

# AccessAbility

Spring 2019  
Number 134

## Medicaid AND CDPA IN THE CROSSHAIRS

BY **Maria Dibble**

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Once again, Medicaid is on the chopping block in Governor Andrew Cuomo's proposed 2019-20 budget.

The state is diverting funds it had previously promised for "health care transformation" toward housing programs, which admittedly need the support, but it should not be done with Medicaid dollars. By taking the \$550 million out of health care, we lose a matching amount from the federal government. It seems senseless to make such a cut.

Cuomo has also proposed to reduce "indigent care" funding, which supports hospitals that serve a large percentage of patients who have Medicaid or are uninsured. Without these dollars, hospitals will be seriously affected, causing some to make critical cuts, or perhaps even close their doors.

Another harmful proposal to entities providing Medicaid-reimbursed services (such as STIC) is a 0.8% across-the-board cut in all rates. While it may seem a small thing to reduce payment by less than 1%, when combined with other detrimental budget items, it will add up to a very serious impact on our ability to continue the level of support we now provide.

There are also troubling proposals to create disincentives for Medicaid Health Homes to provide intensive case management over time (the purpose of Health Homes is supposed to be precisely to provide ongoing intensive case management) and to make it easier for Medicaid managed care plans to reduce services if they are not deemed "medically necessary".

As you will read elsewhere in this newsletter, the most damaging proposals are the changes to the Consumer Directed Personal Assistance program (CDPA). CDPA allows eligible people with disabilities to hire, train, supervise and dismiss their attendants. STIC's role is to serve as a "Fiscal Intermediary" (FI), which entails many responsibilities, including but not limited to: conducting intakes of people with disabilities into the program; processing payroll and benefits; ensuring that all documentation to authorize the service is in each of our 450 participant files; travel to all participants' homes in a three county area at least annually for service review and reauthorization; maintaining files for attendants, including ordering and receiving copies of physicals and other required medical tests; processing time

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EDITOR IN CHIEF: MARIA DIBBLE

MANAGING EDITOR: KEN DIBBLE

EDITOR: ELIZABETH SIGNOROTTI

LAYOUT: RUSSELL RICHARDSON

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*AccessAbility*

Southern Tier Independence Center  
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## Authorship

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

sheets for 600+ attendants; responding to dozens of calls a day from participants, insurance companies and others; auditing files for accuracy and billing; and much more (see page 3).

The reason I list the above, is because the Governor and his staff are under the serious misconception that all FIs do is payroll. They want to reduce the number of FIs in the state by eliminating any agency that became a FI later than 2012. While we don't dispute the fact that 600 FIs may be too many, more than a year ago the Department of Health (DOH) made all FIs fill out a lengthy Authorization Application presumably to achieve this purpose, but then failed to act on those they received. To date, STIC has seen no response to our application. So why start a different process when the previous one was not completed?

Furthermore, the Governor plans to lower the administrative rate paid to FIs by changing the methodology for calculating the rate. Instead of FIs getting a percentage of all the hours billed (the current process), they want to change to a per-member per-month approach, and the number they are proposing would put many FIs out of business. Unfortunately, the legislature can't easily prevent this in the budget negotiations because it previously granted authority to the Governor to do it, but we can't get any info from Cuomo's people about how their numbers were calculated. They insist that the average administrative cost per person per month is \$280, and they want it cut to \$100, a massive 64% reduction by their reckoning, but they can't or won't tell us how they arrived at the figures they are relying on.

The Governor claims the cuts won't have an impact on people with disabilities, but of course they will. Significantly reducing administrative support means cutting the staff here at STIC who do

all the work listed above. This would slow approvals for attendants to begin work and cause delays in conducting intakes, among other things. People will go without services that they depend on for their health and safety.

From an advocate's perspective, in the 1990s I participated in and led many rallies, meetings, etc. in an effort to encourage then Governor Mario Cuomo and the legislature to pass a bill authorizing CDPA statewide. One of my

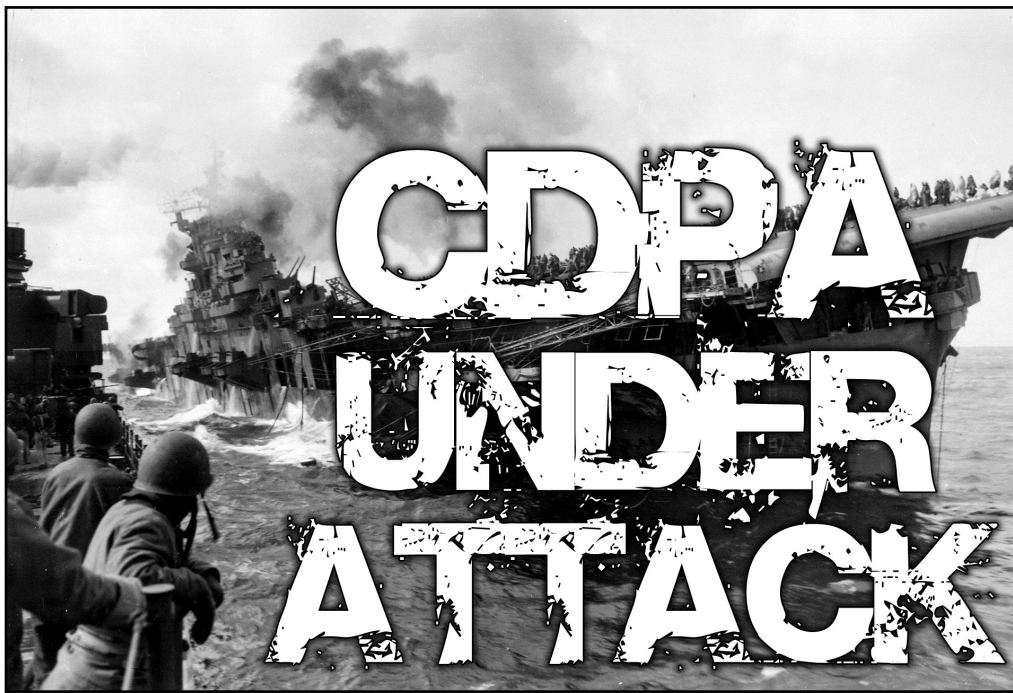
colleagues, who was significantly disabled, attended every event and activity to promote the program. At one protest, he confronted the Governor, holding out his house and car keys and saying, "You might as well have these, because without CDPA I will soon be in a nursing home and I won't need them." Sadly, he passed away before the bill was signed by

the Governor, partially due to a lack of adequate aides and hours. To now see all of our hard work and some people's sacrifices being potentially tossed away like so much useless trash, is a slap in the face to all those people with disabilities who gave so much and fought so hard to make the law a reality.

We need your help especially. If you receive CDPA services, and they are valuable to you, please contact your legislator and the Governor's office to let them know how critical it is to your independence and life. Put simply, if the FIs go away, or are significantly reduced in number, or if we must lay off staff because our rate was cut, it will have a significant impact on how many people we can serve. If you are a Personal Assistant, and are concerned about losing your job, then you need to make the above calls as well. STIC and other agencies are speaking out too, but you are the people that really count in this fight.

*To see all our hard work and some people's sacrifices being potentially tossed away like so much useless trash, is a slap in the face.*





One of the most important proposals in Cuomo's batch of budget measures for this year is an unprecedented attack on the Consumer Directed Personal Assistance program (CDPA). He proposed to completely rewrite the law governing the program with the intent of cutting the number of Fiscal Intermediaries and slashing the rates they receive to administer it. The people in the state Department of Health (DOH) who came up with this idea do not seem to understand how the program works or what Fiscal Intermediaries do. If the proposal gets through the state legislature the CDPA program could be dramatically cut back.

The CDPA program allows people with disabilities who have Medicaid to hire, train, schedule, supervise and fire attendants of their choosing. These attendants can do anything a Medicaid Personal Assistant or Home Health Aide can do, and most things that Visiting Nurses can do, but they are not required to have formal training or licenses for those tasks. CDPA attendants help people with bathing, dressing, using the toilet; cooking and serving meals, including feeding if needed; they accompany (including driving) people for tasks such as shopping, banking, medical appointments or recreational activities; dispensing medications, cleaning tracheotomies, helping with ventilators, and other forms of help, depending on the needs of the individual.

The program is primarily aimed at people who already know other people who they want to be their attendants. Friends, neighbors, or family members who do not have legal or custodial responsibilities for the person

can be attendants. Spouses, and parents if the person is under the age of 21, are excluded.

When the recipient is a child, or an adult who is not "self-directing" (capable of carrying out all of the tasks related to employing attendants in a responsible manner), a "Designated Representative" may take responsibility for those tasks instead of the recipient. Designated Representatives cannot also serve as attendants for the person.

Fiscal Intermediaries (FIs) are agencies that provide a great deal of administrative support for the program. Cuomo's people are justifying their efforts to cut the administrative rate by claiming that all FIs do is "process payroll." That is flat-out wrong.

FIs are required by law to do the following things:

- Collect and maintain required documentation of such things as physical examinations, TB tests and automobile insurance for attendants, which must be provided at hire and updated annually, as well as a variety of releases and doctors' orders for participants, which also must be updated. Getting this documentation requires several reminder mailings.
- Provide "Corporate Compliance" training (essentially a warning not to falsify records and commit Medicaid fraud) to attendants at hire and annually thereafter.

- Make face-to-face home visits with program participants initially and at least annually.
- Provide training to participants in how the program works, and in relevant employment law, including laws forbidding discrimination in hiring.
- Offer optional training to participants on topics such as recruiting, evaluating and choosing attendants, how to supervise attendants, how to fire attendants, and more.

In addition to the legal requirements, which go far beyond "just processing payroll," in order to effectively run a CDPA program FIs must do many other things, including:

- Carrying out redundant checks and verifications of attendant time and travel sheets to avoid billing errors and detect deliberate fraud.
- Keeping track of whether participants have paid their Medicaid spend-downs. If spend-downs are not paid on time, participants lose their Medicaid, and the FI cannot be reimbursed for any hours worked after that point.
- Answering questions from the various Medicaid managed care plans, county officials (for fee-for-service Medicaid), participants and workers on a variety of topics. At STIC this amounts to over a hundred phone calls per week.
- Dunning Medicaid managed care plans for payment; most plans will not pay promptly or pay the full amount owed without repeated reminders and demands.

Although the program was designed to enable people who were willing to take on the considerable work of being an employer to hire trusted family members and friends to provide what are often very intimate services, it has long since grown beyond that original vision. Due largely to economic cir-



*STICsters rally to save CDPA in Albany. Standing (left to right): Matt Schadt, Joanne Carlisle, Peg Schadt, Daniel Schwartz, Tess Savage, Katina Ruffo, Jen Watson, Cathy Sostre, Stephanie Quick, Charlie Kramer. Seated: Sue Link, Nicole Hakes*

cumstances, CDPA is now the most reliable way for many people to get a full schedule of services.

So-called “traditional” homecare agencies had historically been uncooperative with people who wanted to set their own schedules for services, or to choose compatible attendants. Those agencies insisted on their prerogatives as employers for a long time. Traditional agencies, at least in smaller cities and towns in New York, still have problems with choice of schedules and workers, but it’s not because they are deliberately inflexible. Especially in smaller communities, they often simply can’t find enough attendants to enable people to pick and choose workers and schedules. This is because traditional agency workers are often paid only minimum wage with no benefits. The problem has grown worse in recent years, after Cuomo and the legislature enacted a higher minimum wage for fast food workers. The homecare industry can’t compete with McDonalds and Burger King for employees anymore.

Most people in CDPA programs report that they are able to find, and keep, more reliable attendants than they could with traditional agencies. This is in part because they can hire relatives and friends who have strong motivations beyond money to work for them. It’s also because many CDPA programs have much lower administrative costs than traditional agencies, so they can use more of the Medicaid dollars they receive for wages and benefits for workers.

Even so, there is considerable turnover among CDPA attendants, especially for

people with the most significant disabilities who need a lot of hours of service. These participants usually can’t completely fill a schedule with relatives and friends, and must resort to hiring strangers. Unfortunately, the best attendants are usually qualified for better jobs, and as soon as they find one, they take it. Transportation is also a big impediment to reliability for attendants in smaller cities that don’t have good public transit systems. Attendant wages aren’t usually high enough for workers to afford a reliable car, and many workers rely on their own friends and family to get them to and from work. Sadly, that kind of reliance often isn’t reliable enough.

Many attendants would be willing to work regular overtime if they were properly compensated. It is now illegal under federal regulations not to pay attendants enhanced wages if they work more than 40 hours per week. That is perfectly fair; there is no legitimate reason to exploit homecare workers. However, rates paid for CDPA are not high enough to cover overtime costs, so FIs must limit workers to 40 hours per week. This means more workers must be hired by recipients who need lots of hours of service.

What all of this means for FIs is that many of the time-consuming training and record-collection tasks listed above must be repeated over and over for multiple newly-hired attendants every year. The more hours of service a person needs, the more time FIs must spend on administering the program for them. This is a key point that, so far, Cuomo and his DOH have refused to accept, although program operators have demonstrated to them in face-to-face discussions that it is true.

We also have to suggest that some CDPA advocates have backed themselves into a corner by misrepresenting the program. Fiscal Intermediaries, not service recipients, are the “employers of record” (STIC has known this for years but the latest legal ruling to confirm it came from the federal District Court for the Western District of NY on January 30, 2019) and, as such, they have a lot of responsibility for the program. And the program is no longer primarily a way for a small number of people to hire relatives and friends whom they trust. Most CDPA participants are now in Med-

icaid managed care, and most managed care plans try to steer people who need homecare into CDPA programs. That’s because CDPA is less expensive than traditional homecare, not just due to lower administrative costs, but because CDPA participants get all of their homecare services for one low rate, while in traditional programs many tasks cannot be done by low-rate Personal Assistants and must instead be performed by more expensive Home Health Aides or Visiting Nurses. As a result, CDPA is now the way a very large number of people with physical disabilities get Medicaid homecare services in New York, and most of the attendants are strangers who would rather have better jobs.

Advocates quickly organized strong opposition to Cuomo’s proposals among state legislators. They succeeded in getting some of them rescinded in the governor’s 30-day amendments. The amendments removed language allowing DOH to shut down the program if it decided that the federal share of Medicaid being paid for it wasn’t high enough, and they clarified that any Center for Independent Living (CIL, like STIC), new or old, could become an FI if its application to DOH passed muster. The implementation date for the changes, which still include closing down most non-CIL FIs, was moved from April 1, 2019 to January 1, 2020. But the worst part—ending the percentage-of-service-hours administrative rate and substituting a monthly per-person rate, which Cuomo’s people would like to set at \$100, a nearly 65% reduction from the average—is still in the proposal. Also, DOH can still decide to select a single statewide contractor as CDPA Fiscal Intermediary—a move that could be modeled on Cuomo’s creation of what has proven to be a horrendously broken statewide Medicaid transportation management system a few years ago, and one that some advocates believe may be the main purpose of the CDPA proposals. There has been speculation that this proposal was a deliberate act of retaliation against the FIs that sued the state last year over Cuomo’s marketing restrictions.

Because the legislature granted DOH the authority to change its rate formula, they can’t block that change in the budget process. What they can do is make it clear during negotiations that unless Cuomo backs off, they will pass separate legislation revoking DOH’s authority to make such changes after the budget passes. We don’t know if there is any interest in such a bill, but it may be the only solution if Cuomo and DOH can’t be made to see reason.



*Press conference in support of CDPA, February 11, 2019, State Capitol, Albany: Behind the podium is Bob Policastro, founder of Angela’s House. To his right is NYS Republican Assemblywoman Melissa Miller, who is also the parent of a child with a disability. Assemblyman Gary Finch (R-Springport) stands at far right. Also pictured are Republican Assembly members Mary Beth Walsh, Angelo Morinello, Chris Tague, Jake Ashby, Robert Smullen, Joe DeStefano, Mark Walczyk, Democrat John T. McDonald, and several STICsters*



## Adult Home Release Backlash

In December 2018, New York's project to move people out of adult "homes" in New York City and into supported housing, the *O'Toole v Cuomo* settlement agreement, blew up in the news media. ProPublica, the *New York Times*, and PBS's Frontline collaborated on an investigation that criticized the program and described ghastly stories of how some people with serious mental illness were neglected and died, while others returned to the adult "homes." The reporters found disillusioned caseworkers who claimed that between 25 to 50 percent of their clients involved in the project either died, are currently unsafe, or moved into more restrictive settings. This gave rise to calls from the usual quarters to re-institutionalize people with mental illness.

The facts were obscured because New York State had not, until recently, been keeping close track of statistics on how the former adult "home" residents had been doing. When the details were made clear we learned that:

About 4500 adult "home" residents were to be assessed and, if appropriate, given opportunities to move into a range of less restrictive settings, only one of which was scattered-site supported housing.

By December 2018, about 1700 residents had expressed an interest in moving.

By November of that year, 764 had actually moved. Of those, 32 (about 4%) died and 39 (5%) returned to the adult "homes."

The most telling statistic was this: Supported housing operators were initially offered about \$15,000 per person per year to cover rent, utilities, and support services—in New York City, where, in many neighborhoods, a decent one-bedroom apartment alone costs more than that. (Supported housing residents contribute 30% of their income to rent, but for people with serious persistent mental illness that does not respond very well to treatment—the people most likely to need supported housing—a part-time job for minimum wage is the best many can aspire to, and 30% of that income is a pittance.) Only six providers agreed to get involved for that price, and the quality of services offered suffered accordingly. Although the amount and frequency of services provided—even in the most integrated versions of supported housing—are supposed to vary with the needs of the individual when best practices are followed, according to ProPublica, supported housing residents under these contracts only get one monthly visit from a caseworker.

People with serious mental illness whose symptoms are not fully under control probably need daily visits, at least at first. With ongoing treatment (not just medication, but "talk therapy" to develop coping skills, strong efforts to ensure they have something meaningful to do during the day, and good relationships with supportive friends and family members) they may eventually need less help over time.

The amount provided today is \$17,375 per person per year, and it will be increased to over \$20,000 soon. Even at that rate, people with higher needs may not be adequately served.

Cheap rates, naturally, give rise to the range of objectionable practices that were cited in the media reports: Too-high caseloads for care managers; pressure to complete assessments and moves too quickly; demands that outreach workers "sell" the cheapest form of housing supports to adult home "residents" instead of thoughtfully considering more appropriate options (and there is currently a shortage of "mental health housing" in New York, as mentioned on page 6); concerns raised internally but ignored by decision-makers; and suggestions by those decision-makers that the whole story was ginned up by a few "disgruntled" former employees.

Given these facts, it is surprising that 91% of those who have moved are still living in the community. We should not discount claims that many of them are at risk, though.

For those people who keep calling for a return to institutions, we must once again say:

*Of course* people with uncontrolled severe and persistent mental illness are not going to be safe in the community at \$20,000 a year. If we spend enough money, we can surround each person with enough support to ensure that they will be safe, and are able to achieve their potential for a productive and happy life. If you are willing to spend more—anywhere between \$150,000 to \$250,000 per person annually—to keep people in psychiatric centers, then why are you not willing to spend a little more, probably less than \$100,000 per person, to keep people in the community? American citizens—all human adults—have a civil right to live in the community with as much autonomy as they can exercise, with or without support. That right must not be abridged for administrative convenience. You cannot possibly know that community integration for people with mental illness "doesn't work," because you have not actually tried to do it correctly. You tried to do it on the cheap, and you got what you paid for.

Or, as Cliff Zucker, the lawyer who filed the original lawsuit for the organization that be-

came Disability Rights New York, told ProPublica, "I'm sure some of them have their rough days because if you have serious mental illness, you have rough days. But better to have it in your own home and live in freedom."

If you would like to learn more about how effective properly-designed and adequately-funded supported housing programs can be, here are some resources:

*New York/New York III Supportive Housing Evaluation:* <https://shnny.org/research/new-york-new-york-iii-supportive-housing-evaluation/>

*Health in Housing: Exploring the Intersection between Housing and Health Care:* <https://www.enterprisecommunity.org/download?fid=5703&nid=4247>

*Permanent Supportive Housing: Assessing the Evidence:* <https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201300261>

*A Primer on Using Medicaid for People Experiencing Chronic Homelessness and Tenants in Supportive Housing:*

<https://aspe.hhs.gov/system/files/pdf/77121/PSHprimer.pdf>



Since it's spring, we know you have probably been waiting with bated breath for our annual review of the governor's budget proposal, all in one article. Sorry to disappoint you, but we aren't doing it this year.

Much of it is the same sorry story—no increase for Centers for Independent Living, attacks on prescriber prevails and spousal/parental refusal, waivers to let school districts get out of complying with IDEA, and failure to include tax breaks for visitability and for employers who hire workers with disabilities, despite Cuomo's alleged "support" for such ideas.

The big issue is the attack on the Consumer Directed Personal Assistance program (CDPA); that gets its own article on page 3.

Also worthy of note are Cuomo's proposals for criminal justice reform, on page 7.

Our editorial presents a good overview of the other budget issues, and for details you can read the NYAIL 2019 Disability Legislative and Budget Priorities on page 7.

## Child Victims Act Signed

A guest editorial in our last issue (see *AccessAbility* Winter 2018-19) called for passage of the Child Victims Act, a bill to extend the statute of limitations for both criminal and civil actions in sexual abuse cases.

The bill passed both houses of the NYS legislature and was signed into law by Governor Cuomo on February 14, 2019. It took effect immediately.

The law extends the statute of limitations for felony child sexual abuse up to the victim's 28th birthday; for misdemeanors the new limit is age 26. For civil suits, the limit was extended from age 28 to age 50.

There is also a "look-back window" that gives victims a year—that is, until February 14, 2020—to file civil suits against abusers for events that took place decades ago. This provision overcame strong opposition from religious and educational institutions.

Childhood sexual abuse is itself a prominent cause of a variety of mental health disabilities, including post-traumatic stress disorder and depression; in children this often manifests under the catch-all term of "severe emotional disturbance." Also, children with disabilities, and especially those with intellectual disabilities, are sexually abused at a rate much higher than nondisabled children. However, children with disabilities are often ignored or discounted by family members, teachers, and other adults, when reporting abuse, so a law giving them the ability to make these reports on their own as adults is a major victory for disability rights advocates.

# courts watch

## *MG, PC, et. al v Cuomo: Free at Last! ... or Not ...*

This suit was filed by Disability Rights New York and the Legal Aid Society in federal District Court for the Southern District of NY on January 23, 2019. It's a class action lawsuit; the plaintiffs charge that they and other people with significant mental health disabilities are being held in NY state prisons beyond their release dates because the state has refused to ensure that adequate housing and community-based supports are available to them. For example:

MG was "released" on parole on May 10, 2017 and has been waiting since then to actually get out of prison. He has diagnoses of borderline personality disorder and depression; the latter has worsened following the deaths of his daughter, father, and mother. He is being held in a windowless cell in a special section of the Auburn Correctional Facility for prisoners with mental illness. Auburn is a maximum-security prison. Without arrangements being made, he would be homeless upon release. The state Office of Mental Health (OMH) deems him appropriate for community-based supports, including "mental health housing." However, there are no openings available in such housing in his home community. When MG's wife, who had stood by him for a long time, learned that he would not be released at the originally projected time, she assumed that it was because he had done something terribly wrong in prison, and she divorced him.

CJ, who has bipolar disorder, has been waiting since September 28, 2017 to be released. According to the New York State Department of Corrections and Community Supervision (DOCCS), he was allegedly placed in a "residential treatment facility" and subsequently in a "transitional intermediate

care program," but there is no significant difference between these programs and ordinary accommodations for persons with mental illness who are still serving sentences. CJ is still highly restricted, subject to arbitrary prison rules, and may be placed in solitary confinement for infractions of rules.

All of these people have discharge plans and contacts with case managers in the community; they have not been released because there are no openings in "mental health housing" in their home communities. Some inmates appeared to have been pressured to sign so-called "release papers" even though they have not actually been released.

This is another case of a well-intentioned idea going horribly wrong due to a lack of continuous implementation oversight. Every year DOCCS "releases" over 2000 prison inmates with serious mental illness to the "community"—that is, every year over 2000 such inmates finish serving their actual sentences, or get permission to leave prison early due to good behavior. But when a prisoner has a mental illness, s/he gets connected with OMH while in prison. OMH then assesses him or her, arranges treatment, and, as the discharge date approaches, prepares a "comprehensive discharge plan" which addresses housing, ongoing treatment, and support services once back in the community. Clearly, this is a good idea, and it came about because of New York's long and dismal history of mistreating people with mental illness in prisons—in fact, of actually *causing* their disabilities by indiscriminate use of long-term solitary confinement in many cases.

As part of the planning for where to live after release, inmates are supposed to suggest a place they want to go. For example, one inmate had an arrangement to live with his sister and so he suggested that. However, DOCCS gets





to approve or deny such suggestions, and this suggestion was denied for reasons not stated in the complaint. In most cases, the OMH discharge plan requires people with significant mental disabilities to live in so-called “mental health housing”—that is, some sort of formal housing-plus-supports program, ranging from an OMH “community residence” (temporary transitional group home) to scattered-site supported permanent housing. The problem is, there is a major shortage of all types of such housing, because the state has refused

*DOCCS has started calling prisons “residential treatment facilities” and claiming that people living in them have been “released”.*

to allocate enough money for it. The notorious *O’Toole v Cuomo* settlement (see page 5, and *AccessAbility* Summer 2017, among others), now six years old, which required the state to move over 4000 people out of adult “homes” in New York City to supported housing or other community-based options, has also not been fully funded. That situation, along with this lawsuit, could be driving Governor Cuomo’s sudden decision to divert over half a billion dollars of Medicaid funding to housing after he already had announced his budget.

Stuck between these rocks and hard places, DOCCS has started calling its prisons “residential treatment facilities” and claiming that some of the people living in them have been “released.”

Does that sound too snide to possibly be true? It’s not. “Residential Treatment Facility” (RTF) is defined in NY law as a “community based” place to live that is in or near the community in which a resident lives and has social ties. Mental health treatment services are supposed to be provided to residents, and RTF residents are supposed to be allowed to leave the facility for any appropriate “rehabilitative” purpose, including to go to work, take part in rehabilitation programs, spend time with family, and participate in community activities. OMH “CRs” are RTFs. But “RTF” is now also a designation that DOCCS has applied to several ordinary state prisons,

most of them medium or maximum security institutions. Although many people with significant mental illness in NY prisons now receive some sort of halting, rudimentary “mental health treatment” (which advocates have pointed out is low-quality, infrequent, and sometimes even withheld as a punishment), in some of these prisons there are no separate special quarters for people “in” RTFs. The prisons designated as RTFs apply the same restrictive, punishment-oriented rules to RTF “residents” as they do to ordinary prisoners with mental illness, even to

inmates who are not on parole or any form of conditional release—they have completely served out their full sentences—and they do not permit them to leave the prison for any reason.

There is probably no good reason why somebody can’t live with his sister and receive an array of community-based mental health treatment and support services—except that the programs that provide those things aren’t set up that way. This is because the supported housing lobbyists have effective control of the funding process, and independent living advocates who keep saying that services should be available separate from housing have consistently been ignored.

We’ll continue to follow this case and keep you informed.

## **Criminal Justice Reform Proposals**

As our regular readers know, many people with significant disabilities that affect behavior who do not have adequate supports may run afoul of the criminal justice system. As human beings gain a better understanding of how the brain works, and how both genetics and environment affect behavior, we see more and more situations in which criminal behavior is not actually voluntary. In many—though certainly not all—such cases, it may be possible to help people learn to understand and control their behavior without casting them out of society.

Governor Cuomo’s 2019-20 budget proposals contain some interesting measures to address the new things we are learning.

Unfortunately, his proposals concerning solitary confinement in prisons are not adequate. Instead, STIC supports the “Humane Alternatives to Long Term Solitary Confinement” (HALT) bill. The bill was passed last June in the Assembly. We don’t know what its status is in the legislature this year. The most important difference between HALT and Cuomo’s more limited budget proposals is that HALT forbids use of solitary confinement for people with “mental health needs” (presumably both mental and developmental disabilities) or physical disabilities, and it establishes a maximum limit on solitary confinement stays of 15 days. Both HALT and the governor’s proposal would beef up mental health treatment for prisoners and create separate “rehabilitation” residential units within prisons.

However, some of the other proposals in the governor’s package are welcome:

- A proposal to reduce the use of cash bail for people who do not pose a genuine risk to public safety. When poor people accused of crimes on shaky evidence are given a choice of “pleading out” or spending time in jail, many of them plead guilty to a lesser offense even when they are innocent. This is especially true when their only legal representation is an overworked, underpaid “public defender.” This is fundamentally unjust. Concerns about failure to show up for trial can be adequately addressed by use of an ankle bracelet without exposing people to the often violently unsafe, as well as trauma-inducing environment of a jail.
- Removing barriers to community re-entry, including such things as unnecessary suspensions or revocations of drivers or professional licenses, sharing of mugshots without a legitimate need, and more opportunities for compassionate or merit release.
- Support for the Domestic Violence Survivors Justice Act, which takes into account the fact that 90% of women in prison have experienced severe sexual or physical violence; the Act allows judges to reduce sentences for women whose crimes are determined to have resulted at least in part from domestic violence.

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# NY Association on Independent Living 2019 Disability Legislative and Budget Priorities

(abridged)

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The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. NYAIL leads state-wide ILC efforts to eliminate physical, communications, attitudinal, and other barriers to all aspects of life. NYAIL advocates for the civil rights, independence, and full participation of all people with disabilities.

Over the past several years, New York has advanced a number of initiatives intended to promote the independence and inclusion of people with disabilities. From the Olmstead Report, to the Employment First Initiative, and most recently, the ABLE Initiative, our community has supported and applauded the goals and intent of these initiatives. Yet, we have seen little advancement through legislation and financial investments to make the goals of these initiatives a reality. NYAIL's 2019 budget and legislative priorities would advance independence and community integration for New Yorkers with disabilities. Now more than ever, with dramatic policy changes being advanced at the federal level, it is imperative that NY follows through on its promises to our community and enacts laws to protect the civil rights and programs that allow people with disabilities to live independent, integrated lives in their communities.

Six years ago Governor Cuomo issued the State's Olmstead plan, which outlined how the state would advance community integration efforts for people with disabilities. Further, last year's ABLE Initiative purported to be aimed at supporting community living for New Yorkers with disabilities. Little has come out of the ABLE Initiative, and this year's Executive Budget proposal does not help achieve these goals. In fact, cuts to Medicaid and level funding for chronically underfunded programs like ILCs, home care, Access to Home, and the Long-Term Care Ombudsman Program (LTCOP) illustrate a lack of commitment to *Olmstead*. Threats from the federal level mean that New Yorkers with disabilities rely on the state to protect our rights and

independence. We urge the Legislature to take legislative and administrative action in the 2019-20 budget as outlined below toward the full integration of New Yorkers with disabilities.

## HOUSING

**Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law.** A.10077 (Mosley) and S.8606 (Parker) of 2018

There is a housing crisis in New York State for people with disabilities due to the lack of affordable, accessible housing. People with disabilities who are on fixed incomes, or who have low wage jobs, can't afford to rent without a subsidy. More than a third of people with disabilities are severely rent burdened, spending more than 50 percent 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, resulting in a situation where people with disabilities are often unable to find housing. New York must make discrimination based on tenant's source of income illegal under State Human Rights Law.

NYAIL is extremely pleased that Governor Cuomo included legislation in his Executive Budget proposal to amend Human Rights Law to add lawful source of income as a protected class and to prohibit housing discrimination on the basis of lawful source of income! This has been a priority for the disability rights community for a decade.

NYAIL also applauds Governor Cuomo's proposal to cap security deposits at one month's rent. Charging excessive security deposits also prevents New Yorkers with disabilities from obtaining housing. NY can help address the crisis by supporting Governor Cuomo's proposals and passing them in the budget!

**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 costly institutions. For many people, adding a ramp to their front door makes the difference between being able to leave the house and being homebound. Access to Home was cut by 75% several years ago. Ever since, 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.

While the state has invested in programs designed to help people leave nursing facilities, without adequate or associated funding for home modifications, many people still can't leave the nursing facility. 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 including visitable features at the time of construction.**

Despite strong legislative support, Governor Cuomo vetoed legislation to create a visitability tax credit three years in a row. In the veto messages, the Governor indicated support for the program, but stated that it would need to be handled during budget negotiations. Governor Cuomo has again failed to include this tax credit in his proposed executive budget. This is a priority for the disability community. 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 in the state budget.

## EMPLOYMENT

**Prohibit the practice of paying people with disabilities below the minimum wage in New York State.** A.11290 (Skoufis) of 2018



People with disabilities have long been segregated from the rest of society, shut away in institutions and facility-based employment settings. At these segregated settings, agencies have been allowed to pay people with disabilities well under minimum wage under section 14(c) of the Fair Labor Standards Act (FLSA). But the Supreme Court's *Olmstead* decision holds that people with disabilities have the right to live and receive services in the most integrated setting.

The majority of facility-based employment settings are segregated, focused on production style work. They fail to provide adequate training or employment to people with disabilities and thus do not result in competitive, integrated employment. We must stop equating people with disabilities with this form of employment. New York must update its employment model away from segregated, subminimum wage settings to an Employment First model, developing people's talents and allowing them to become successfully employed like their nondisabled peers.

**Waive the State's sovereign immunity to claims under the Americans with Disabilities Act (ADA) and Section 504.** A.1092 (Lifton)

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.

## GOVERNMENT OPERATIONS

**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.** S.1674 (Skoufis)

The disability community desperately needs a voice in state government that represents all people with disabilities. Reinstating the Office for the Advocate for Persons with Disabilities is a critical

first step. Established by Governor Mario Cuomo, this office was responsible for advising and assisting the Governor in developing policies designed to help meet the needs of people with disabilities and serving as the State's coordinator for the implementation of the Federal Rehabilitation Act of 1973 (which would now include the ADA and *Olmstead*).

Despite the existence of the Office on the books, any advocacy function in state government disappeared when the Justice Center reorganized itself without any advocacy functions. A new home for advocacy and independent living must be established.

**Pass critical voting reforms including early voting, automatic voter registration and same day voter registration to make it easier for people with disabilities to vote.** A.780 (Lavine) and S.1102 (Myrie)

NYAIL supports expanding access to voters by implementing early voting, automatic voter registration and same day voter registration. The laws regarding equal opportunity are clear. Whenever, wherever, and however elections are held, e.g., early voting, voter registration and same day voter registration, the state and localities must make all voting accessible to all voters with disabilities. Accessibility must be a priority when enacting these reforms.

Where forms are used, they must be provided in alternative formats such as Braille and large print. Early voting accessibility requirements must be held to the same standard that they are on Election Day, as stipulated by the Help America Vote Act (HAVA) and ADA. The state must mandate that all polling sites are accessible and have a universally designed Ballot Marking Device (BMD) available during early voting as required by federal law.

NYAIL applauds the legislature and Governor for the voting reforms that have already been signed into law this year, and supports the additional reforms in the proposed Executive Budget. However, NYAIL maintains that accessibility for voters with disabilities must be prioritized in all of these reforms. Funding for early voting must be included in this year's budget to provide counties with the necessary funding to implement early voting this November.

## TRANSPORTATION

**Require transportation service providers, taxis, limousines, and Transportation Network Companies (TNCs), to provide an equivalent level of accessible service to wheelchair and other mobility-impaired users as that offered to non-disabled passengers.**

**Require counties to expand paratransit beyond ADA minimums, including ensuring riders can connect to other paratransit services between counties.**

Limited availability of accessible transportation services is a major barrier for 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. Providing accessible transportation is essential to the state's community integration obligations under *Olmstead*. Though New York City made some of their taxis wheelchair-accessible, companies such as Uber, which do not offer accessible vehicles, have undermined this and are putting the accessible taxis out of business. Outside New York City, there is virtually no wheelchair accessible taxi service. It is imperative that all for-hire transportation services—including new transportation network companies—ensure a percentage of their fleet is accessible.

The ADA mandates that all counties provide paratransit services to people with disabilities unable to take the fixed route bus. Service must be provided to locations within  $\frac{3}{4}$  of a mile of the closest fixed route bus stop. Counties can and should provide transportation services to people with disabilities throughout their service area and connect them to paratransit services in surrounding areas. Too often, people with disabilities are isolated and unable to work, go shopping, or to church because they don't have reliable transportation. There is a real need to ensure comprehensive paratransit services are provided throughout the state.

## INDEPENDENT LIVING

**Increase base funding for Independent Living Centers (ILCs) to \$18 million in SFY 2019-20 as recommended by the State Education Department and Board of Regents, with the ultimate goal of increasing the state appropriation to a much-needed \$25 million.**

Independent Living Centers (ILCs) provide critical services to people with disabilities 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 redesign health care in ways that are intended to increase quality and decrease costs, ILCs play a crucial role. ILCs provide a wide range of services based on the local needs, all of which are aimed at addressing the social determinants of health: education, employment, housing, transportation, and other independent living skills.

ILCs have been severely underfunded for the past fourteen years while the cost of providing services has increased dramatically, creating a crisis for centers and the people with disabilities they serve. In 2017, the state's network of ILCs served nearly 110,000 people with disabilities, family members and others; an increase of approximately 30,000 in just six years. This demonstrates the pressing need for IL services in communities, and the number served would likely be higher had the IL funding kept up with the capacity needs of centers.

Over the past few years, the Board of Regents and the Legislature have all acknowledged that ILCs are essential providers for some of their most vulnerable citizens, yet have not been able to meet the needs of their local communities due to this severe underfunding. The Board of Regents recommended a \$5 million increase to the network of ILCs in their budget recommendations for the third year in a row. There has been strong support in the Legislature and the Senate and Assembly both included an increase in their one-house budget proposals for ILCs last year. However, in the final budget, these increases disappeared and ILCs received no increased funding once again. NYAIL is hopeful with new leadership in the Senate that a stronger commitment will be demonstrated, resulting in a much-needed increase.

Investment into ILCs saves the state money it would otherwise be obligated to spend. Data from the New York State Education Department, ACCES-VR, shows that the work of ILCs to transition and divert people with disabilities from costly institutional placements saved the state more than \$2.5 billion since 2001. ILC transition and diversion activities save the state more

than \$9 in institutionalization costs for every state dollar invested in ILCs.

## HEALTH

### **Address the homecare crisis by providing a living wage to home care workers.**

People with disabilities who require homecare 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 not enough people want these jobs due to low pay. The state has a legal obligation under *Olmstead* to ensure people have access to appropriate care in the most integrated setting, their home communities.

One way to address the homecare crisis is to pay homecare workers rates equivalent to those of providers under OPWDD. By increasing rates, the state will truly help address the current homecare crisis by offering essential workers a living wage.

### **Establish a funding mechanism to ensure Managed Long-Term Care (MLTC) plans receive adequate funding to serve those with the greatest needs.**

NY's FY 2019-20 budget must ensure that MLTC plans are adequately incentivized so their members with the greatest needs have the services they need to live in their home communities. Previous years' budgets included a commitment to explore a high needs community-based rate cell with CMS. It is our understanding that NY based its proposal on the cost of providing services, and CMS denied this request. We recommend a revised proposal to CMS based on functional needs along with the cost of providing services. DOH is collecting better data on the services provided to high-needs populations, and this data should be optimized to strengthen a revised submission for approval by CMS and increase the likelihood that it would be approved.

### **NYAIL supports funding the ILCs' role in New York Connects at \$6.5 million annually.**

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 unbi-

ased information about long-term service and support options and linkages to services is essential as NY continues to implement major systemic reforms to the state's Medicaid system that drastically change the way long-term care is delivered. AAAs and ILCs are successfully working together and have expanded the program, with numbers served continuing to increase. NYAIL applauds the state for acknowledging the work of the NY Connects network and adequately funding the program with a separate and increased allocation for ILCs.

### **NYAIL strongly supports the proposal to reimburse the National Diabetes Prevention Program (DPP) for all Medicaid members.**

The national DPP is an evidence-based program focused on helping individuals make positive lifestyle changes, such as eating healthier and getting more physical activity. NYAIL is working as part of a national grant to expand availability of the national DPP to people with disabilities. The funding limits this work to four NY counties—Putnam, Greene, Fulton & Montgomery—but reimbursement through the Medicaid program would help expand availability of this program to people with disabilities in communities across the state.

### **NYAIL strongly opposes the drastic changes proposed for the Consumer Directed Personal Assistance (CDPA) program.**

The Independent Living community was instrumental in designing and implementing CDPA in New York, which empowers people with disabilities to have full control over their lives and independence. It puts people with disabilities in charge of determining how, when and by whom their services are provided. Fiscal Intermediaries (FIs) provide necessary assistance to ensure CDPA consumers are successful and maintain their independence in the community through training, peer mentoring, ongoing support, payroll and other administrative assistance. This budget proposal threatens to decimate CDPA as we know it.

**Limiting FIs**—The Governor's proposal would limit the organizations allowed to operate as FIs and allow DOH to award a no-bid contract for a statewide FI. NYAIL urges the state to use the authorization process that is in the early stages of implementation to weed out FIs that are not run-



ning the program as intended rather than make such drastic and harmful changes. ILCs are singled out as entities that could apply to remain as FIs, which makes sense. The additional wrap-around services provided at ILCs are aimed at helping people with disabilities live independently in the community, making ILCs uniquely strong FIs. However, existing ILC FIs would have to apply to DOH for approval to continue running their program, and there is no guarantee their applications would be approved. A radical and rapid reduction in FIs threatens existing consumers. Transitioning all CDPA consumers into one or a few statewide FIs is a bad idea. FIs must have a local presence to be successful in their role supporting consumers to manage their own services, and individuals must have choice when selecting their FI.

*[Editor's note: After the NYAIL Priorities were published, the Governor's 30-day amendments removed provisions to replace the entire CDPA law with new language, and to allow the Commissioner of Health to end the program if federal funding is not "adequate." The amendments also clarified that new as well as old CILs can apply to be FIs, and removed an explicit grant of authority to the Commissioner to change the CDPA reimbursement methodology—but the Commissioner already has such authority.]*

**Reimbursement**—DOH has indicated its intent to change to a per-member, per-month fee. This proposal assumes that FIs are nothing more than a payroll processing agency and puts at risk the many wrap-around services FIs provide that help to ensure CDPA consumers maintain their independence. It shifts the risk from managed care organizations—insurance companies that receive a monthly per-person rate—to fiscal intermediaries whose role is to support people with disabilities managing their own services, which creates a disincentive for FIs to serve people with significant disabilities who have larger numbers of attendants, hours and support needs.

NYAIL urges the legislature to reject this harmful proposal that could end CDPA in NY!

**NYAIL strongly opposes eliminating spousal refusal protections.**

Spousal refusal is a longstanding provision of state law that ensures that indi-

viduals can access the Medicaid-funded services and supports they need to live in the community when their spouses “refuse” to spend down their resources to support their spouse. With Medicaid income levels below the federal poverty line, all of the couple’s resources are vital to meet their living expenses and to prevent the spouse from being impoverished and needing Medicaid as well. The alternatives are to force couples to divorce, live separately, or to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias. This proposal would also eliminate the right of “parental refusal” for parents of children with significant disabilities in need of costly services.

**NYAIL strongly opposes eliminating provider prevails.**

This proposal would repeal an important patient protection in the Medicaid program which restored “prescriber prevails” for prescription drugs in fee-for-service and managed care programs. A prescriber, with clinical expertise and knowledge of the patient, should be able to override a preferred drug. Different individuals may have very different responses to different drugs in the same class. Prescribers are in the best position to make decisions about what drug therapies are best for their patients. NYAIL urges the state to recognize the importance of specific prescription drug combinations and protect provider prevails.

**NYAIL opposes extending the Medicaid Global Cap through 2021.**

The Medicaid Redesign Team’s efforts to limit Medicaid spending growth resulted in the Medicaid global spending cap. Thus, essential programs and services for people with disabilities and seniors have faced significant cuts. NYAIL and other consumer advocacy groups have put forth proposals to help advance the state’s Olmstead Plan, but they have not been enacted due to spending constraints under the global cap. Meanwhile, many programs are “carved out” of the global cap and receive vastly more funding. Yet, the services and programs that people with disabilities and seniors rely on to live in the community are subject to this artificial spending cap. In fact, this year’s budget proposes carving in the Nursing Home Transition and Diversion

and Traumatic Brain Injury Medicaid waivers, two of the few programs for people with disabilities remaining outside the cap. NYAIL calls on the state to end the global cap!

**AGING**

**Increase state funding for the Long-Term Care Ombudsman program by \$3 million.**

The Long-Term Care Ombudsman Program (LTCOP) is a 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 receiving, investigating and resolving complaints made by or on behalf of residents. The LTCOP receives federal funding, but it is insufficient to provide adequate services in NYS. Despite this, NY’s match is one of the lowest when compared to other states. NYAIL urges the state to increase its share of funding by \$3 million to ensure the state’s population of people in long-term care facilities are adequately served.

**EMPLOYMENT**

**Establish a small business tax credit for employing people with disabilities.**

There is a dire need to address the extremely high rates of unemployment and poverty among people with disabilities. Governor Cuomo recognized this by establishing an Employment First Commission. The Employment First report recommended creating a cross-disability tax credit. Legislation which would have established a tax credit for small businesses was passed by the legislature last session, but then vetoed. The administration expressed support for the proposal in the veto message, but said it needed to be handled during budget negotiations. And while the proposed budget extends a tax credit for people with developmental disabilities, this broader, cross-disability tax credit aimed at small businesses was not included. This tax credit would provide a real incentive for small businesses to take a chance and hire people with disabilities.

For further information, please contact:

Meghan Parker, Director of Advocacy

Phone: (518) 465-4650

Email: mparker@ilny.org



# STIC NEWS



## Maria's in the Hall!

We at STIC are extremely proud to announce that STIC Executive Director Maria Dibble has been nominated for the New York State Disability Rights Hall of Fame.

Maria was the prime mover behind the establishment of STIC as a Center for Independent Living in 1983, and she has been a leader on the statewide disability rights scene for most of the time since then. This recognition is long-awaited and well-deserved.

Maria will be inducted at a ceremony in Schenectady on June 13, an event we'll cover in the fall 2019 edition of *AccessAbility*.



## The Wizard and the Dragon are Coming—Spring 2019: Our Latest Xscapes Adventure!

by Bill Bartlow

### Creating a Magical Space

Let us go then, you and I, on a fantastic journey.

It was 45 years ago when I lived for 2 ½ years in a land far away: a land of glaciers and volcanoes, earthquakes, geisers, massive waterfalls, perpetual light or perpetual dark at the solstices, a land settled by the Scandinavian Vikings and the Celts, a land rich in Norse mythology: Iceland.

The Icelandic people are well-traveled and well-read, highly educated and multi-lingual, and the majority believe in Alfir (elves) and Huldafolk (the invisible people). Not like the Easter bunny or the tooth fairy, but seriously believe that they exist, to the point of diverting highways to avoid disturbing elf dwellings or gathering places. It's quite understandable that there should be this sense of enchantment under a sky that is filled horizon to horizon with the nightly panorama of dancing northern lights. What can be more magical? The seeds were planted and are now coming to fruition.

There could not be a better setting for a tale of "The Wizard and the Dragon".

You do not have to travel to Iceland, but can experience this adventure right here

in Binghamton when we open our newest escape room this spring. This five-chambered complex of over 1000 square feet will begin when you enter the wizard's home, then travel to the dwelling of the Moon Elves and the Huldafolk and finally, to the Dragon's Lair.

The Xscapes team has been building "Wizard" since December, and we anticipate having an opening by early May.

As always, schedule your Xscapes adventures here:

<https://xscapes-stic.com/>

We're available afternoons Monday through Saturday, and evenings Thursday through Saturday.



SERIES TITLE AND LOGO FROM THE TWILIGHT ZONE - COURTESY OF CBS BROADCASTING INC. CBS





## Home Health Aide Coverage Continues to Shrink:

## Attention Must Be Paid

from the *Center for Medicare Advocacy*  
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As we have reported in the past, the ability to get Medicare-covered home health aide care has greatly declined in recent years. This is true even when individuals meet the law's homebound and skilled care requirements—and thus qualify for coverage. Sadly, and incorrectly, Medicare beneficiaries are often told the only aide care they can get is a bath, and only a few times a week. Sometimes they are told Medicare simply does not cover home health aides. The Center has even heard of an individual being told he could not receive home health aide care because he was “over income”—although Medicare has no such income limit.

In fact, Medicare law authorizes up to 28 to 35 hours a week of home health aide (personal hands-on care) and nursing services combined. 42 USC 1395(m)(1)-(4). While personal hands-on care does include bathing, it *also* includes dressing, grooming, feeding, toileting, and other key services to help an individual remain healthy and safe at home. 42 CFR 409.45(b)(1)(i)-(v).

(Read the full story at <https://www.medicareadvocacy.org/home-health-aide-coverage-continues-to-shrink-attention-must-be-paid/>)

### Case Spotlight: A Medicare Beneficiary in Need of Home Health Aides

#### The Problem

Mrs. B contacted the Center for Medicare Advocacy seeking assistance with Medicare home health coverage. She lives with her husband who has advanced Parkinson's disease. He receives physical therapy and speech language pathology through a Medicare-certified home health agency, but the agency told Mr. and Mrs. B they are “over Medicare's income limit for a home health aide,” so they are paying the agency privately for a home health aide, 24 hours a week. Although Mrs. B is past full retirement age, and would like to retire, she works to support the private payments for her husband's home health aide. The aide helps Mr. B get in and out of bed, does his grooming, helps him to eat and take medications, and takes him to the porch where he can enjoy the sunshine. The aide also sweeps the floor of his room and takes him to the doctor.

#### Analysis and Guidance from the Center for Medicare Advocacy

1. B is homebound and receives Medicare-covered skilled therapy. Under the law, this

makes him eligible for necessary personal hands-on care from a home health aide for up to 28 hours a week (35 hours a week if specifically documented by his doctor). **There are no income limits in Medicare**—everyone who receives Medicare is eligible for the same benefit coverage. The Bs should not have to pay privately for a home health aide for Mr. B's personal hands-on care for up to the hours coverable under the law.

2. Federal Regulations define the kinds of personal hands-on care from a home health aide that are coverable by Medicare (42 CFR 409.45(b)(1)(i)-(v); see definitions, below). The services include getting Mr. B in and out of bed, grooming, assistance with eating and taking medications, and helping to get to another area of the house. While sweeping the floor of his room is not directly hands-on personal care, Medicare allows for such services “incident” to personal care. When Mr. B moves barefoot from his bed to the bathroom, crossing a clean floor is important and, therefore, sweeping his bedroom floor, which takes little time, can be included as part of the home health aide services. On the other hand, driving Mr. B to his doctor is not a coverable service, since Medicare-covered aide services are limited to hands-on care performed in the home. Mr. B will need to make private arrangements for the transportation.

3. The Bs should contact Mr. B's doctor to make sure the services provided by a home health aide have been ordered by the physician and are included in Mr. B's Plan of Care. The physician can be very specific about the reason for the services and the best time of day to provide the care. Realistically, however, the Bs may need to be flexible in order to work with the agency regarding the hours of the day when the aide is available.

4. All home health services must be organized through a single Medicare-certified home health agency. However, if that agency cannot provide all the required services, it can make “arrangements” for the services it cannot provide with another agency. All Medicare payments must go to the original agency which must share them with the other agency as appropriate. In practice, when home health agencies decline to provide home health aide services, they usually will not arrange with another agency to provide them. If Mr. B's current agency cannot (or will not)

provide Medicare-covered home health aide care, and if the Bs are not attached to that particular agency (because of Mr. B's physical therapist and speech language pathologist, for example), they might want to seek services from another Medicare-certified home health agency that serves their zip code. They can find information on other available agencies by inserting their zip code at: <https://www.medicare.gov/homehealthcompare/search.html>

5. The official Medicare publication describing home health services may be helpful to support a conversation with a home health agency, home health aides are referenced on pages 8 and 9: <https://www.medicare.gov/Pubs/pdf/10969-Medicare-and-Home-Health-Care.pdf>.

6. There is also a great deal of information about Medicare home health coverage on the Center for Medicare Advocacy's website, [MedicareAdvocacy.org](http://MedicareAdvocacy.org).

#### References:

**A. The Medicare Act includes personal hands-on care provided by home health aides as a Medicare covered service for individuals who are homebound and need and receive skilled nursing or therapy: 42 USC §1395x(m)(1)-(4)**

**B. Federal Regulations: 42 CFR §409.45(b), defines Home Health Aide Services as follows:**

Home health aide services. To be covered, home health aide services must meet each of the following requirements:

(1) The reason for the visits by the home health aide must be to provide *hands-on personal care* to the beneficiary or services that are needed to maintain the beneficiary's health or to facilitate treatment of the beneficiary's illness or injury. The physician's order must indicate the frequency of the home health aide services required by the beneficiary. These services may include but are not limited to:

(i) Personal care services such as bathing, dressing, grooming, caring for hair, nail and oral hygiene that are needed to facilitate treatment or to prevent deterioration of the beneficiary's health, changing the bed linens of an incontinent beneficiary, shaving, deodorant application, skin care with lotions and/or powder, foot care, ear care, feeding, assistance with elimination (including enemas unless the skills of

a licensed nurse are required due to the beneficiary's condition, routine catheter care, and routine colostomy care), assistance with ambulation, changing position in bed, and assistance with transfers.

(ii) Simple dressing changes that do not require the skills of a licensed nurse.

(iii) Assistance with medications that are ordinarily self-administered and that do not require the skills of a licensed nurse to be provided safely and effectively.

(iv) Assistance with activities that are directly supportive of skilled therapy services but do not require the skills of a therapist to be safely and effectively performed, such as routine maintenance exercises and repetitive practice of functional communication skills to support speech-language pathology services.

(v) Routine care of prosthetic and orthotic devices.

(2) The services to be provided by the home health aide must be:

(i) Ordered by a physician in the plan of care; and

(ii) Provided by the home health aide on a part-time or intermittent basis.

(3) The services provided by the home health aide must be reasonable and necessary. To be considered reasonable and necessary, the services must:

(i) Meet the requirement for home health aide services in paragraph (b)(1) of this section;

(ii) Be of a type the beneficiary cannot perform for himself or herself; and

(iii) Be of a type that there is no able or willing caregiver to provide, or, if there is a potential caregiver, the beneficiary is unwilling to use the services of that individual.

(4) The home health aide also may perform services incidental to a visit that was for the provision of care as described in paragraphs (b)(3)(i) through (iii) of this section. For example, these incidental services may

include changing bed linens, personal laundry, or preparing a light meal.

**C. Medicare Benefit Policy Manual, Chapter 7, Section 40 - Covered Services Under a Qualifying Home Health Plan of Care (Rev. 1, 10-01-03) A3-3118, HHA-205, Authorizes Medicare Coverage of Home Health Aide, as follows:**

Section 1861(m) of the Act governs the Medicare home health services that may be provided to eligible beneficiaries by or under arrangements made by a participating home health agency (HHA). Section 1861(m) describes home health services as...

...The term "part-time or intermittent" for purposes of coverage under §1861(m) of the Act means skilled nursing and home health aide services furnished any number of days per week as long as they are furnished (combined) less than 8 hours each day and 28 or fewer hours each week (or, subject to review on a case-by-case basis as to the need for care, less than 8 hours each day and 35 or fewer hours per week). See §50.7.

For any home health services to be covered by Medicare, the patient must meet the qualifying criteria as specified in §30, including having a need for skilled nursing care on an intermittent basis, physical therapy, speech-language pathology services, or a continuing need for occupational therapy as defined in this section.

The Center for Medicare Advocacy can assist individuals to resolve problems with Medicare coverage.

<https://www.medicareadvocacy.org/>

**Center for Medicare Advocacy, Washington, DC Office**

1025 Connecticut Avenue, NW, Suite 709  
Washington, DC 20036

Phone: (202) 293-5760

Home health care link:

<https://www.medicareadvocacy.org/medicare-info/home-health-care/>



Center for  
**Medicare Advocacy**

[MedicareAdvocacy.org](http://MedicareAdvocacy.org)



# Hi! I May be Dangerous! Here's My Card!

The New York State legislature passed a bill last year to authorize OPWDD to issue special ID cards to people with developmental disabilities. The idea is to prevent first responders from misinterpreting the actions of people who may have behavioral issues. But here is what the cards say:

“I have a developmental disability. I may have difficulty understanding and following your directions or may become unable to respond. I may become physically agitated if you prompt me verbally or touch me or move too close to me. A developmental disability is not an excuse for illegal behavior. I am not intentionally refusing to cooperate. I may need your assistance.”

We understand the concerns behind this idea. But please consider this: If somebody is behaving in a potentially violent or physically disorderly manner, the cops are not likely

to step close and take and read a card—if it occurs to the person to offer it. The police may, after they have first immobilized the person to protect themselves—hopefully not by shooting the person—search and find the card, but probably not. The damage that the people who proposed this idea are trying to avoid will already be done before the card is read. What we really need are two things:

1. Mandatory annual disability awareness training for all police officers.
2. A reversal of the usual police policy of “shoot first, ask questions later” when dealing with people who are obviously behaving strangely and just as obviously do not present a serious imminent threat.

Let's pass a law to put those things in place.

In the meantime, we have serious reservations about labeling people, in writing, with

the information that they can be expected to behave badly. Imagine, for example, if you give your adult child such a card and he, wanting to be open and friendly, hands it over during a job interview.

Still, if you are serious about this, you can get a free card from OPWDD here:

<https://opwdd.ny.gov/iddidcards>



## DIA Watch Party at STIC

On January 15, 2019, STIC held a party to celebrate the reintroduction of the Disability Integration Act (DIA) in both houses of Congress.

The bill was co-sponsored in the Senate by NY Senator Chuck Schumer (D) and Cory Gardner (R-CO), and was introduced in the House by Jim Sensenbrenner (R-WI); a co-sponsor there was our own region's Anthony Brindisi (D).

The DIA would require long-term care insurance plans to offer services and supports in community settings, including for anyone who lives in his or her own home, among other things.

Those on hand for the celebration included: (standing, left to right) STIC Assistant Director Jennifer Watson, STIC Systems Advocacy Coordinator Sue Ruff, John Zick, Chief Operations Officer at AIM Independent Living Center, Mike Jean from Sen. Schumer's office, Joan Gibson, Megan Wise, Person-Centered Community Advocate for Behavioral Health at the Broome County Health Dept., Harris Weiss from Representative Brindisi's office; (seated, left to right) Susan Link, STIC Peer Counseling Coordinator, Mahalah Neller.





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

**THANK YOU!**

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