **Add disability-owned businesses to the Minority and Women Business Enterprise (MWBE) program.** S.3785 (Marcellino).

CIVIL RIGHTS

State workers who have been discriminated against cannot sue their employer in federal court for money damages, including lost wages. Businesses, schools, cities, counties, towns and villages and private employers cannot violate the ADA without the prospect of being held responsible in a court of law. State

government must be held to the same standard. This bill would restore the same protections to state workers that they had from the passage of the ADA in 1990 until the *Garrett* decision in 2001—the same protections that ALL other workers still have.

- **Waive the State's sovereign immunity to claims under the ADA and Section 504.** A.2546 (Lifton) and S.1522 (Avella).

GOVERNMENT OPERATIONS

- **Creation of an Office of Community Living.** A.5597 (Weprin). Currently, people with physical disabilities have no state agency representing their needs and interests. The creation of an Office of Community Living

would provide a focal point within state government to address the community integration needs of people with disabilities.

TRANSPORTATION

The limited availability of accessible transportation services is a major barrier faced by people with disabilities, often leading to unemployment, inability to access medical care, lack of access to voting sites, and isolation from friends, family, and full community participation. Accessible, affordable transportation is essential to the State's community integration obligations under *Olmstead*. New York City has gotten a percentage of their taxis wheelchair accessible,

but companies such as Uber, which do not offer accessible vehicles, have undermined this progress and are putting the accessible taxis out of business.

- **Require transportation service providers, such as taxis and limousines, to have accessible vehicles.** A.5537 (Weprin). NYAIL also supports full wheelchair-accessibility for transportation network companies such as Uber and Lyft.
- **Cap fares for paratransit at levels no higher than the base fares for transportation of non-disabled adults using public transit systems.** A.3980 (Sepulveda) and S.2382 (Alcantara).



Getting DSRIPped

New York's Delivery System Reform Incentive Payment (DSRIP) program contains a lot of things, but you may have received mail recently about one of them: sharing your medical information with other health care providers.

DSRIP is part of the Affordable Care Act (ObamaCare), which sought to create centralized electronic medical databases. This isn't being done to spy on you, it's so any doctor that you need to see (including in some other part of the state if you happen to get sick while visiting) can easily and quickly look at your full health history, your diagnoses, and your medications. This can keep them from making mistakes, like prescribing wrong meds, that could hurt you.

The state Department of Health (DOH) has been sending letters to Medicaid recipients to explain the program. You can opt out of having your information shared. If you take no action, your information will go into the central database.

The DOH letter contains a form that you can send in to opt out. Or you can call (855) 329-8850. More information is here:

https://www.health.ny.gov/health_care/medicaid/redesign/dsrp/opt-out_process_faqs.htm

New Medicare Cards Coming this Spring

(from Disabled in Action)

As you may already know, Medicare will be issuing new Medicare cards starting in April 2018. From April 2018 to April 2019, Medicare beneficiaries will be mailed new Medicare cards with new Medicare IDs, which are not related to one's social security number. The new Medicare IDs will be a random mix of letters and numbers. Spouses' Medicare numbers will be different, even if one spouse receives Medicare benefits based on their spouse's work record. Since it will take over one year for everyone to receive their new cards, be sure to open your mail and be on the lookout.

This is being done to make "identity theft" a bit harder for criminals, which is a good thing. But *please beware of SCAMS*—some have already been reported. Medicare or Social Security will **NEVER** call you and ask you for your Social Security number, your credit card number, or your bank routing number.

Once you have received the new Medicare card, you will need to present it to your providers. And, if you have other insurance that works with Medicare, such as retiree or union coverage, you may need to provide your new Medicare information to them as well. If you have any questions about the new Medicare cards, call (800) MEDICARE (633 4227). For assistance from a trained Medicare counselor,

call 311 and ask for HIICAP. The Health Insurance Information, Counseling and Assistance Program (HIICAP) is a free source for objective Medicare information.

Your new Medicare card will be sent automatically by mail to the address on file with Social Security. If you have moved recently, please make sure your mailing address is up to date. If you need to change your address you can:

- Change your address online using your online Social Security account:

https://www.ssa.gov/myaccount/?URL=/apps6z/ICOA/coa001.jsp?utm_campaign=20171221updateaddress&utm_content=english&utm_medium=email&utm_source=govdelivery

You may also follow this link to create an account if you do not already have one.

- Call Social Security at (800) 772-1213 (voice) or (800) 325-0778 (TTY).

- Change your address in person at the local Social Security office. Call (800)772-1213 to locate the Social Security office closest to you.

Here's a YouTube video about the new Medicare card:

<https://www.youtube.com/watch?v=5KZpPrqMqCc>

STIC NEWS

ASAC Thanks You!

by Susan Hoyt

The Accessibility Systems Advocacy Committee (ASAC) is an advocacy group at STIC that works with local business and municipalities to help make our community more accessible for people of all abilities. If you know of an issue in the community that limits accessibility, please contact STIC and make us aware so we can work on getting the issue resolved.

ASAC would like to recognize the following business for their efforts in making their community more accessible for all people:

Kohls

3208 Vestal Parkway E, Vestal, NY 13850

Thank You for fixing the height of the restroom accessories to make them accessible.

Xscapes

STIC's premier Puzzle Rooms raise money exclusively for STIC's programs and services. We have evening and daytime hours available for your group of friends or co-workers. Book your adventure at www.xscapes-stic.com today!

COMING IN SPRING 2018 TO XSCAPES-STIC.COM
SOUTHERN TIER'S PREMIER ESCAPE ROOMS

THE TWILIGHT ZONE

BINGHAMTON'S
ROD SERLING EXPERIENCE

BOOK ONLINE AT WWW.XSCAPES-STIC.COM

VALLEY OF THE KINGS

Your archaeological team's quest is to attempt to unlock the secrets of Pharaoh's Tomb. Other teams have attempted and vanished during their search. The Ancient Egyptians were known for their mystical ways, opulence and power. Upon the death of a pharaoh, the corpse was enclosed inside a sarcophagus, with provisions for the after life. Work together with your team to find the tomb and escape the Valley of the Kings.

BOOK ONLINE AT WWW.XSCAPES-STIC.COM

PULSE

The FBI has detained a former civilian consultant at a U.S.A.F. Research Lab, for involvement in the alleged plot to activate an Electromagnetic Pulse device. Your team from the Department of Homeland Security EMP Task Force has been dispatched to gather evidence related to this conspiracy. An EMP would cripple the US electrical grid and disable all electronic devices leading to chaos and societal collapse. Agents should proceed with extreme caution.



SCAPES

SOUTHERN TIER'S PREMIER ESCAPE ROOMS

COMMUNITY HEALTH SURVEY

Are you interested in taking a survey regarding community health concerns in Broome County? If so, please visit the following link to access the Broome County Health Department's website: www.gobroomecounty.com/hd

To take the survey, scroll to the center of the Broome County Health Department webpage and click: "Click **HERE** to take the newest **Community Health Assessment (CHA) Survey**"

The name of the survey is "Community Health Assessment (CHA) Survey #1: Community Health Concerns".



Every day, seven people in the U.S. die in home fires, most in homes that lack working smoke alarms. In partnership with local fire departments, community groups, and corporate supporters, we are offering **FREE** smoke alarms to residents in need and providing fire preparedness education to hundreds of local families through our ongoing Home Fire Campaign.

To schedule a free smoke alarm installation, please fill in and return the coupon below, email smokealarms.st@redcross.org or call 607-785-7207

Sound the Alarm - Free Smoke Alarm Installation

Name: _____
Street Address: _____
City: _____ State: _____ Zip: _____
Phone: _____ Email: _____

**Please Return To: American Red Cross, Attention: Disaster Services
620 East Main Street
Endicott, NY 13760

STIC



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: Gerard Griffin
Rachel Schwartz Maria Walensky Medina

BENEFITS & HOUSING SERVICES:
Joanne Carlyle

DEAF SERVICES: Heather Shaffer

DEVELOPMENT: Bill Bartlow

ECDC: Laurie Wightman

Kathy Ryan Kelly Mikels

EDUCATION SERVICES: Gayle Barton

HABILITATION SERVICES:

Krista Acker Matthew McLain

Hannah Hickox Kim Kappler

Lucretia Hesco Terry Valdes Julia Massaro

Steve VanAustin Kathleen Scanlon

Cathy Sostre Katie Trainor-Leounis

HEALTH EXCHANGE NAVIGATORS:

Chad Eldred Winta Michael

Joy Stalker Patricia Lanzo Christy Sodan

Brittany Pritchard Loretta Sayles

HEALTH INFORMATION SERVICES:

Elizabeth Berka

INTERPRETER SERVICES: Stacy Seachrist

MONEY FOLLOWS THE PERSON:

Peg Schadt Sann Dee Walter

NHTD RESOURCE CENTER:

Daena Scharfenstein Danette Matteo

Laura O'Hara Ellen Rury Pamela Lounsberry

NY CONNECTS:

Angela VanDeWeert Marcy Donahue

PEER COUNSELING: Jane Long

Danny Cullen Robert Deemie

Richard Farruggio Susan Link

PERSONAL ASSISTANCE SERVICES:

Susan Hoyt Tess Savage

Katina Ruffo Chelsea Neiss

PSYCHOTHERAPY:

Charlie Kramer Jane Long

PTAC: Sue Lozinak Beth Kurkoski

Shannon Smith

RVR-CES:

Sarah Winter Kim Luther Karen Lawrence

SERVICE COORDINATION:

Jo Anne Novicky Marci Germond

Erin Gabriel Jessica Arnold Stacey Engel

Cynthia Meredith Kristin Phillips

Emily Neville Rebecca Smith

Tammy Virgil Kathy Sas Craig Lucas

Laura DiRenzo Marisa Hadden

Leslie Hadden Cynthia Lord

Jessica Hinton Kim Bailey Poreda

SUPPORTED EMPLOYMENT:

Kandi Stevens Amber Babcock

Michelle Dunda Michelle Slabicki

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER: Belinda Turck

Ellen Rury Courtney Medovich Lori Wilmot

Valerie Soderstrom Melissa Rafael

TECHNOLOGY SERVICES:

Keesha Agron Kevin Jackowski