

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

# AccessAbility

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## REFLECTIONS

by Maria Dibble

Southern Tier Independence Center (STIC) is celebrating our 35th. anniversary this year.

As I reflect back on my 35 years as Executive Director, I'm struck by how much we've accomplished, how much we've grown, and how much change we've helped to bring about through advocacy.

We began with a staff of four in 1983, and in 2018 we employ approximately 800 individuals.

We served very few people in our first year as we were working hard to spread the word about STIC, while as of October 31, 2017 (the last full year of data), we provided services to more than 4,300 people. This includes people with disabilities, family members, medical and service professionals, and more.

In 1983 we had one grant of \$100,000, and today, we have more than 60 funding sources and a budget of about \$18 million, 90% of which is spent on employees' salaries and related costs.

People often ask me what I think are our greatest achievements over the decades. My first thought is adoption of the Americans with Disabilities Act (ADA). While we obviously didn't do it alone, we were a part of a large number of people across the nation advocating for the bill. It passed in three years, and is landmark legislation promoting equal rights for people with all types

of disabilities. The ADA has brought us accessible transportation, more businesses accessible to people with disabilities, more curb cuts at our street corners, and in general, in many areas of our lives, a more level playing field. Sadly, however, it has had little impact on the number of disabled people who are unemployed, the figure continuing to hover in the 60%+ range. Still, it has done much to improve the lives of people who are disabled, as well as their families and friends, and it is still something to be proud of. I seriously doubt that the ADA could ever pass Congress today, with the partisan politics that has become the norm.

STIC was specifically responsible, through our award-winning advocacy on behalf of people with traumatic brain injuries (TBI), for the creation of the TBI Medicaid waiver, which helps to transition people from institutions into the community, and also assists with services so that people with TBI won't be in danger of entering a nursing home or other institution. This is a very successful statewide program that has been serving people for more than 15 years. STIC is the Regional Resource Development Center for this program, as we are for the Nursing Home Transition and Diversion waiver, which provides similar supports for people with other types of disabilities.

One goal I worked toward for almost 30 years was the closure of Broome Developmental Center, which finally occurred in 2016. STIC

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was the only agency that came forward to support the closure, and I received death threats for our position. I have always believed that segregated programs, services, and living and working situations are detrimental to people in those environments, and I was sadly proven right when the Poughkeepsie *Journal* and NY *Times* printed exposes on abuse in developmental centers and group homes.

If there is one lesson that I've learned over the years—one that conflicts with an often uttered cliché—it's that we can indeed "fight city hall". We can prevail if we unite and fight together, even if it takes years. We can use our votes to send a message, make a phone call, write a letter, or send an email. Every contribution counts, making the whole much greater than the sum of its parts, especially in advocacy endeavors. I hope you'll think about that when you are asked to play your part in improving the lives of people with disabilities.

I can go on and on here, but I won't. We've of course had our failures as well, programs

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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.

that we thought were needed that just never took off, but with each issue, there is a lesson to be learned, and I can only hope we've been quick studies.

Do I have any regrets? Perhaps a few. I wish we could afford to have an attorney on staff to file class action suits when government goes astray. I have always wanted a much larger advocacy department; right now it is just one person. I wish I'd been able to inspire people with disabilities to become leaders in our movement so that we'd be better equipped to take on the current challenges, as well as those that will assuredly arise in the future. There is still time though; I'm not going away just yet.

The past 35 years have seen many employees come and go, but we still have a large core of folks who have been here more than 20 years, and many more who have stayed for ten years or longer. I like to call this group "lifers".

None of our successes could have happened without the dedicated group of people who

have come together under the STIC roof to serve people, advocate for change in policies and laws, provide administrative support, process payroll, and do all the other tasks necessary to keep a busy organization functioning. This includes our Board of Directors, which has been stalwart in the fight against segregation in any form. They have stood firm, even in the face of major conflict, adhering to our principles and goals.

I'm proud and pleased to say that throughout this journey, STIC has stayed true to our mission, values and philosophy, which you can review on page 12.

I've been fortunate to have a job I love, to be surrounded by dedicated and committed people and to have played a role in facilitating many changes in our state. Thank you all for helping to make STIC the organization it is, and for doing your part to make a difference in people's lives. And come celebrate with us! See page 12 for details on STIC's 35th Anniversary Celebration on July 26.

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# State Budget Decisions: *What Does It All Mean, Anyway?*

Now that most of the screaming and flailing about over what, to most people, seemed like really obscure details concerning managed care in the budget debate is over, we'd like to take a little time to explain what it was all about, and why you should care.


One of the reasons why managed care is touted as cutting medical costs is its alleged ability to prevent people from getting sicker. If you have people looking over your entire life situation regularly, identifying health risks and providing relatively inexpensive preventive measures, supposedly you won't need so many costly tests, medications, and surgeries later on. Plus, you'll feel better and be able to do more.

There is truth in this, and there are many medical professionals and kind-hearted progressive people who believe it.

The trouble is, while it's a valid theory, it's pretty hard to do in practice, especially on

a large scale. First, it's complicated, and in order to make it work, the care "managers" must carry all that information in their heads, think carefully, make thoughtful recommendations, and figure out how to persuade and cajole people to follow them. This takes a great deal of time and attention to detail. Most humans, though, are not particularly thoughtful or detail-oriented. So really good care managers are hard to find. Those who just shuffle paper are more common.

Second, it's really hard to keep the "kind-hearted" part when the system is run by government agencies and insurance companies. The company gets a monthly fee to serve you, and of course it tries to spend as little of that as it can. If the government doesn't issue detailed regulations requiring the company to do all of that careful kind-hearted work, it won't. And even if the government does issue those regulations, if it doesn't monitor the company to make sure the regu-



# HOMECARE SHORTAGE

lations are followed, and impose penalties for failing to follow them, the company still won't. Then managed care becomes just a big fat shovel for moving taxpayer dollars from the treasury into the pockets of insurance executives and stockholders without getting much in return (as occurred a few years ago in NY with senior adult day care; see *AccessAbility* Spring 2018).

So what happens when a wonderful theory collides with politicians who, for the most part, only really care what the people who give them money think? The image of the two-faced politician is such a cliché that I hesitate to restate it, but here goes: The politicians tell voters that managed care will make people healthier and happier and save money, then turn around and tell their campaign contributors to hold their pockets open wide and get ready for the ... oh, never mind.

In this year's budget round, a main focus was on closing a theoretical state budget shortfall of about \$4 billion. It turns out that at least \$2 billion of that was based on the mere *possibility* that the federal government *might* cut a big chunk out of Medicaid in some future federal budget year. When that didn't happen, the Cuomo Administration continued to insist on big cuts for healthcare anyway. The ongoing political buzz is that Cuomo's primary motivation is to appear "tough on spending" for a run for the presidency in 2020.

Whatever his overall motivation, he proposed several specific changes to Medicaid managed care for the state 2018-19 budget that could only have cut availability and usage of services, without any regard whatsoever for the beneficial role managed care is supposed to play in people's lives. While some other politicians objected strongly and publicly to these proposals, and in the end some were rejected, others were accepted, and still other new measures were added in the final budget negotiations. There is a disturbing anti-integration bias in the results.

## UAS Scoring

The Uniform Assessment System (UAS) is a set of questions whose answers are used to decide if a person qualifies for a "nursing facility level of care" (LOC), which is required for eligibility for Medicaid "long-term managed care" services. A nurse sits down with the person and asks the questions, and is also supposed to carefully observe the person, and talk to someone else who knows her well if she isn't expected to provide reliable responses. Each answer has a value, and the values are totaled. The higher the "score," the more disabled you are. Scoring at or above a certain number gets you the nursing facility LOC. Currently that number is 5. People with this score are obviously quite disabled; they have issues with movement, self-care, and/or thinking that are so significant that they

can't survive without help for more than a few hours. If the world had no homecare or adaptive equipment, they would have to live in a nursing facility to stay alive.

Here's where it gets confusing. Cuomo proposed to raise the number from 5 to 9, so the person would have to be much more disabled to qualify for managed long-term care. If you didn't qualify, you would get Medicaid "mainstream managed care" instead. What does that mean?

Either way, it's still Medicaid, and it's still managed care. Under Cuomo's grand "Managed Care for All" vision, eventually all New Yorkers who get any Medicaid services—not just ordinary doctor visits and medications, but all of the services and supports that people with developmental disabilities, brain injuries, mental illness, and severe physical disabilities get—would get them only through managed care, and—here's the key—*at least* in the "mainstream" and perhaps also in the "long-term" version.

Policy Wonkiness Alert: Advocates are often confused about this, not surprisingly, because the distinction between "long-term" and "mainstream" has never made much sense. But it is clear that Cuomo's Department of Health (DOH) plans to add *all* of the services in the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD)



waivers to **both** long-term and mainstream managed care plans, and the Office of People with Developmental Disabilities (OPWDD) waiver services will be moved **only** to the mainstream variety.

However, due to determined advocacy by people with most of those kinds of disabilities, the movement of those services to managed care has been indefinitely delayed. In this year's final budget agreement, the start date for moving the TBI and NHTD waivers was moved back again, to January 2022. The OPWDD start date for downstate is effectively 2021, and 2023 for upstate. A lot can happen in that timeframe, and we've had subtle hints that the Cuomo Administration's enthusiasm for managed care is fading.

So the only "long-term care" services that are currently in Medicaid managed long-term care plans are some specialty medical services, "senior social adult day care," nursing facility care, and certain forms of homecare, including Consumer Directed Personal Assistance (CDPA) services. Homecare, including CDPA, is also already available in mainstream managed care, though. So who, if anyone, would "lose" if Cuomo's UAS score hike took effect?

Bear in mind that just about everything you can get from Medicaid managed care is also still available through "fee-for-service" Medicaid. Federal law and regulations require that if you have a need for a service that appears anywhere in the state's list of the services it will cover for you, then you must receive it, regardless of whether there's a managed care option for it.

Despite this, Cuomo's budget gurus said that raising the minimum UAS score for managed long-term care would save many millions of dollars. The state legislature rejected this proposal. But if they had accepted it, somebody would have had to lose something, right? Keep reading.

### **"Permanent" Nursing Facility Placements**

Cuomo originally proposed that anyone who stayed in a nursing facility continuously for more than 180 days under a Medicaid managed long-term care plan would be "carved out" of managed care and moved back into fee-for-service Medicaid. The argument was that if you're in a nursing facility that long, you're not likely to leave, and the facility is "managing" everything for you, so the state shouldn't also pay an insurance company to

do it. This is disingenuous; the fact is that **all** forms of Medicaid long-term care services were already "managed" in that way, whether by a waiver service coordinator or a county caseworker, long before the state began imposing the managed care insurance model on them. We and other advocates have been saying that for a decade or more. Why did Cuomo's team suddenly echo that argument now? Read on.

The legislature rejected the 180-day carve-out. Perversely, though, they set the limit to a **lower** number: 90 days. Although not typical, 90 days is not unheard of for a "post-acute rehab" stay, where you are released from a hospital but need intensive physical, occupational and other forms of therapy before you can go home.

There is no theoretical downside for people whose nursing facility stays really are temporary. There's no loss of services, because nobody will be discharged due to a change from managed care to fee-for-service Medicaid, and if you leave the facility you'll still be able to get homecare. It's just a loss of time on the managed vs fee-for-service books. Are you beginning to see the pattern here yet?

### **Restricting Access to Homecare**

Cuomo initially proposed to limit the number of Licensed Home Care Service Agencies (LHCSAs) in the provider network of any given plan to 10. Remember, there's a shortage of homecare workers across most of NY, and some communities (like ours) have only a handful of provider agencies, all of which have real problems if asked to put together a schedule for people who need a lot of service. But in theory, limiting the number of agencies reduces duplication of administrative costs, and doesn't keep existing agencies from expanding to serve more people.

The ten-agency limitation was not approved. But the final budget agreement includes a 2-year "moratorium" on awarding new LHCSA licenses, unless the licenses are for a new agency that resulted from the consolidation of two or more existing agencies, or the agency intends to provide services only as part of an assisted living (segregated congregate) program.

LHCSAs are what we call "traditional" homecare providers. It's not necessary to be "licensed" to operate a CDPA program. But Cuomo went after CDPA programs too, big time.

He proposed to forbid CDPA programs that subcontract with managed care plans to "market" their services, or to serve anyone whom they refer to a managed care plan. There's a "conflict of interest" argument here, we suppose, but it hasn't been made for any other type of service provider in Medicaid managed care. Hospitals, doctors, and nursing facilities that accept Medicaid managed care funds can plaster your TV with commercials without restriction. Since all long-term and mainstream managed-care plans are required to pay for CDPA services, all well-run CDPA programs have contracts with every managed care plan in their regions. When a CDPA program "refers" somebody to a managed care plan, the conversation goes like this:

Consumer: I heard about your CDPA program from so-and-so. How can I get the service?

CDPA Program: Do you have Medicaid?

Consumer: Yes.

CDPA Program: Is it managed care?

Consumer: Yes.

CDPA Program: Then you have to ask your managed care plan to evaluate you for the service.

Does anyone see a conflict there? Anyone at all? Neither do we.

Although CDPA programs are popular, most people enrolled in them, at least upstate, only heard about them from the programs themselves. Under Cuomo's proposal, the conversation between the consumer and the managed care organization (MCO) probably would have gone like this:

Consumer: I'd like the CDPA service. I understand you can pay for it.

MCO: Who told you that?

Consumer: Such-and-such CDPA program.

MCO: Okay. If you're eligible, we can pay for it, but you can't get it from that program.

Consumer: Um...well then, where else can I get it?

MCO: We don't know; it's the only one in our service area.

As it turns out, a growing number of LHCSAs have been establishing CDPA programs of their own. However, some advocates have

observed that these agencies don't actually allow people with disabilities to exercise full control over the services the way they are supposed to. DOH claims that one of the goals of these proposals was to prevent creation of bogus CDPA programs.

At any rate, the outright prohibitions on "marketing" and referrals were not adopted. However, the legislature agreed to require all CDPA programs to submit marketing materials to DOH for approval. DOH insists that it won't actually enforce that measure until "guidance" is issued, though it refuses to put that promise in writing. Once the rule takes effect, DOH is supposed to turn marketing materials around in 90 days, but if they don't—well, if a CDPA program distributes unapproved information more than once, it can lose its operating certificate. As experience with DOH's ObamaCare insurance exchange (NY State of Health) and the TBI and NHTD waiver programs has demonstrated, DOH rarely approves materials within 90 days, and often doesn't respond to submissions at all. The only reason you've learned anything about those programs from us is because there is no penalty for not waiting for approval.

A large group of advocates has formally notified DOH that the marketing rules for CDPA programs, which apply to no other managed-care-financed service providers, are unfair and an infringement on speech, and if they are implemented legal action will follow.

### **A Dark Future?**

So where's the common thread in all of this?

We'll start by substituting the name "Jason Helgerson" for "Cuomo's team." Helgerson was, until April, the NYS Medicaid Director, the architect of the "Managed Care for All" scheme, and the author of a largely botched similar effort in Wisconsin. You might think Helgerson was a former medical insurance company executive from the way he engineered things to benefit managed care companies, but he wasn't, as far as we can tell. He was a university professor in the field of public policy. He seems to be a true believer in the kind-hearted managed care theory, or at least he was at some earlier point in his career. But perhaps due to his ivory-tower history, his approach has been to engage in clever and complicated shifts in money and rules to magically produce cost "savings," while insisting that nobody is being harmed,

that in fact, everyone is benefiting, because the theory of Beneficent Managed Care states that it must be so. Sadly, as Republican Senate Health Committee Chair Kemp Hannon told him at a public hearing earlier this year, he had "no idea what the bureaucracy does to actual care."

Helgerson told the legislators that "elder care" had become the biggest expense in the Medicaid managed care budget, and that therefore it had to be cut. This is the predictable result of the effort to force people into managed care in previous years, in order to cut costs for fee-for-service Medicaid. As we've pointed out, "Whack-A-Mole budgeting" is a team sport in New York; the goal of the proverbial "three men in a room" (the Governor and the leaders of the Assembly and Senate) is simply to cut the biggest line item for the current year, and when that cut causes a spike in some other line item the following year, why, they'll cut that line, and so on and so forth year after year, with complete disregard for how those cuts affect total spending over multiple years, or for how people's lives are disrupted and their bodies harmed.

Helgerson probably genuinely believed that all he was doing was shifting pots of money around to "maximize federal financial participation" in Medicaid, thereby reducing the state's share of expenses. But it is managed care companies that make decisions about what services people can get, and if they can get out from under a losing proposition like providing homecare to high-needs people year after year by moving them into nursing facilities for a few months, after which they'll be off their books, they are likely to do it. In theory, the UAS score change, the "carve-out," stopping formation of new LHCSAs and prohibiting CDPA programs from marketing would not affect people's "on paper" access to services. But when people get shifted back and forth between managed care and fee-for-service, between nursing facilities and their own homes, there are delays, uncertainty, stress, anxiety and actual interruptions in service that contribute to declines in health. People who spend months in nursing facilities waiting for integrated services to be re-approved and

re-established face another risk; as Democratic Assembly Health Committee Chairman Richard Gottfried said, "They'll have no home to go to." And if something truly meaningful isn't done about the homecare shortage, those who manage to keep their homes will have no services to go home to. So why did Gottfried and Hannon vote for a final budget that actually increased the likelihood of this happening, by defining 90 days, instead of 6 months, in a nursing home as a "permanent placement"? Why did they agree to single out CDPA programs for an effective marketing prohibition when no other long-term care service faces such a limitation? Why didn't they demand an increase in the minimum wage for upstate homecare workers to the same \$15/hour that fast-food workers will eventually get?

Neither Gottfried nor Hannon nor any of the other legislators at that boisterous hearing in February were among the "three men," but it is hard to believe that these highly influential committee chairs and "insiders" could not have blocked all of this non-

sense if they had really wanted to, especially when the actual budget deficit was less than half of what Cuomo claimed.

The ire that various state legislators directed at Helgerson at the hearing may have been genuine, but we now know that he was on his way out months before that, and at least some of those legislators knew it too. The proceeding, in retrospect, now resembles more of a ceremonial "show trial" of a scapegoat already pronounced guilty and on his way to execution than an actual fact-finding exercise.

Because behind the scenes there lurk some very ugly facts. First, there is the ongoing refusal by many Medicaid managed care plans to enroll high-needs people even though state law mandates that they be enrolled. Then there is the steady trickle of plans dropping out of the program entirely. There was some noise about including a requirement for the state to offer a "high needs rate cell" for people with the most significant disabilities, so the plans could get more money to serve them, and keep them in their homes. The fact is that the state agreed to do this last year, and

*Behind the scenes there lurk some very ugly facts.*

they have asked the feds for approval, and the feds have not responded. And then there is the relentless aging of the entire Western world. Every year there are more older people who need more long-term care services, and fewer younger people who are making money to pay for those services or able to do the actual work. The homecare shortage is not new; it goes back to the turn of this century, and each year it gets worse.

By 2030 one in five Americans will be 65 or older, and one in three will be working-age adults. It may be inevitable that there won't be enough money, or workers, to provide individual services to everyone in their homes, especially in smaller towns and cities, not only in NY but across North America and beyond. A couple extra billion dollars might have made a difference in NY this year, by raising wages and improving benefits to recruit and keep more workers. But in a few years a couple billion won't be nearly enough, and in ten years it won't matter how much money we throw at the problem because there *won't be enough workers, period.*

Maybe these realities have stunned our political leaders like deer facing oncoming headlights.

### The Best of the Rest

By comparison, the rest of the budget news doesn't seem so bad.

As usual, Centers for Independent Living did not get an increase to their general operating funds, Access to Home did not get an increase, and there is still no tax credit for adding visitability features to homes (however, Governor Cuomo recently proposed his own bill to extend a prohibition on source-of-income discrimination by landlords across the entire state, a longstanding goal of disability advocates). Also as usual, attempts to eliminate spousal refusal and spousal impoverishment rules failed.

The Medicaid cap on physical therapy sessions was raised from 20 to 40 per year, but 20-visit caps remain on occupational and speech therapy, in defiance of common sense and the federal Medicaid "medical necessity" rule.

Neither a revived Office of Advocate for People with Disabilities, nor a new Office of Community Living, were included. We don't know why anybody would think we need both.



# Getting **STARTed** *...or Not*

As we've reported, if you have both developmental and mental health disabilities in our region, you're likely to be shifted back and forth between the two state agencies that serve those conditions, because neither wants to accept responsibility for you. The result is a lack of effective crisis response or long-term support services, leading to people being hospitalized outside the region or the state, or ending up in jail (including teenagers; see page 9), or homeless, or worse. Family breakups are a common side effect of the stress. This is part of a larger problem in upstate NY—the extreme shortage of qualified mental health service providers in general.

We've been hearing about the START program for a few years now. START stands for "Systemic Therapeutic Assessment Resources & Treatment." It's a model for addressing these problems by coordinating and providing services to people with co-occurring developmental and mental health disabilities. It was developed by the Institute on Disability at the University of New Hampshire, and it's been implemented successfully in some states.

New York's Office of People with Developmental Disabilities (OPWDD) has committed to establishing a START system in NY. They are working with the Center for START Services to design and, eventually, accredit the system. START has been rolling out in other regions of the state for a few years. Ours, known as OPWDD Region 2, is the last. The region is vast, extending from Binghamton in the south to Plattsburgh and the Canadian border in the north. The Center began collecting data last year through a widely-available online survey, telephone interviews with families, and several focus groups, including one at STIC. This past May, the Center hosted a web conference to

announce its findings and recommendations, which we cover below.

To understand how we got here, we need to know some history. Decades ago, OPWDD and the state Office of Mental Health (OMH) were one agency called the Department of Mental Hygiene. It's true that there are important differences between various developmental disabilities and mental health conditions. But those differences were not why the agencies were separated. The sad fact is that the break-up was largely due to the snotty attitudes that people who worked in those different fields had toward each other—attitudes that we now know resulted from ignorance. The divorce was acrimonious, and the mutual hostility continues to this day.

Here's what we've learned in the meantime:

The definition of "developmental disability" as a distinct phenomenon contains some elements that, in light of modern knowledge, seem suspect. One is the idea that DD can be differentiated from other disabilities that have similar symptoms by the fact that they occur before age 22. It's now clear that serious and persistent mental illnesses, including psychiatric diseases, can appear in young teenagers, and that abused children experience post-traumatic stress disorder (PTSD) immediately after the abuse occurs, at any age. Another problematic part of the DD definition is the one that says that people with DD have a permanent need for substantial supports similar to those required by people with intellectual disabilities—something that allegedly is not a part of mental illness. Although there is much to be said for the "recovery model" of mental health treatment, the term is often euphemistic. Yes, we all know of people with serious psychiatric conditions who, with medication and psychotherapy, have suppressed most of their symptoms and are productive and hap-



py individuals. But we also all know about chronically homeless people, most of whom are people with similar conditions for whom medication and therapy didn't work so well. And even those whose treatment is highly effective can relapse and require temporary inpatient services followed by long-term assistance to get back on their feet. In other words, a need for significant levels of life-long support, including habilitation, is not unusual among people with serious mental health conditions.

Beyond that, around 35% of people with developmental disabilities also have co-occurring mental health diagnoses, a fact which OPWDD formally acknowledged just recently. People with developmental disabilities are the most likely people on earth to be physically or sexually abused (by both paid and unpaid "caregivers"), and the resulting PTSD is one of the most common mental health conditions in our society. Serious anxiety disorders are frequently seen in people on the autism spectrum. Suicidal depression is also common in the DD community. Schizophrenia, including command hallucinations, is also seen.

Some mental health practitioners say that people with developmental disabilities "can't benefit" from psychotherapy. Leaving aside the fact that intellectual limitations are not present at all in many people with DD, only 5% of those who do have intellectual disabilities have IQs below 50. People above that level can learn to read and do simple arithmetic; they can talk about their feelings and beliefs and aspirations; and they certainly do benefit from "talk therapy." It is an accepted fact that for people who have significant mental health conditions, regardless of whatever other diagnoses they may have, mere medication is not likely to be enough to keep them stable and productive; psychotherapy to enable them to understand and cope with their symptoms and circumstances is a critical component of effective treatment.

Some mental health practitioners acknowledge that people with developmental disabilities can have mental health conditions but claim they "don't know how" to treat them. Maybe they would have known how to treat them if they had remained in partnership with the DD system.

In fact, it turns out that is the only viable solution. We are slowly coming full circle;

the divorced partners must now put on their grown-up pants and work together "for the good of the children." That's where START comes in. But this is not going to be easy, or quick.

The START Center is working with OPWDD to develop a Request for Applications (RFA) to operate the program in Region 2 now; they expect to have this out by the end of the year, and they would like to announce the "winner" by April 1, 2019. Among the recommendations announced in May were requirements the Center would like OPWDD to include in the RFA.

OPWDD badly wants formal accreditation for its START program, and that's a very good thing for us. The START Center requires that its model be followed in every particular before it will accredit a program. The crux of the model is that there must be qualified professional staff who are well-versed in both developmental and mental health disabilities, available to respond to a crisis, face-to-face, in any part of the state, within two hours of a request for help. These staff must be members of a team of experts that can provide psychiatric treatment, behavioral support plans, psychotherapy, information and referral, training and "therapeutic coaching" for families, and intensive assistance to get people with disabilities hooked into a network of both natural and formal supports so they can move beyond crisis and into productive, integrated lives.

The service will be available to people who have dual developmental and mental health disabilities age 6 and older who live in a natural home in the community (there may be further eligibility limitations based on individual assessment results; we don't know). Direct services won't be available to people living in group homes, which are supposed to have adequate staff for the purpose already. However, the START program will provide training to group home staff so they can do a better job with these issues.

START teams will operate out of several "hub" offices within the region, all under the direction of a central "resource center." The resource center will also have four intensive treatment/respite "beds" available for one-week stays as needed.

Meeting these service availability requirements translates into hiring a huge number

of highly educated and trained people in a region that largely lacks qualified candidates. More than that, the START Center is strongly recommending that the program operator must have extensive experience in providing both mental health and developmental disability services. As best we can tell, there is no single agency in the entire region that meets that requirement. This means that at least two, and probably more, service agencies will have to form close, and truly cooperative, partnerships to get this thing off the ground.

Some aspects of START have been approved for funding by the feds as a Medicaid waiver service, effective July 1 of this year when OPWDD transitions to the state's global "Partnership" 1115 waiver. There are also some separate funds for start-up and administration of the resource center. But due to the extreme scarcity of existing mental health crisis-response and stabilization services in the region, the START people have been very clear that both OPWDD and OMH must cooperate at the state level and come up with more money to pay for these services. That most likely will require additional appropriations by the state legislature.

The START people were frank in saying that if they were to plunk a resource center down in Region 2 today, it would fail. They believe that providers all across the region need to start talking to each other, networking, and establishing agreements on how they are going to be part of this system right now, so they can demonstrate that real collaboration and cooperation will occur as part of the process of applying for the start-up funds. The START Center will make such networking opportunities available, but if the squabbling doesn't stop and people don't show up ready to compromise and work together, we aren't going to get to the next step.

Some details of the process are not clear, but all members of the START teams must receive a year's worth of specialized training before they can be certified to provide services. This training probably won't begin until a resource center opens in the region in 2019 or later. So don't look for any services to be available before 2021. And if you people don't drop the attitudes and start cooperating, don't look for any services to be available at all.



This past March, and again in May, dozens of ADAPT activists staged a series of sit-in protests in Washington, DC to try to get the federal Food and Drug Administration (FDA) to issue a ban on the use of electric shock punishment devices on people with disabilities.

As we reported a couple years ago (see *AccessAbility* Summer 2016), the FDA was requesting input on new regulations to do just that. The agency received thousands of responses (including ours), nearly all of which strongly supported a ban. About the only comments opposing the ban were from the Judge Rotenberg Center, a private institution in Massachusetts that is the only known program that uses the devices, and from a handful of parents who have been deluded into believing, despite a barrage of scientific evidence to the contrary, that the devices are the only thing that can keep their children from engaging in harmful behavior.

About six years ago, Massachusetts regulators succeeded in restricting use of the devices to a “grandfathered” set of Rotenberg residents whose parents obtained court orders to continue the “treatments.” Around the same time, the facility’s founder, Israel Rotenberg, was convicted of lying to a grand jury about how the treatments were administered. He was forced to retire and accept five years probation in lieu of going to jail. Although the Rotenberg center continues to operate, and use other forms of so-called “aversive conditioning” on its residents, we do not believe that the shock devices are being used on any “new” residents.

While this specific issue affects a very small number of people, those people are still being tortured according to the United Nations and many experts in behavioral support services. In fact, most such experts agree today that “aversives” of any kind are less effective than a system of “positive behavioral supports.” New York’s Office of People with Developmental Disabilities (OPWDD) has prohibited the use of aversives for several years now.

The FDA appeared poised to release the final rule banning the shock devices after all of the supportive comments, but then the agency went silent on the subject. It is actually not very unusual for a federal agency to take two years to finalize a rule after receiving comments, especially when a new administration takes over in the middle of the process, but in this particular case the issues aren’t all that complicated. It is possible that, as sometimes happens, somebody privately issued a credible threat to sue the agency. A not-so-private threat of legal action derailed CMS’s proposal to prohibit nursing facilities from requiring residents to agree to binding arbitration for disputes a couple years ago.

Activists are suspicious of the Trump Administration’s generally hands-off approach to regulation, with good reason. But the FDA has not moved this issue off its “active” list (as Trump’s Department of Justice did with proposed regulations requiring businesses to make websites accessible) and the agency issued a formal statement that it continues working on these regulations and expects to finalize them at some point.

## Vouchsafe to Deliver?

*(Okay, that’s REALLY obscure; it’s from the old-style Anglican Mass.)*

As part of the grand bargain that Congress made to pass spending bills for the current federal fiscal year (which is almost over), the federal Department of Housing and Urban Development (HUD) got a 10% increase in its total budget. This translates to about \$4.6 billion in new money.

Some HUD programs will get increases, our favorite being the “Section 8 mainstream voucher” program. This lets low-income non-elderly individuals with disabilities, or families containing such individuals, get vouchers to pay for housing in ordinary rental units. The unit does not have to be in a public housing complex, or in a special “affordable housing” development.

The vouchers pay a large enough portion of the rent to ensure that the person or family doesn’t have to spend more than a reasonable share of their own money for housing. But there are limitations: the units have to meet certain HUD standards and the total rent must be at or below what HUD calls “fair market value.” Also, landlords aren’t required to accept the vouchers.

Who gets a voucher is determined by your local Public Housing Authority (PHA; in Binghamton that’s the Binghamton Housing Authority, or BHA), which accepts applications and maintains waiting lists. The new funds will be used to serve people already on those lists, which are quite long. PHAs have to apply to HUD themselves for new voucher funding by June 18 of this year. If you’re on such a list, you may want to contact the PHA and ask what they’ve done about this.

Some of the HUD increase will be used to develop new housing units to serve people who are homeless or people with disabilities who are at risk of being placed in an institution or trying to get out of one. Although the fiscal year is mostly gone, we think the money will remain available as long as applicants get some level of approval for new construction projects before October 1.



# courts watch

## ***AT v Harder: A Hard-Won Victory***

We've been following this case for a while (see *AccessAbility* Spring 2018); it's the one where teenagers with disabilities held in the Broome County jail sued to stop the jail from placing them in solitary confinement.

On April 4, 2018, federal District Court Judge David Hurd issued a preliminary injunction ordering Broome County Sheriff David Harder to immediately stop "23-hour disciplinary confinement" of juveniles, and requiring other changes in how the jail handles children. But it may not be a final result. Sheriff Harder said he disagrees with the order but will follow it. At press time we did not know if he would continue to defend against the suit and go to trial. Still, because federal courts can only issue preliminary injunctions like this when it is likely that the plaintiffs (those suing the sheriff) would win the case if it goes to trial, this is a good sign.

The judge's order contained some interesting information. He summarized several affidavits provided by jail staff. One, from the "Inmate Grievance Coordinator," claimed that, despite the statements of the plaintiffs and other juvenile inmates that they asked to see him and either received no response or were told that their complaints weren't "grievable," he never got any grievance complaints from juveniles. A few others concerned an incident when a teenager was locked in solitary merely because he reported to a guard that the birthdate on his record was wrong. The guards claimed that it was necessary for his protection "and that of other juveniles" to keep him in solitary for seven days while they "investigated," and finally determined that he was telling the truth. And several guards claimed that they never saw any adult inmates harassing juveniles. The judge did not issue an opinion on the truth of most of this, though he implied that he did not believe the Grievance Coordinator's claims, and he seemed incredulous

that anyone could find it necessary to lock a kid in solitary for a week while checking his birthdate.

Jail staff credibility was also challenged by an April 25 Binghamton *Press & Sun Bulletin* story. Three former employees sued (either the jail or its medical services contractor, Correctional Medical Care, Inc. (CMC); the story is unclear on that point) for firing them, allegedly because they refused to follow orders to alter inmate medical records to hide failures to provide proper medical treatment. The employees said CMC told them to record medical visits and dispensing of medications that did not actually happen. According to the PressConnects website, the legal complaint called medical treatment at the jail "barbarian," and described cases where an inmate with a broken arm and another with an amputation were denied pain medication. In another case an inmate with a thyroid deficiency was denied medicine and "had 'dangerously low' thyroid levels." CMC is known for past negligence; according to PressConnects, "In 2014, the company settled with New York State, agreeing to pay \$200,000 in connection with an investigation into the deaths of six inmates in five county jails over four years." We can only wonder how many employees opted to falsify records and keep their jobs.

In any event, Judge Hurd pointed out that the facts in dispute in the affidavits did not bear on whether the jail used solitary confinement inappropriately for juveniles.

The full terms of the injunction follow:

"Defendants ... are hereby IMMEDIATELY ENJOINED AND RESTRAINED, pending the final determination of this action, from imposing 23-hour disciplinary isolation on juveniles at the Broome County Jail;

Defendants shall IMMEDIATELY only lock juveniles in their cells for disciplinary purposes if the juvenile poses an immediate threat to the safety or security of the facility and only after less restrictive measures have

been employed and found inadequate to address the particular threat;

Under no circumstances shall a juvenile be locked in their cell for greater than four hours for disciplinary purposes;

If a juvenile remains an immediate threat to the safety and security of the facility after four hours, a psychiatrist shall be consulted and a plan put in place to ensure the juvenile's safe return to the general juvenile population;

Defendants shall IMMEDIATELY ensure all juveniles have access to at least three hours of educational instruction each day as well as any IDEA-mandated special education and related services; and

If a juvenile with a mental health or intellectual disability will potentially lose access to the benefits, services, and programs offered at the facility as a result of the disciplinary process, defendants shall ensure mental health staff will perform an individualized assessment of the juvenile as soon as possible. This assessment shall at minimum include: (a) a review of the individual's mental health needs; (b) a determination regarding whether any reasonable modifications can be made to eliminate future risk; (c) a determination regarding whether the individual with a disability continues to pose a risk; and (d) whether placement in segregation is medically appropriate."



## ***Stewart v Azar: You Can't Waive That***

Although this case concerns Kentucky's Medicaid program, it is important because it is perhaps the first challenge to the Trump Administration's move to approve work requirements for Medicaid that has received a response from a federal judge. The case is in its preliminary stages, but it's one we're going to follow closely from now on.

In April, a judge refused to allow the case to be moved from the District of Columbia Circuit Court of Appeals to the Circuit for Kentucky (Sixth Circuit) because of its national implications. The Sixth Circuit is widely believed to be considerably more conservative than the DC Circuit.

Kentucky applied to the federal Centers for Medicare and Medicaid Services (CMS) for an 1115 Medicaid demonstration waiver that made many changes to the state's Medicaid program. Most importantly for our purposes, it imposed a work requirement as a condition of receiving Medicaid coverage, and it cited as one of its goals reducing the number of people enrolled in Medicaid and the state's costs for the program. Such waivers had been proposed by some states under the Obama Administration; Obama's CMS always responded that they violated the requirements of federal Medicaid law. Since Trump's CMS director had announced her intention to allow such waivers, the agency naturally approved Kentucky's application, though with some changes to make it somewhat less deliberately destructive.

At that point, in January 2018, several organizations, including the National Health Law Program, the Southern Poverty Law Center, and the Kentucky Equal Justice Center, filed a class action suit on behalf of several KY Medicaid participants, including Ronnie Maurice Stewart, against Alex M. Azar, the federal Secretary of Health and Human Services, the agency that houses CMS. The suit alleged violations of the federal Administrative Procedures Act (APA), which requires government agencies to carry out a rational and objective process when issuing regulations and making decisions such as approving waiver applications. Various federal court rulings

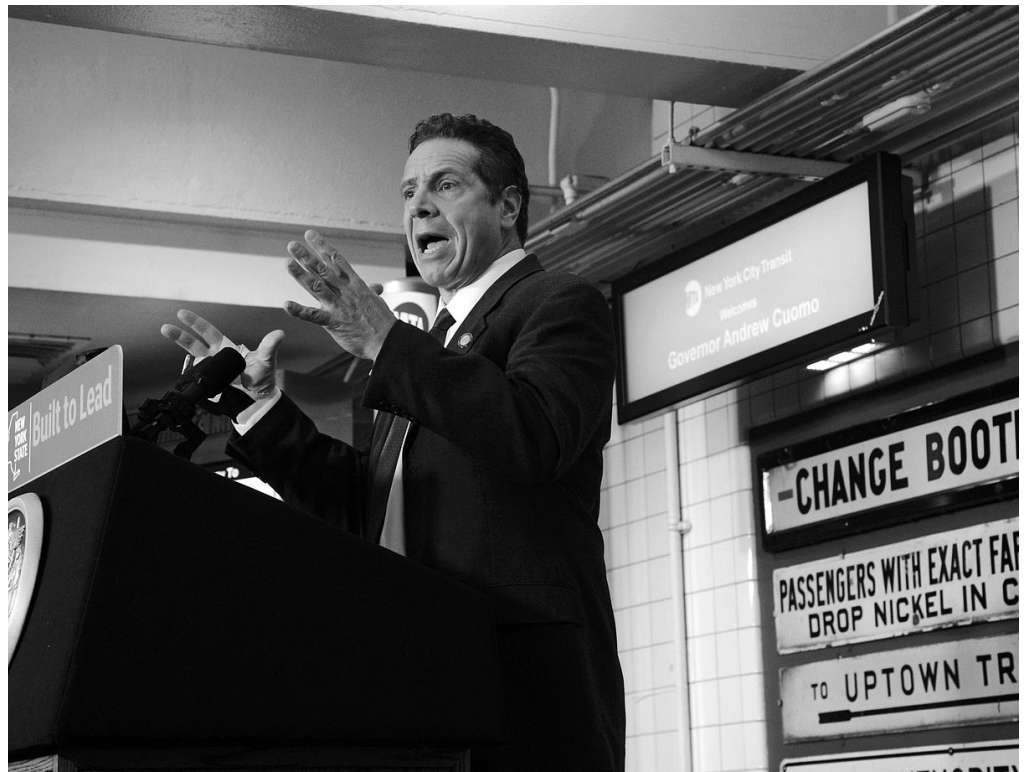
have said that, under the APA, CMS must "examine all relevant factors," consider "reasonably obvious alternative[s]," and provide "a satisfactory explanation for its action [including a] rational connection between the facts found and the choice made, [with] a reasoned analysis for [any] change." If a court finds that "the agency has relied on factors which Congress has not intended it to consider, entirely failed to consider an important aspect of the problem, offered an explanation for its decision that runs counter to the evidence before the agency, or is so implausible that it could not be ascribed to a difference in view or the product of agency expertise," then the agency's action is "arbitrary and capricious," and therefore illegal.

The plaintiffs have a very strong argument, which is basically this: CMS's power to waive rules that are in the federal Medicaid law (the Social Security Act) is strictly limited by that law to certain specific rules. The law requires states to serve certain "population groups" and lets them choose to serve other groups. These groups are defined by medical condition, age, and income eligibility. States are not permitted, by law, to pick and choose which members of a particular group to serve—such as by refusing to provide medical coverage to people below a particular income threshold unless they get jobs. That rule is not among the rules that can be waived. Further, al-

though some members of Congress have tried several times to pass legislation to add work restrictions to the law, they have never succeeded in doing so. Finally, the stated purposes that are a required part of Kentucky's waiver application have nothing to do with the purpose of the federal Medicaid law. As the plaintiffs' plea for summary judgment says, "That purpose—expressed in the text of the Act—is to enable states to 'furnish medical assistance' and 'rehabilitation and other services' to families and individuals 'whose income and resources are insufficient to meet the costs of necessary medical services.' Defendants' embrace of objectives such as 'strengthening workforce participation' and 'lessening dependence on government assistance' and 'familiarizing beneficiaries with ... the commercial market' is thus beside the point: Those are not the purposes Congress set forth in the Act." Federal courts usually take it very seriously when a federal agency tries to do something that Congress has specifically refused to grant it the authority to do; they generally don't permit it.

## ***O'Toole v Cuomo: Dear Administrator***

This is the never-ending "adult home" case. The last interesting thing we reported was an apparent attempt by NYS Department of Health (DOH) officials to conspire





with a lawyer representing the adult homes to get a NY State Supreme Court judge to overturn DOH's own regulations prohibiting new admissions of people with mental illness to the facilities and thereby derail the entire 5-year-old settlement that requires the state to move such people out of the "homes" and into integrated supported apartments (see *AccessAbility* Summer 2017). When this was revealed, the state's Attorney General asked to be relieved of responsibility for any involvement in the settlement since he now had staff working both sides of the case. This enraged the federal judge who approved the settlement, Nicholas Garaufis. He hauled the principals back into his court and threatened them with a grand jury investigation. Confronted with evidence that the adult home lawyer had fraudulently claimed that at least one former adult home resident who had moved out wanted to move back in, Garaufis ordered a "guardian ad litem" to meet personally with all of the former residents who allegedly were dissatisfied and verify that they actually did want to return to the facilities.

Meanwhile, the "special master" overseeing the settlement reported that there have been unconscionable delays in the move-out process. There were reports that adult home staff were interfering with the process of informing residents about their right to move out by directly threatening residents or preventing them from meeting privately with outreach workers.

We recently learned that DOH finally responded to this issue with a "Dear Adult Home Administrator" letter dated October 5, 2017 (published online much later). In it, DOH said, "These reports of interference or failure to cooperate with the implementation of the regulations [concerning outreach to adult home residents] are very concerning." It's nice to hear that the agency that tried to get the settlement voided is now so "concerned." We believe DOH was ordered to issue this letter, perhaps by Judge Garaufis, but we aren't sure.

The letter clarifies that adult homes must allow representatives from any of the agencies doing evaluation or outreach to meet privately with any resident in the facility, whether in the resident's room or other space, at least ten hours per day (between 9 am and 8 pm) without a prior appointment or having to tell staff who they plan to meet with. Further, adult home staff are prohibited from making "disparaging remarks regarding an individual's ability to live independently with the necessary supports." That's a comfort.

### ***DRNY v Justice Center: To Summarize, "So There!"***

Also known as *DRNY v Wise*, we last reported on this in the fall of 2016, though the case has been ongoing for longer than that. Disability Rights New York (DRNY), the state's "protection & advocacy" agency which the federal government authorizes to oversee and investigate various state

agencies that provide disability services, asked the state's Justice Center for the Protection of People with Special Needs to turn over all documents related to its investigation of four cases of abuse and/or neglect. The Justice Center delayed responding, and eventually provided some heavily redacted summary reports, citing state law that limits access to that information. So DRNY sued the Justice Center in federal district court. The Justice Center asked the judge to dismiss the case on the grounds that DRNY had no valid complaint.

Back in 2016 the judge refused to grant the dismissal. He pointed out that federal law requires, in plain language, the Justice Center to turn over all records concerning its investigations, without editing ("redacting") anything, and that federal law trumps state law in this matter. Because of this, the judge said, DRNY certainly did have good reason to sue, and the case could go to trial.

The Justice Center refused to accept these black and white facts. So the case proceeded, and DRNY requested a "summary judgement." Courts can award summary judgements without proceeding to trial when the facts are so one-sided that the outcome is obvious.

This was such a case. In February 2018, the judge issued a summary judgment ordering the Justice Center to turn over everything DRNY had asked for, without redactions.

The correct decision in this case is so clear that even a caveman could see it, to coin a phrase. There is no rational basis for the Justice Center to appeal except to force a full trial. It could then appeal the inevitable defeat in that trial to the Circuit Court of Appeals, and then appeal that inevitable loss to the Supreme Court, where it would lose for the last time. This would take several years, during which, perhaps, some of the individuals responsible for the neglect and abuse might escape justice, by means of the statute of limitations, or by death from old age. If the Justice Center intends to appeal, that would be the only possible reason.

*It's nice to hear that the agency that tried to get the settlement voided is now so "concerned."*





# STIC NEWS

## “Southern Tier” Isn’t Necessarily STIC

We would like to clear up some confusion about Health Home Care Coordination in our region:

STIC stands for “Southern Tier Independence Center”. But just because an agency that does care coordination has “Southern Tier” in its name doesn’t mean that agency is STIC.

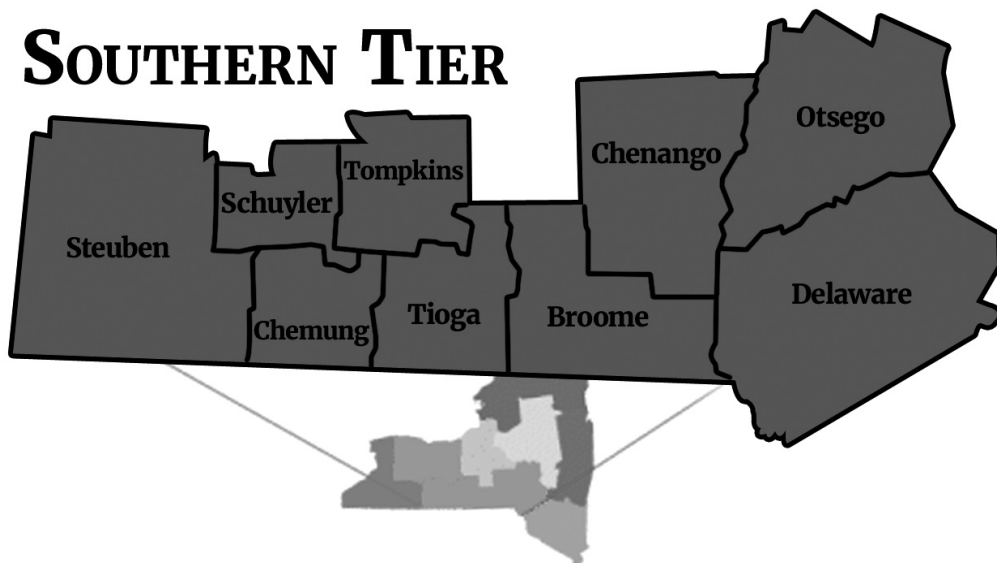
**STIC** works with **Prime Care Coordination** (PCC, or just “Prime Care”). For the next year, STIC will provide Care Coordination very similar to the Medicaid Service Coordination that we provide now. Very little will change if you choose to remain with STIC.

If your STIC service coordinator chooses to work for a different Health Home agency, you **do not** have to leave STIC. **You can choose a different STIC service coordinator** and stay with us.

A year or so from now (July 2019), STIC’s service coordinators will become employees of Prime Care. But they will stay here with us, because STIC will be the Southern Tier hub for Prime Care.

Prime Care’s main office is in Rochester, but Prime Care will blanket our region

## SOUTHERN TIER



with services. STIC has had branch offices in the more rural parts of our service area, including Cortland, Owego, Ithaca, Norwich and Oneonta, for several years. If you choose Prime Care you’ll have the option of meeting with staff in one of those offices, as well as at AIM in Corning. And Prime Care has other hubs all across western and central New York.

### Southern Tier Independence Center’s Independent Living Philosophy

People with disabilities should be empowered to control the direction of their own lives. This means choosing their goals, plotting their course and taking responsibility for their actions and the results. People with disabilities have the right to make their own choices and decisions and the right to make mistakes and learn/benefit from those mistakes. Centers for Independent Living (CILs) foster independence, help disabled people to develop networks and supports and promote self-reliance. CILs advocate for

the inclusion and integration of people with disabilities in all aspects of community life.

### STIC’s Mission

STIC’s mission is to shape a world in which people with disabilities are empowered to live fully integrated lives in their communities. We offer assistance, advocacy and services to children and adults with all disabilities, increasing their independence and allowing them to pursue their dreams. We also support their families and friends, as well as businesses, agencies, and governmental entities, enabling them to better meet the needs of people with disabilities. Finally, we educate and influence our community and public policy so that all of you can “Access Your World.”

### STIC’s Values

- We value the ability of every human being to reach for their dream.
- We hold that each individual has strengths



“More than a day at the beach” ★

• 35th  
**Anniversary!**  
**and ADA Celebration**

**July 26, 2018**

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Face Painting  
Beanbag Toss  
Wheelchair Pingpong  
Wheelchair Basketball  
Wheelchair Obstacle Course  
Xscapes “Immunity Quest”  
Escape Tent  
Slushies – Hot Dogs

# That's the Signpost up Ahead

by Bill Bartlow

We are finishing construction and puzzle design on our next Xscapes room, aiming for a mid-June opening. We're anticipating that the interest and excitement expressed by many parties in our "Twilight Zone / Rod Serling Experience" theme will bring quite a few teams of players to the attraction.

Every effort is being made to make it our premier Xscapes room. It will be about three times larger than our first two rooms, and will challenge your puzzle-solving skills in six distinct areas. Remember Rod's introduction to the Twilight Zone episodes of the third and fourth seasons:

"You unlock this door with the key of imagination. Beyond it is another dimension—a dimension of sound, a dimension of sight, a dimension of mind. You're moving into a land of both shadow and substance, of things and ideas. You've just crossed over

into the Twilight Zone."

We want to make this an unforgettable experience for you while appropriately recognizing the life and works of the most honored and awarded man in television history, who called Binghamton his "Home Town".

We wish to offer our most sincere thanks to the Rod Serling Memorial Foundation, the

Serling family, and to CBS for their support and for helping us to make this unique entertainment possible.

Stay tuned to our web sites for the latest details and to make your reservations:

[www.xscapes-stic.com](http://www.xscapes-stic.com)

[www.stic-cil.org](http://www.stic-cil.org)



*STIC's Values (cont. from page 12)*

and weaknesses that must be taken into account in their journey toward their dreams. Each individual must accept the responsibility for the dream, the journey, as well as the work to get there.

- We offer support, ideas, tools, training, respect and concern.
- We will not do for, when it can be done by, the person.
- We will not patronize for the sake of efficiency, or in the guise of caring. We will try to understand when this causes fear, anger and frustration.
- As we develop programs and policies, we will be guided by the dreams and abilities of the people we serve.
- No matter how difficult the road, we will always choose the path of inclusion and integration.
- We will not sacrifice our principles or values for money, convenience or expediency.
- We will not shy away from controversy if that controversy will further our mission.
- We offer hope and continue to look at each person as a unique and joyful experience that will teach us, and take us on a journey where we have never been.

## Now Hiring Direct Support Professionals

### Must Have:

*Flexible Hours  
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Personal Vehicle*

\$12.00/hour

*Come join the Habilitation Team  
at the Southern Tier Independence Center  
to provide one-on-one support to individuals  
with disabilities*

*Please email your resume  
to [apply@stic-cil.org](mailto:apply@stic-cil.org)*

135 East Frederick Street  
Binghamton NY 13904  
607-724-2111







# Community Programs

# Want to Grow Your Own Food?

The Gregory Lane Community Garden has wheelchair-accessible raised beds available for those who can make use of them. The garden is in the First Ward, across from the parking lot of St. Cyril's Church. There is a bus stop nearby on Clinton St. Help is available for tending your bed and watering. The cost is \$10 but scholarship funds are available.

If interested, contact Scott Lauffer (607) 341-3746 or [lauffer.scott@gmail.com](mailto:lauffer.scott@gmail.com).

This is a project of VINES, a non-profit organization committed to developing a sustainable and just community food system in Binghamton.

<http://vinesgardens.org/programs/communitygardens>





## Medicaid Managed Care Grievance and Appeals Changes

from CDPAANYS

Thanks to the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) for the following. To avoid confusion, we'll just add that the requirement to exhaust a managed care plan's internal appeals process before requesting a Fair Hearing was issued by the federal government as part of new managed care regulations. It was not optional, and it was not a decision made by New York State officials.

Beginning **May 1, 2018**, changes in federal regulations to the Medicaid managed care Service Authorization grievances and appeals process took effect in New York State. As of now, a Medicaid managed care plan enrollee wishing to challenge a plan's decision to deny, reduce, or terminate services must now complete an internal appeal process before requesting a Fair Hearing. There are also important changes to the timeline for plans to fast track decisions, ensure aid service continuity through the appeals process at an enrollee's request, information sharing, and member proxies. These rules will apply to all Medicaid managed care plan enrollees, including Consumer Directed Personal Assistance (CDPA) consumers. Please note the following procedural changes:

**Plan Appeal:** Before May 1, 2018, enrollees were able to request a Fair Hearing immediately after receiving an Initial Adverse Determination (IAD), which is written notice of a plan's decision to deny or partially deny (approve less service than requested) a service request, to reduce or terminate services an enrollee is receiving, or to deny payment for a claim. Enrollees are now required to first work with the plan's internal appeal process and request a Plan Appeal from their plan if they wish to contest the IAD. Enrollees have **60 days from the IAD date to request a plan appeal**. Members may not request a Fair Hearing until the plan issues a Final Adverse

Determination (FAD). If a plan decides to overturn its IAD after an internal review, it has 72 hours from the decision to approve or provide the contested services, or sooner if necessary for the enrollee's health. If the plan issues a FAD, the plan must send the enrollee information about their Fair Hearing rights.

**Aid to Continue:** If an enrollee wishes to continue to receive their current services uninterrupted through the Plan Appeal process they must now request "aid to continue" **within 10 days of notice or the effective date** of the plan's decision to reduce or terminate services.

**Fair Hearing Request:** An enrollee may request a Fair Hearing only after following the Plan Appeal process and the plan issuing a FAD or Deemed Exhaustion, which occurs if a plan fails to decide an appeal or respond within the allotted amount of time—30 days for typical plan appeals, 72 hours for Fast Track, and any extensions. Enrollees must request a Fair Hearing within **120 days of the FAD** date issued by the plan. If the enrollee wishes to keep their services intact through the Fair Hearing request process in the case of a plan's FAD to deny or reduce services, they must request the Fair Hearing within **10 days** of the FAD or the decision's effective date, whichever is later.

**Fast Track:** Plans must Fast Track service authorization requests **within 72 hours** if the requesting enrollee's health is at risk. Plans will Fast Track all requests for additions or extensions of members' current services. Plans formerly had three days to Fast Track decisions.

**Appeal Proxy:** Members may now use a proxy, such as a relative, medical professional, or other trusted party, to request an appeal on their behalf. To do so, they must submit a paper signed and dated by both the member and their chosen proxy granting consent for the proxy to make the request on their behalf.

**Case Files:** Plans are now required to provide enrollees requesting a plan appeal with a copy of their case file.

**Managed Care Complaints:** Formerly known as grievances, complaints are made directly to plans by enrollees or their proxy in regards to the quality of care services. Plans must send written notice of their decision regarding complaints to enrollees within 45 days of receiving all of the information related to the complaint and no more than 60 days after receiving the complaint, or 48 hours of receiving all of the related information and no more than seven days after receiving a fast tracked complaint.

**In Summary:** *A Fair Hearing decision is still final. However, enrollees must now request a Plan Appeal and be issued a Final Adverse Determination (FAD) before they can request a Fair Hearing.*





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## 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.**

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**MAIL TO:** Southern Tier Independence Center, Inc.  
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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!**

## Southern Tier Independence Center

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Maria Dibble

### ASSISTANT DIRECTOR

Jennifer Watson

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**ADA SERVICES:** Frank Pennisi

**BEHAVIORAL CONSULTING:** Gerard Griffin  
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Laura O'Hara Pamela Lounsberry

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Danny Cullen Robert Deemie

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**PTAC:** Sue Lozinak Beth Kurkoski

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**RVR-CES:**

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Emily Neville Rebecca Smith

Tammy Virgil Kathy Sas Craig Lucas

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Valerie Soderstrom Melissa Rafael

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