

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

AccessAbility

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THE TIMES, ARE THEY A'CHANGIN'?

by Ken Dibble



We recently elected a new president who claimed to be a true “agent of change.” The post-election analysis suggested that fewer than half of those who cast ballots wanted major change, while many other citizens were uninspired by the choice offered to them and did not vote.

It remains to be seen if “real” change will come in the way that many voters imagined, but Donald Trump and his representatives have talked about changing things that affect people with disabilities, so we thought we should offer some preliminary remarks here.

As of this writing (late November), no useful details have been made public about any actual plans being developed by the Trump Administration, so I emphasize that we do not know what is going to happen. It is far from clear whether the actions will match the campaign rhetoric, nor do we know how much support there is in Congress for really radical change. We urge everyone to stay relaxed but alert, and to speak up whenever there is an opportunity to provide input.

From our point of view, there are two major, and somewhat interrelated, issues: The Affordable Care Act (“Obamacare”) and Medicaid.

Trump campaigned on “repealing” Obamacare, but already statements from his transition team suggest that the law will not be fully repealed. There is interest in retaining the prohibition on denying coverage for pre-existing conditions, and the requirement for family coverage to include adult children up to the age of 26.

A lot of people dislike the ACA rule that people who don’t have insurance through their employers, Medicaid, or Medicare must buy it or pay a penalty. We can tell you that some of the ACA provisions for employers are bad news. If they remain unchanged, they will eventually force us either to reduce the quality of the coverage we provide to our staff, or require them to pay more for it, or both. Many employers agree with us on that point.

STIC has contracts to provide “navigator” services to assist people using the “New York State of Health” exchange to buy insurance under Obamacare. We have heard people say that if the insurance exchange portion of the bill is repealed, New York could still run this program. The state, we understand, is footing the bill for the navigator services, and might continue to do so.

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However, it is not clear whether any insurance companies would still want to sell insurance to individuals, with or without the exchange, if the subsidies for customers and the incentives for companies that come with the ACA are gone. There may be nothing to navigate. Time will tell.

Most relevant to people with disabilities, Obamacare allowed states to expand Medicaid coverage to people with somewhat higher incomes for very little cost to the state, and it includes the “Community First Choice” (CFC) option that we’ve been writing about for several years.

We’re not going to repeat most of what we’ve said about CFC; you can look at our back issues on the website to learn about it. We actually doubt that many, if any, of those who want to repeal the ACA know what CFC is or that it is part of the law. It will be up to disability rights advocates who want to fight for the program to educate them. We’ll

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

just say that although NY has approval from the feds to implement CFC, so far it hasn't done so. Nobody is being served by it, and if it goes away, no New Yorkers' lives will be affected. The state could proceed with its other plans for Medicaid community long-term services and supports without it.

That is, it could if there are no significant changes to Medicaid. That is a big unknown.

The first thing we don't know is if whatever Trump does to Obamacare will mean that the Medicaid expansions it authorized for NY and several other states will be withdrawn. One of the things the exchange has done is hook up a lot more people with Medicaid—maybe even more than those who used it to buy private insurance. Reversing that provision alone will cause many millions of people to lose their insurance. Vice President-Elect Mike Pence is said to be very proud of the ACA Medicaid expansion that he oversaw as Governor of Indiana, so there may be some hope there.

Trump has also referred to Medicaid "block grants," as have Republican Congressional leaders, in recent months. This idea goes back to the early 1980s in various forms. We emphasize again that we do not have any details on what specific plans these people have in mind.

Medicaid is an "entitlement" program, in the sense that if a state chooses to participate (and all states do), then it must make a certain minimum package of benefits available to everyone who meets the minimum eligibility requirements. Those eligible are "entitled" to the benefit. There is no way to control the number of people who receive the services, and it is difficult to control the spending, because each eligible recipient may use an unpredictable amount of services.

Medicaid is a federal-state partnership, so some of the rules come from the feds and

are non-negotiable. Other rules are chosen by the state and written into a plan that the feds must approve. There are mandatory and optional services, as well as a variety of optional "waivers" that states can use to change, or "waive," some of the federal rules.

New York has the second most-expensive Medicaid program in the nation. We have one of the most service-rich programs as well, including many of the "optional" services, and a variety of waivers to provide custom services to different populations. All of this comes with a tremendous amount of federal regulation to govern how the state operates the program, including the mandatory aspects as well as those that are optional and custom-built.

One view of Medicaid block grants is that most of this regulation goes away, along with the entitlement. There would be no mandatory services, and no mandatory minimum eligibility rules. States could set any rules and service options they wish—and they would not be required to actually serve all those whom their own rules make eligible. In return for this flexibility, the amount of money provided by the feds to the states would be reduced, and capped annually, on the theory that more regulations impose more costs, and in a less regulated system states could provide the same coverage for less money.

Although Medicaid regulations are complex, it's important to remember that it is a huge program, involving billions of taxpayer dollars that must be safeguarded, and covering a very broad variety of needs and ways to meet those needs. It's not a simple system, so the rules cannot be simple either. Many of those long and complicated regulations are really as simple as they could possibly be to achieve their purpose. Some of the regulations are counterproductive and needlessly limiting. And some of



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the regulations are there to protect people and ensure that their needs are fully met.

There are three groups of people who see benefit to getting rid of Medicaid regulations.

The first group includes those who are opposed to the federal government providing benefits to anyone because they believe people should have to shift for themselves. This group sees Medicaid block grants as a first step that is relatively easy to achieve. Once it has been achieved, they will move forward gradually with further efforts to cut the program's funds, and even reimpose regulations limiting its usefulness, until it no longer exists.

The second group of people want to reduce the size and strength of the federal government so that officials on the state and local levels have more power to restrict civil rights and control taxation to benefit their interests. This group doesn't necessarily oppose government health benefits, but its members may have ideological or religious beliefs that they think should be allowed to control how the benefits are provided, and to whom, or they are trying to divert as much taxpayer money as possible into the pockets of their particular buddies in the healthcare and health insurance industries.

The third group includes people who want to get rid of counterproductive rules in order to make the program work better and serve more people more flexibly, and gain overall improvements in public health, while keeping costs down.

Of course, everybody who wants to block-grant Medicaid says they are in the third group. Most of them are just bald-faced liars, including a lot of state governors, members of the second group who want more control over the program, but absolutely do not want the funding cut. We at STIC have been heavily involved in Medicaid policy on the state level for several years. We really are in the third group, I assure you. In fact, I personally believe that Medicaid should not be the source of funds for non-medical support services for people with disabilities at all. Stuff like supported employment, respite services, skills training, or help to take a bath is not medical and it should not be regulated or priced like medical services.

There should be a completely different, non-medical, federal funding stream for those things. And those people with disabilities who choose it should be able to receive this money as a monthly lump sum with no strings attached, to spend as they see fit, just like Social Security retirement benefits.

There is some hopeful speculation that state governors, most of whom are Republicans, will stop any block-grant plan that cuts funds for the states. These speculators may be granting these governors more influence than they actually have with the radical right. STIC believes that the first two groups are so dangerous, and their members so influential, that once block grants take effect, they will dismantle the Medicaid program and roll back all of the social benefits—real jobs, real homes, real relationships, and real participation in real community places and events—that people with disabilities have gained from it. Despite my personal beliefs, for us as an organization of advocates, the value of the opportunity to rewrite Medicaid from scratch to make it better is far, far outweighed by the likelihood that malignant people will deliberately and gleefully use that opportunity to destroy it.

Which brings me to malignancy of a different kind. Elections, of course, have consequences. But those who won this election did not win the right to be cruel, vicious, vindictive, or hateful toward anyone, and they did not win the right to reintroduce segregation, demonization, or infantilization of people with disabilities as social policy. STIC will stand strong against any and all of that, wherever it appears.

But you must also know that if it is only STIC that stands strong, we will fail. We are entering a time when all of you will need to do more to protect yourselves and your rights. We have worked long and hard to empower people with disabilities, and you have gained a great deal of personal power as a result. In the coming months and years, all of you will need to rise to your full height and exercise all of your power, as individuals and in groups, to keep moving forward.

So take this holiday time to rest and prepare, and gird your loins for the days ahead. We'll see you in January.



E.B. et al. v Cuomo: A House is Not a Home

E.B. and others are adults with developmental disabilities and their parents or guardians. They are suing the state for failing to provide "supported community residential opportunities necessary to prevent the unjustified isolation of adults with developmental disabilities and the concomitant adverse impact on the residential caregivers for these adults." According to OPWDD, there are over 11,000 people on its waiting list for residential supports. The state has slowed down its process of creating new group "homes," and nearly all new development is focused on residences for four or fewer people to house those leaving the developmental centers and ICFs that the agency must close.

Why is that? Two reasons: Cost and federal regulations.

Financially, New York can't afford a rapid pace of building or renovating residential real estate. That's expensive for anyone, and the regulatory demands that the state imposes on the design of these facilities inflate their cost well beyond what ordinary homeowners would pay for similar housing. Plus, it's a lot of high-value residential property that is permanently off the tax rolls.

The new federal regulations for person-centered planning require that every single person getting Medicaid-funded home and community based services must be offered a choice of living in ordinary non-disability housing, or in disability housing that doesn't require them to accept roommates, or the ability to choose who their roommates are, in addition to more traditional group "homes." And every year the person's choice must be revisited. As a practical matter of compliance with this, building or buying housing is a huge problem. First, it's very slow. Beyond that, buying buildings for people to live in tends to lock people into those buildings, because mortgages must be paid and every "bed" must be kept occupied to do so. This fails to address the possibility that people who are "placed" in

those buildings will dislike each other and won't want to live together from the get-go, or the likelihood that, over time, even if they were okay with it initially, some of them may want to live elsewhere, perhaps with other people.

This case was filed in federal District Court in Buffalo in September. The only official document we've seen is the plaintiffs' memorandum to support certification of a class action lawsuit. They argue that there are two "subclasses": "adults ... who are not capable, by virtue of their developmental disabilities, to live in the community without assistance and support," and "caregivers [who] have no legal obligation to provide support and services to the aforementioned adults, but instead ... only provide care for these individuals out of love and necessity." This document doesn't list the legal grounds on which the plaintiffs are asking a federal court to order the state to provide the services they want. However, the phrase "unjustified isolation" suggests they will bring in the ADA and the *Olmstead* decision. The memorandum also asserts that the plaintiffs are "entitled" to services, which would bring in the Medicaid entitlement (for as long as it survives the resurgence of right-wing block-grant ambitions).

As our readers know, there are also two subclasses of "supported community residential opportunities": those that segregate people and restrict their personal autonomy and freedom of association, and those that don't. Let's see if we can guess which kind these plaintiffs want.

The memorandum refers to the adults with developmental disabilities as the "Potential Resident Class." "Resident" is the term used in the industry to refer to people who live in segregated congregate settings that are owned or controlled by service providers. As for the caregiver class, they "would not elect to provide such care" to their loved ones if the state would do it instead, and they want them to have "the opportunity for social interaction with peers."

"Interaction with peers" is often used by segregation advocates to refer to what they consider to be "justified" isolation solely among other people with developmental disabilities. Although the plaintiffs want this opportunity "among other things," that's the only one they chose to mention specifically, and they don't explain why their loved ones can't interact with "peers" while living with them, and can only have that opportunity if they get services from the state.

We deal with hundreds of families of people with developmental disabilities at STIC. We understand the tremendous difficulties they often face. When we can show them a better way to address those problems than segregating people, they almost always go for it, and are happy with the results. Although most people come to us

via word-of-mouth from other satisfied people, we don't think the families we serve are unique in their needs. We just think they're better informed about possible solutions than people like the plaintiffs in this lawsuit.

This suit generated a lot of media accounts that did not report on the important differences between

segregated, restrictive residential services and those that fully integrate people with disabilities and support their civil rights of freedom of action and association. Just because OPWDD doesn't want to build a lot more old-style group "homes" doesn't mean it can't meet people's real needs for housing supports by other means. However, we agree that the agency needs a strong push to do so.

As we've reported (*AccessAbility* Spring 2016), an extensive housing survey conducted by OPWDD revealed some striking results. "60.7% of caregivers said that they would like their family member to remain living at home if they had more services," and "32.8% of caregivers reported that owning or renting a home where needed supports and services would be available was desired for their family members." OPWDD also reported that "Over 90% of respondents are interested in learning

about residential options other than those that provide 24/7 staffing support."

These numbers don't really bode well for the plaintiffs' lawyers' claim that their suit fairly represents all 11,000 members of the class of "Potential Residents" of group homes. These plaintiffs are in the minority with regard to having their adult family members live with them, and they are remarkably incurious about options that don't segregate or restrict people.

On the other hand, "62.0% reported preferring a residential setting where services and supports are provided by an agency."

If you read between the lines, these numbers suggest that what people really don't like is OPWDD's take-it-or-leave-it approach to flexible personalized services. The agency will let you design your own paid supports in an ordinary home where you make the rules, but only if you take on the work of arranging, training, supervising, and managing those supports, and the responsibility for troubleshooting problems and providing backup. Some very dedicated and creative family members have accepted this "Self Direction" challenge and gotten good results. This proves that owning a building, clumping people together in one place, or rigidly scheduling their lives is not necessary to achieve a satisfactory solution. But the vast majority of people whose relatives need support don't have the time or the ability to do that. OPWDD has refused our suggestion that all residential service providers be required to provide that kind of flexibility and paid staff to manage it, while remaining responsible for ensuring reliability. After all, if unpaid amateur parents can do it, then surely trained, experienced, and well-compensated professionals can. Right? Some providers, such as Syracuse's Onondaga Community Living, do it, but not nearly enough.

We have also urged residential service providers to lease the places where people live. This housing stays on the tax rolls, helping to offset the local share of the cost of Medicaid-funded services. A lease can be broken with reasonable notice, so when tenants choose to go elsewhere, the provider does not face the dilemma of either forcing desperate people on their waiting list to accept "placement" in whatever facility has a vacancy (known as "backfilling") whether they like it or not, or being stuck with a mortgage on a place that doesn't



house enough people to pay for it. This removes a common reason why providers try to discourage or prevent people from moving out. And in most communities, finding other places to rent for people who want to move is a lot faster than waiting to build, or buy and renovate, more housing. Recently OPWDD endorsed this position and urged housing service providers to consider leasing as a way to reduce their waiting lists more quickly. Unfortunately, the bricks and mortar model is comfortable for providers because it offers a more predictable source of funds, so they are not likely to start leasing merely because OPWDD “suggests” it. The agency needs to adjust its financial incentives and disincentives to bring about real change.

We’ll follow this case in the months ahead and keep you informed.

DRNY v Unified Court System: Who Guards the Guardians?

Also in September, Disability Rights New York (DRNY) sued the state’s court system to block judges from granting Article 17A guardianships.

DRNY is the state’s official protection and advocacy agency for people with various disabilities under federal laws governing services for people with developmental and/or mental health disabilities.

As we’ve reported (see *AccessAbility* Winter 2015-16), New York offers two types of guardianship proceedings for people whose disabilities render them unable to manage their own affairs. Article 81 of the state Mental Hygiene Law applies to people with all types of disabilities, and it requires clear and convincing evidence of a person’s specific “incapacities” in relation to making decisions about money, health care, where to live, and/or with whom to associate to be presented in a court hearing in which the person with the disability has legal counsel. The resulting guardianship, if any, must be limited only to the specific types of decisions for which it is needed. Article 17A of the state Surrogate Court Procedure Act applies only to people with developmental disabilities, and allows judges to declare individuals “incompetent” in all respects, without evidence of incapacity or a hearing, merely because two medical professionals sign a form stating that the person has a developmental disability. Article 17A also

does not require the affected individual to be informed that the action to impose guardianship is being taken, let alone have legal counsel to oppose it.

Advocates have long urged the repeal of Article 17A, and reform of the state’s guardianship laws has been part of the state’s “Olmstead Plan” for over three years. A bill to make 17A much more like Article 81 was introduced in the state legislature this year at OPWDD’s request, but the Cuomo Administration did not put any weight behind it and it went nowhere. We understand that some parents of people with disabilities who have the ear of state officials don’t like the idea.

Having given the state three years to act and seeing no results, DRNY filed suit in federal district court in New York City alleging that Article 17A violates the US Constitution as well as federal disability civil rights laws.

According to DRNY’s complaint, the 5th and 14th Amendments to the Constitution “provide that neither the federal nor state government shall deprive any person ‘of life, liberty, or property without due process of law.’” DRNY cited federal case law to show that “due process” has a very specific meaning, and that when government restricts people’s rights for cause, it can only do so when the action is “narrowly tailored to serve a compelling governmental interest,” and the action must be the least restrictive possible way to achieve that goal. Since the state’s Article 81 achieves the goal in a far less restrictive and much more narrowly tailored manner than Article 17A, it should be clear that 17A is not necessary and violates people’s rights.

The 14th Amendment also guarantees equal protection of the laws to all citizens. The existence of a carefully limited evidence-based adversarial process for restricting the rights of people with mental health and cognitive disabilities, alongside a much broader provision based on professional opinion and requiring no opportunity for defense, only for people with developmental disabilities, is clearly not equal protection.

These separate processes are also discriminatory on the basis of disability, making them illegal under federal civil rights law.

DRNY asked the court to grant a permanent injunction against the establishment

of any further 17A guardianships, and also to order the state to notify everyone who is currently under a 17A guardianship that they have a right to request a court hearing to have it be modified or terminated.

We’ll let you know what the court does.

Lacey v Visiting Nurse Services: Blow the Whistle

This suit was actually filed in 2014 in federal district court in New York City. As a “whistleblower” case under the federal False Claims Act, the complaint was initially sealed while state and federal officials investigated. The federal Department of Justice, facing a backlog of such cases, has been unsealing them before reaching a decision on whether to intervene. Although the court documents are unsealed, they aren’t freely available online yet, so we are relying on media reports for this story.

Edward Lacey was the Vice President of Operations and Improvement for the not-for-profit homecare agency Visiting Nurse Services until January of this year (VNS, which operates in several downstate counties, should not be confused with VNA, a homecare agency serving central New York). He alleged that the agency ignored doctor-ordered plans of care and provided fewer Medicare-funded services than specified while still collecting full reimbursement. For example, a person who had lupus and double below-the-knee amputation, and used a wheelchair, was ordered to receive 27 rehab and 38 nursing visits over two months. VNS provided no rehab and only 5 nursing visits but still collected over \$3,500 from Medicare.

Lacey also claimed that the agency falsely reported impossibly high levels of service in order to receive more money. He said that each nurse visit should take around 35 minutes, and allowing for travel time, on average nurses should be able to make 6 visits per day, but that VNS routinely billed for three times that number of visits per nurse per day.

Lacey said he tried to get top executives of the agency to correct these practices but he was ignored.

According to the *New York Times*, “Richard Rothstein, a spokesman for the agency, called the lawsuit ‘self-serving and base-

less.’ He said its allegations were made by ‘a disgruntled former employee with no responsibility for and little knowledge of the clinical realities of our business who has spun a tale out of whole cloth.’”

That statement might be more believable if VNS, and its affiliated Medicaid managed long-term care company, VNS Choice, had not been involved in a host of questionable activities leading to audits, investigations, and another lawsuit, over the past few years. The other suit was filed by federal prosecutors and involved fraudulent enrollments in Medicaid managed “social adult day care” programs (see *AccessAbility* Summer 2013). That suit was settled; VNS agreed to pay \$35 million back to the feds and also admitted its wrongdoing.

In his suit, Lacey named then-VNS chief executive Mary Ann Christopher as one of the people who knew that the agency was not providing services that it claimed to provide. A previous VNS CEO was Carol Raphael, a Cuomo crony whom he appointed to his Medicaid Redesign Team. Raphael resigned from VNS in 2011, possibly after the federal fraud investigation began in February of that year. Another federal investigation was begun in August 2013 to determine whether Cuomo or his people had illegally interfered in that probe; this may be one of the things that we keep hearing that federal prosecutor Preet Bharara is still looking into.

Against this background, we were not reassured to learn in October that the NY State Department of Health’s new Director of the Division of Long Term Care is Andrew Segal, VNS’s Director for External Affairs and Government Relations. We are hoping

to see the official court documents in this lawsuit to find out if he was one of the executives with whom Lacey had discussed his charges. If we do, we’ll let you know.

Access Living v Uber: Accessibility uber Alles

In October, Access Living, a Chicago Center for Independent Living like STIC, sued the ride-sharing service Uber for failing to provide equal service to people who use motorized wheelchairs. We haven’t been able to see any official court documents and are relying on news reports and press releases for this story.

Although Chicago is a big city far away from the Greater Binghamton Region, this case is directly applicable to upstate New York. Whether or not to allow Uber and similar ride-sharing companies to operate in various New York communities has been a topic of public and legislative debate. In fact, OPWDD has suggested using these kinds of services to address the lack of inexpensive public transportation for people with disabilities. Uber is notorious for providing a taxi service that is nearly completely unregulated. Stories abound of how Uber drivers discriminate against people of color, and the issue of accessible service has been much discussed in New York City. Some Uber drivers, who are considered by the company to be independent contractors for whom Uber has limited responsibility, have complained of mistreatment, and some are even trying to form unions.

The issue of accessible taxi service for people who use wheelchairs, and especially motorized wheelchairs, is difficult. Some people can transfer from chair to car seat and the chair can be folded and put in the trunk or back seat. Uber drivers, who use their own cars, can accommodate such riders, though it is unclear how often they do so. For people who can’t transfer or who use motorized devices, the vehicles must be substantially altered to provide ramps or lifts and adequate space and headroom. There are manufacturers offering fully accessible cabs at a reasonable cost, and New York City advocates have been trying to get the city to require cab operators to buy them. There has been resistance from operators who claim the cabs aren’t “stylish” and that they would repel customers, an unlikely claim given the high dependence

New Yorkers have on cabs. The city has its “medallion” licensing system for independent drivers who own their own street-hail cabs. Although these cabs are not accessible unless a driver chooses to use an accessible vehicle, the number of these cabs is limited. New York also has cab companies (or “car services”) whom riders must call to arrange a trip—the way most cab services operate outside of the largest cities—and this is the model that Uber is competing with. These cab companies require drivers to short-term lease the vehicle from the company and act as independent contractors who must nevertheless follow some company rules. Uber drivers use their own vehicles, and the alleged attraction for them is the opportunity to make a few extra bucks in their spare time without incurring a lot of expenses or meeting a lot of requirements. “Independent contractor” is a complicated legal concept that is often abused in order to cut costs and exploit workers in many industries. If Uber is found to be violating the rules, it may not survive in any case, but if it does, it may be impossible to impose an accessibility requirement on the Uber business model.

In Chicago’s case, Uber has a separate system, UberWAV, that customers are supposed to be able to use to get a wheelchair accessible ride, but according to Access Living, only 14 accessible rides were provided to Chicagoans by Uber over four years. How UberWAV is supposed to work was not explained by our sources. In New York, Uber offered to address concerns by having its cell phone app contact the local paratransit service—in other words, to shift responsibility for providing accessible rides completely away from the company.

The larger question is, what happens to the taxi transportation market in a community when Uber is allowed to compete with companies that own the vehicles? Since Uber purports to be significantly cheaper, its inaccessible service could almost completely supplant companies that could run accessible cabs.

Uber also claims to be working on providing driverless cars. If it succeeds, the problem of regulatory authority may disappear since such vehicles would have to be owned by the company, which would then face an unambiguous mandate to make its service accessible.

So it’s unclear how suing Uber can solve this problem in Chicago or elsewhere, but it will be an interesting case to follow.

Whether or not to allow Uber and similar ride-sharing companies to operate in various New York communities has been a topic of public and legislative debate

YOUR *MONEY* OR YOUR *LIFE*



In October the NYS Inspector General released a report criticizing OPWDD facilities for allowing employees to steal money. In a statement reported in the media, Inspector General Catherine Leahy Scott said, “With disturbing regularity we have seen the shameless preying on a vulnerable population by those charged with their care.” She also said the problems were the result of “systemic mismanagement” and a “lack of adequate accounting or safeguards.”

The IG’s office investigated ten cases, nine of which involved OPWDD misuse of personal funds belonging to residents of group homes. In one such case, a house manager stole over \$7,400.

You can read the report yourself; it’s here:

<https://ig.ny.gov/sites/default/files/pdfs/OPWDDPatientAccounts0393.031.2013FinalReportResponseCover%20Pages%209.16.16.pdf>

We’re sorry to disappoint you, but the actual text of the report doesn’t really justify all the outrage.

First, although money was stolen, the regional offices’ routine audits discovered the thefts and all of the residents were paid back with state money.

Second, in almost all of the reported cases, the guilty individuals were arrested, pled guilty, and were required to pay back the stolen funds plus fines and other penalties. Although in some cases the amount stolen justified felony charges, as best we can tell, the criminals were not treated differently from other first offenders in larceny cases involving similar amounts. Plea bargains are very common in such cases, and jail terms are rare.

All of the guilty parties either resigned or were fired. It does seem as though it is easier for OPWDD to fire people who

steal than to fire those who physically or sexually abuse the people in their care. There are numerous cases of such abusers who are still OPWDD employees, though on “administrative leave.”

In one of the nine cases involving residents’ personal funds, the only “crime” was that a staffer purchased some things for residents with her own credit card and reimbursed herself from the residents’ funds later. Nothing was stolen; the residents received the purchased items, and all of the receipts were legitimate and matched up. But this sort of thing is forbidden by OPWDD regulations, which prohibit “borrowing or lending” between staff and residents.

In another case, a family care provider seems to have used resident funds for things the residents needed but which are supposed to come out of the stipends the provider received from the state, such as toiletries. Not nice—but these stipends are pretty slim, and it’s not like the money was used to buy lobster dinners or pay-per-view movies for the provider or something. The provider withdrew from the family care program. In this one case, however, the OPWDD employee whose job was to periodically check the provider’s records, and who said that she knew that questionable activities were happening but didn’t bother to look into them, does not appear to have been punished.

There certainly were some creative scams. One group home manager concocted a fake group trip to a theatrical performance. She bought tickets with resident funds and used them to take her family to the play instead. She went so far as to get souvenirs from the performance and give them to the residents, and she brought in a DVD of the play and had all the residents watch it in case any investigators asked them about what they saw. But she was caught when two other staff members who she claimed attended the performance with the residents told investigators that she was lying.

Another dodge involved claiming that legitimate receipts were “lost” and using a blank receipt book to replace them, conveniently omitting important information from the homemade receipts, such as the name of the place where things were purchased. In some cases, the low-level

staff responsible for conducting the most frequent reviews of expenditures accepted these receipts when they should not have.

The IG recommended a lot of things that probably won't help much. For example, they want supervisors to be better trained and to have clearer instructions for monitoring use of funds. But several of these thefts were committed by supervisors, who are always going to be in a better position to fake a paper trail than ordinary line staff. In other cases, such as those involving made-up receipts, the supervisors clearly knew they were not appropriate and chose to accept them anyway to protect their underlings. You can "train" people not to do something like that all you want, but if they are crooked, they will still do it.

The thing is, they were not only crooked, they were stupid, because anyone with a brain would have known that when real financial auditors looked at this stuff, they would see the fraud. And that's what eventually happened, in every case.

We might get on our high horse and point out that all these things happened in OPWDD-operated group "homes," and the victims would have been better off living in their own homes with appropriate paid supports.

Well, probably not. For one thing, this behavior isn't exclusive to OPWDD. The NYS Attorney General recently announced prosecutions in six cases where nursing facility employees robbed residents, and such incidents are rather common in nursing facilities nationwide. But regardless of whatever institutional setting one avoids getting stuck in, there are plenty of instances of homecare workers ripping off people with intellectual or cognitive disabilities in their own homes. When the issue is physical abuse or neglect, having different workers who do not know each other come into the home does help bring these situations to light. Bruises, cuts, unwashed bod-

ies and filthy conditions are easily visible, and shocking, and in these cases the workers are less likely to protect each other and keep silent than are employees in congregate settings who have relationships with each other. But financial shenanigans are harder to see, and more unlikely even to be suspected. A smart and caring attendant may be interested enough to check receipts against inventory in the house, and perhaps service coordinators should be expected to, when the service recipient is clearly unable to do her own shopping. But one of

the many advantages of living in your own home is that you don't have to be regimented as though you lived in an institution. We can't get into demanding that people with disabilities themselves keep their receipts and be able to prove that all of their own money was spent only by them, or as they wished. Coercion and manipulation are very subtle things, and cash is untraceable.

One of the recommendations of the report is that OPWDD use bank cards for all purchases involving personal funds, to avoid misuse of cash. In one case, the local OPWDD office required all personal accounts to be accessed via debit or bank cards, which were to be used to get cash from ATMs only "if absolutely necessary." Nevertheless, a group home employee was able to pull cash from these accounts at ATMs and steal it. Of course, the agency could have forbidden use of ATMs and cash entirely. That would mean restricting people's ability to spend money to venues that accept these cards. Remember, they're not credit cards, which are accepted in a very large number of places; they're debit or bank cards, which many venues will not accept. And many other small places are cash-only. Do we want to prohibit people from going to farmers markets, street fairs, flea markets, swap meets, curio shops, and lots of other places just so we can keep somebody from stealing a few bucks from them? And, of course, in group homes the rules are enforced much more rigidly

against the residents than they are against the staff. Having a rule against using a resident's bank card to get cash from an ATM would not stop a crooked staff member from marching into the nearest supermarket and doing it anyway, but a rule against letting residents have cash surely would mean that no resident would get any of his own money.

The fact is that there are a lot of jerks in the world, and one of the favorite activities of jerks is preying on vulnerable people. Industries that provide services to vulnerable people in any kind of setting attract these miserable excuses for human beings like a child's dropped ice cream cone attracts flies. This preying is shameless, as Leahy Scott said, and the regularity of it is sad—but it should not be surprising to anyone who knows anything about this business. This stuff is going to happen. We wish it wasn't, but it is.

The mismanagement wasn't "systemic"; it was caught, in every case, by the system. There were many safeguards in place; that's why it was caught—not by crusading outside investigators like the Inspector General, but by ordinary OPWDD staff in the course of doing their jobs. There was a lack of perfect safeguards, because perfection is impossible.

We have to keep reminding ourselves that we were led into the whole dehumanizing segregated institutional morass by our good intentions. We tried to prevent vulnerable people from being mistreated, but the cure was ultimately worse than the disease. It is pretty much inevitable that people with significant intellectual or cognitive disabilities are going to be tricked, bullied, robbed, neglected, and abused more often than people who do not have those disabilities, no matter where they live or who works with them. Nevertheless, it remains true that living a real life in a real home with real friends and real, meaningful things to do is better than a protected, artificial, hidden existence.

Of course people who steal from people with disabilities need to be caught and punished. But in trying to do so, we must make sure we do not ourselves steal those intangible things, more valuable than money, from those we wish to protect.

*The thing is,
they were
not only
crooked,
they were
stupid*



Annual Campaign

Thank You

We at STIC would like to thank those generous folks who contributed to our 2016 Annual Campaign. We do thank all of you very much! The names below are those of contributors who agreed to let us publish them.

If you haven't sent in your response form with your donation, there's still time! Please do!

Gordon and Alice Allen

Joshua M. Bieber

Barbara Devore

Sharon DiGennaro

Harlan and Laurie Forrest

Peter and Mary Beth Gamba

Barry Kinney

Michael and Rachel Leonard

Sam J. Liberto, Jr.

in memory of Saverio and Filomena Liberto

William and Helen Mizera

Janet A. Ottman

Ronald E. and Lorelei A. Russ

Matthew and Mary Ellen Salanger

James and Pamela Vincens

Robert D. and Dawn Watson

Karl and Sara Wokan

Exit, Stage Right

by Bill Bartlow

In Shakespeare's play *As You Like It*, the melancholy philosopher Jacques muses these frequently quoted lines:

"All the world's a stage, and all the men and women merely players; they have their exits and their entrances, and one man in his time plays many parts, his acts being seven ages."

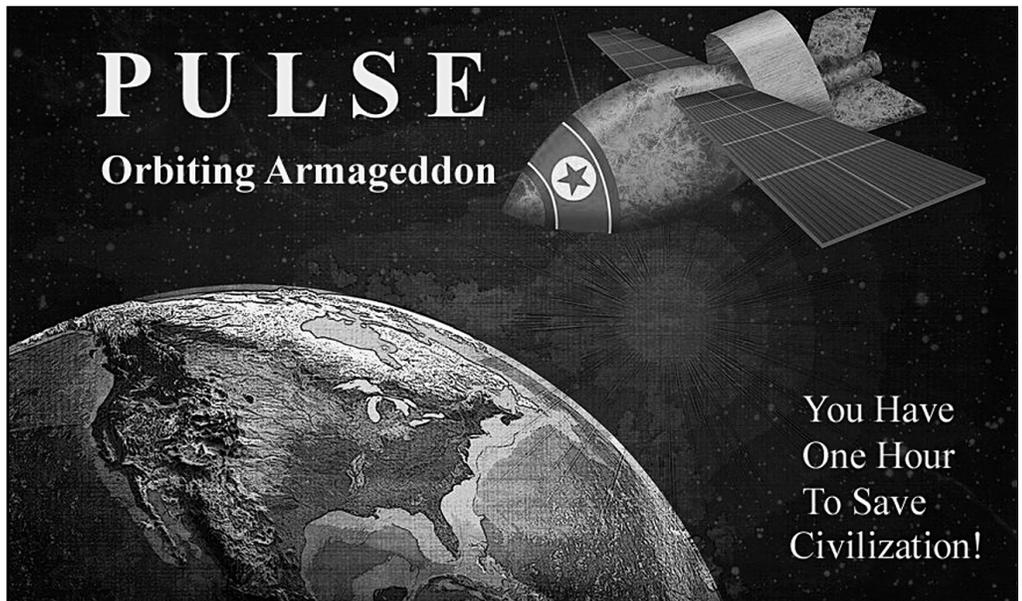


He then describes the seven stages of a man's life spanning from infancy to demise. Haunted Halls of Horror's infancy was, coincidentally, seven years ago, and similarly progressed through seven seasons from entrance to exit.

Unlike Macbeth's lament that life is a "walking shadow, a poor player that struts and frets his hour upon the stage and then is heard no more. It is a tale told by an idiot, full of sound and fury, signifying nothing," HHH's volunteer players have performed for their hour and have had untold significance. Aside from entertaining over ten thousand visitors through the years, they, along with our generous sponsors, have helped to raise many thousands of dollars to benefit people in our community. We thank you all for making this fundraiser mega-successful.

Our patrons should not "Trouble deaf heaven with your bootless cries and look upon yourselves and curse your fate" (Sonnet 29). "But soft! What light through yonder window breaks? It is the east and 'Xscapes' is the sun" (*Romeo & Juliet*—sort of).

There's light on the horizon. Our first escape room, "Valley of the Kings," continues to do well, and following our Halloween clean-up, we will continue to build our second, the eagerly awaited "PULSE."



Coming Soon: PULSE

The FBI has detained a former civilian consultant at a USAF research lab for involvement in the alleged plot to activate an electromagnetic pulse device. Your team from the Department of Homeland Security EMP Task Force has been dis-

patched to gather evidence related to this conspiracy. An EMP would cripple the US electrical grid and disable all electronic devices, leading to chaos and societal collapse. Agents should proceed with extreme caution.

ASAC Committee

by Sue Hoyt

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

ASAC would like to recognize the following businesses and officials for their efforts in making their community more accessible for all people. Thank You!

Twin River Commons, Jeff Transvaag, Manager, 45 Washington St, Binghamton

For the extra modifications made to a student's room in their building to make it accessible for that student.

Ray Standish, City Engineer, City of Binghamton

For his efforts in getting damaged curb cuts repaired and putting in new curb cuts where needed. We look forward to seeing more improvements in the city as you continue to work to make Binghamton more accessible!

The NY State Fair

ASAC would like to recognize the NY State Fair. They have been working on many updates to the fairgrounds, making it more accessible for all people, including new ramps and wider aisles for many of the buildings, and as always, there were ASL interpreters provided for the concerts (all 24 of them). We look forward to seeing more new accessible changes at the 2017 Fair!

STIC Trees at Roberson

Home for the Holidays is Roberson Museum and Science Center's largest annual event and busiest time of year, featuring hundreds of elaborately decorated trees, dazzling holiday displays, and the International Forest, a collection of adorned trees and displays that represent the holiday traditions of cultures from around the world. The excitement and magic of Home for the Holidays has made it a community favorite for over 60 years.

Once again, this year STIC has provided two trees to the exhibit. STIC's agency tree is in Mr. Roberson's study. The tree for our Xscapes fundraiser is also shown here.

Home for the Holidays Hours of Operation

Saturday – Wednesday:

Galleries are open from 11 am – 5 pm;

Gift Shop 9 am - 5 pm

Thursday and Friday:

Galleries are open from 11 am – 9 pm;

Gift Shop 9 am – 9 pm

Closed after 3 pm on Christmas Eve;
Closed Christmas Day, New Year's Eve,
and New Year's Day



Xscapes Valley of the Kings

Your archaeological team's quest is to attempt to unlock the secrets of Pharaoh's tomb. Other teams have attempted and vanished during their search. The ancient Egyptians were known for their mystical ways, opulence, and power. Upon the death of a pharaoh, the

corpse was enclosed inside a sarcophagus with provisions for the afterlife. Work together with your team to find the tomb and escape the Valley of the Kings.

Bookings Available
Thursday, Friday, Saturday
5 pm 6:30 pm 8:00 pm
www.xscapes-stic.com

Glossary of Abbreviations

We try to define every abbreviation the first time it appears in every article. Sometimes there isn't space to do that, so here's a list of some of the most common ones.

ACA – Affordable Care Act, also known as “Obamacare”

ACCES-VR - NY State Adult Career and Continuing Education Services – Vocational Rehabilitation; formerly “VESID”

ADA – Americans with Disabilities Act, federal civil rights legislation

ADAPT – A national grass-roots disability rights organization with many local chapters, including one in our region

BHO – Behavioral Health Organization; a form of Medicaid managed care for people with mental health disabilities

CDPA – Consumer Directed Personal Assistance program; “self-directed” personal attendant services where the consumer hires, trains, schedules, supervises and fires his/her attendants, with paperwork and billing help from an agency; available in NY under ordinary and managed-care Medicaid, and some OFA programs

CIL – Center for Independent Living; a not-for-profit local consumer-controlled cross-disability service and advocacy agency like STIC

CMS – Centers for Medicare and Medicaid Services; the federal agency that oversees those programs

DC – Developmental Center; one type of large institution for people with developmental disabilities

DD – Developmental disability

DISCO – Developmental Disabilities Individual Support and Care Coordination Organization; OPWDD's proposed new managed care organization

DOCCS - NY State Department of Corrections and Community Services, which administers state prisons

DOH – NY State Department of Health

FIDA – Fully Integrated Duals Advantage program; a federal managed care demonstration grant program to offer a broad array of HCBS services to people who have both Medicaid and Medicare

FPL – Federal Poverty Level; an amount of income, adjusted for family size, below which people are considered to be impoverished

HCBS – Home and Community-Based Services, a category of Medicaid-funded services for people with disabilities defined by CMS, intended to support people in settings other than nursing facilities, DCs, ICFs, and psychiatric hospitals

ICF – Intermediate Care Facility (sometimes called “ICF/ID” or “ICF/DD”); a segregated congregate residential setting of any size for people with developmental disabilities which meets certain CMS regulations to provide intensive medically-oriented supports and services; all DCs are ICFs, but not all ICFs are DCs

ID – Intellectual disability, a type of developmental disability, formerly known as “mental retardation”, or “MR”

IDEA – Individuals with Disabilities Education Act; a federal law that requires school authorities to provide public-school-age children with disabilities a free, appropriate public education in the least restrictive environment

IEP – Individual Education Plan; a plan to ensure that a child with disabilities gets a free, appropriate public education, as required by IDEA

IRA – Individual Residential Alternative, a residential program for New Yorkers with developmental disabilities; it can range in size from one resident to 12 or more and can be provided in any type of residence; it is supposed to be designed and staffed to meet the specific needs of the individuals who live in it; almost all IRAs are group “homes” with 6 or more beds and owned and operated by OPWDD or not-for-profit agencies

MFP – Money Follows the Person; a federal systems change grant program that gives

NY extra Medicaid money to promote getting people out of nursing facilities

MISCC – Most Integrated Setting Coordinating Council; a committee of NY State agency heads and interested others charged in 2002 with creating an “Olmstead Plan” for the state, it now apparently only exists to allow disability activists to mau-mau the flack-catchers (see the Tom Wolfe essay, “Mau-Mauing the Flack Catchers”)

MLTC – Managed Medicaid Long-Term Care; a form of mandatory managed care for people with significant permanent disabilities; already in use in New York City and slowly being expanded to the rest of the state

MMC – “Mainstream” Medicaid Managed Care; currently available to and required for all nondisabled and many disabled New Yorkers

MRT – Medicaid Redesign Team; a group established by the Cuomo Administration to devise its Medicaid “reform” plan

NHTD Waiver – Nursing Home Transition and Diversion waiver program; a federal HCBS Medicaid waiver intended to enable people with physical or cognitive disabilities not served by other waivers to leave, or avoid entering, nursing facilities

OASAS – NY State Office of Alcoholism and Substance Abuse Services

OFA – NY State Office for Aging

OMH – NY State Office of Mental Health

OPWDD – NY State Office of People with Developmental Disabilities

SHU – Special Housing Unit; a name given to “solitary confinement” cells in prisons

SSI - Supplemental Security Income; a federal stipend for people with certain disabilities who have never been employed or are very under-employed

STIC – Southern Tier Independence Center; hey, that's us!

TBI – Traumatic Brain Injury

SELF HELP

Medicaid Transportation Tips

by Sue Ruff

On October 26, 2016, people from across the Southern Tier came together for a conference, "Getting There: Bridging the Transportation and Healthcare Gap." The goal of the conference was to bring stakeholders together from across the Southern Tier to examine the challenges faced by our communities in a time of transportation losses and increasing barriers. The Rural Health Network and many partners worked very hard to put this conference together.

County public transportation (especially in rural areas) had, in the years before managed care, received Medicaid payments to assist people with getting to their doctors, therapists, and hospitals. In an attempt to "save Medicaid costs" (especially downstate), a few years ago the NYS Department of Health contracted with a company in Syracuse, Medical Answering Services (MAS), to handle the medical transportation arrangements for eligible individuals. This change had very serious ramifications for counties, however.

In Tioga County, fixed route and dial-a-ride services began in 1991. This county had developed transit rides not only within the county, but also to neighboring counties for workers, college students, and people needing medical services that were not available in Tioga County. Around the time that MAS took over the duties of Medicaid transportation a few years ago, Tioga County had been assisting over a thousand Medicaid recipients a month with rides to their medical providers. The county lost over \$400,000 in revenue when the Medicaid transportation was shifted to MAS. In November 2014, the county ended public transportation, as they could not operate with such a large deficit. As a result, taxi companies now handle most Medicaid rides to local doctors and clinics, as well as out-of-county appointments. Tioga, like other rural counties, has struggled to find alternative ways to assist their residents who are not Medicaid eligible, but need

help to get to appointments, as well as to jobs or school.

Broome County officials responsible for funding or operating the BC Transit system have cited the loss of Medicaid funds as one of the reasons for drastic cuts or changes to routes and service capacity in recent years. These changes have imposed severe hardships on people who do not use the system for Medicaid transportation, including many job losses because people can no longer get to their workplaces. Cortland and other small municipalities across the state have suffered similar drastic curtailment to public transit systems.

MAS, which handles Medicaid transportation for 55 upstate counties, presented a "how to" guide for conference participants. They average about 25,000 calls per day. Their staff determine if the caller is eligible, if the appointment is a medical appointment covered by Medicaid, and what level or mode of service is needed (bus pass, taxi, wheelchair, or stretcher van).

Within the mode of transportation, there is freedom of choice of vendors. 98% of people know which vendor they wish to use and the website lists vendors by county: www.medanswering.com/page.taf?. People with cars can get gas reimbursement. Riders can request a "compliance survey form" from MAS to share information with the company on specific vendors or trips.

People are asked to schedule their rides as far in advance as possible, in order to accommodate needs. One of the speakers said there is a one-hour window on either side of the requested pick-up time, so it is important for users to plan accordingly. Some people request standing orders because they have regular, scheduled appointments (e.g. dialysis, cancer treatment, etc.); the standing order process takes fifteen days to arrange initially.

Sometimes, service outside your area is denied due to a Medicaid policy that claims if a service can be found in the patient's local area, that is where the patient must go. It is important for your doctor to fill out

the request for transportation outside the common medical marketing area, if your primary care physician wants you to see a specialist in another area of the state or outside the state.

The company representatives said that the majority of rides go smoothly. They did share their contact and call list and we are printing it here:

To schedule, cancel or inquire about services: (855) 852-3294 or www.medanswering.com.

Transportation vendors and on-line trip ordering require login username and password, which can be accessed through Terri Pulaski, Tpulaski@medanswering.com or (315) 299-2799. She handles bus passes, mileage reimbursement, and trip processing.

Medicaid Field Liaison for our area is Leslie Regan, lregan@medanswering.com or (315) 412-1340. If you have a problem, call Leslie first.

Day-to-day management and oversight of requests for transportation, vendor relations, and medical provider relations is handled by Notchaca Cosby, ncosby@medanswering.com or (315) 299-2792.

Jennifer De Lucia is the Chief Compliance Officer and Director of Quality Assurance. She oversees complaints as well as the staff who process ability forms (the form that defines what kind of ride you will get—bus, taxi, wheelchair van, etc.) and the out-of-county requests. She can be reached at Jdelucia@medanswering.com or (315) 299-2754.

The President of the company is Russ Maxwell, (Rmaxwell@medanswering.com or (716) 983-3726) and the Chief Operating Officer is Wayne Freeman, (wfreeman@medanswering.com or (315) 701-7009). We are including their contact information in case you have issues that have not been resolved by other staff listed above.

Transportation continues to be a very real challenge for people with disabilities. STIC invites people to join the Transportation Advocacy Group, which meets the first Thurs-

day of each month from 3-4 pm at STIC: www.facebook.com/TransportationAdvocacyGroup/

Open Doors

by Dacia Legge

The Open Doors program is here to assist individuals by supporting their wishes to return to their community with the supports they want, after staying in nursing homes or rehabilitation or developmental centers. Often people have to battle a medical-model mentality and other attitudinal barriers that suggest most people leaving a facility need 24/7 services or supervision. However, this mindset ignores the fact that people have rights to self-determination, dignity of risk, and to be in the least restrictive setting they choose. Open Doors staff will advocate alongside you or your loved one, to provide a voice for what individuals want for supports, and how they want to live their lives.

Each edition of *AccessAbility* will feature individuals' stories on how they returned to the community, what services they used, if any, and what barriers were encountered.

Kevin Wahl—3 years in the hospital and Bridgewater Center for Nursing and Rehabilitation—moved back to his home in Delaware County.

Kevin is a 49-year-old man who has managed his whole life with spina bifida. As he aged and his skin integrity declined, he became more prone to bedsores (also known as pressure sores). The severity of these sores landed Kevin in the hospital, and just shy of three years later, he was *still* in an institutional setting (Bridgewater), where many medical staff thought he was better off living.

Luckily, over the years, Kevin had been using his SSI funds to continue to pay his rent, so he could maintain his accessible cottage in the village of Hancock in Delaware County, always believing he would one day be able to return home. Somehow, the nursing facility never took control of his SSI income. If that had occurred, Kevin would have been left with \$50/month for his use, and he would never have been able to maintain his cottage in the community he calls home.

Open Doors started working with Kevin in May of 2014 under the former Money

Follows the Person Program (MFP). Delaware County refused to consider even evaluating Kevin for services, as they felt his needs were too great to be in the community, especially in the rural community of Hancock. Kevin and MFP brainstormed and explored other options. Kevin at one point even considered living in Binghamton, where he was told there was a higher potential of finding service providers and accessible housing. Once again, he was denied, this time by Broome County CASA, which issued him a denial letter stating his needs exceeded community supports. His case was closed in June of 2014 and Kevin just gave up, discouraged.

Kevin reached out to our new program, Open Doors, in June 2016 and was excited to share that he now has a fiancée who is willing to be his live-in caretaker. Kevin and his fiancée were excited to hear about the possibilities of returning to Delaware County where he continued to pay for his cottage, even though he had not lived there for 3 years.

Because Kevin had both Medicare *and* Medicaid, one of the Managed Long-Term Care (MLTC) insurance companies had to pick up his case and provide community-based services and supports, and Kevin chose to go forward with Visiting Nurse Association (VNA; not to be confused with VNS Choice, an MLTC serving downstate counties). MLTCs have a live-in caregiver rate, and his fiancée met the criteria to be paid for some of the care she provides Kevin.

But things did not go smoothly with VNA, either. Before Kevin left the facility, he had arranged a new patient visit and met a new community primary care physician in Hancock, Dr. Berg, who is part of the Lourdes Primary Care team. He thought things went well. Kevin would be able to navigate independently to the office in his power chair, as it was right down the street, and things seemed to be okay, until Dr. Berg informed Kevin that someone from “his insurance company” called him and told him that Kevin should never have been released from the nursing home and that he is not safe in the community. Kevin was not told by Dr. Berg the name of that individual, but Dr. Berg would no longer work with Kevin and stated he did not feel he could provide primary care for him.

Now Kevin has to be transported, by Medicaid, to Vestal for his appointments, instead

of being able to use his community provider, whom he chose and where he could attend appointments independently. Now Medicaid has a large, unnecessary transportation expense to transport Kevin over an hour, each direction, to a provider he did not choose. Most importantly, Kevin now has to spend 2 1/2 hours just in transportation time to see his new primary care physician. This is the type of continual sabotage and attitudinal barriers that individuals experience from medical providers when trying to move back into their community with appropriate supports.

His fiancée, who should be paid as his live-in help, *still* has not received pay and there is *still NO* other staff set up to work with Kevin. Kevin has been with VNA effective 9/1/16, but his live-in provider is working 24 hours 7 days a week for free, with no additional help. Open Doors has filed three separate reports with the NYS Department of Health, and this has helped move some things along, but not the huge issue of staffing or pay.

However, Kevin is so happy and thankful to be back in his community, and wants to do what he can to advocate for others in the same situation.

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

Dacia Legge, LMSW

Open Doors Regional Lead Coordinator
Southern Tier Independence Center
dacial@stic-cil.org

(607) 724-2111 x329 (phone)

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

Resources for Students with Behavioral Needs

Our conference, “Creating Supports for Students with Mental Health and Behavioral Concerns,” held on October 28, was well attended and well received.

Some folks asked for “magic bullets” for addressing the needs of children whose levels of anxiety are so high that they affect their ability to learn and participate in school. The question is facetious, of course, but we do understand that many school professionals have to deal with situations for which they are not well prepared.



The problems and solutions are as many and varied as the individual children who have them. One size does not fit all. But there is a real “magic bullet” that will help in most cases: Collaboration.

Success does not come from dumping problems in the lap of one professional and expecting him or her to solve them. Success comes when everyone who interacts with a child comes together to share information, especially about what situations can trigger behavioral issues and what works to reduce them. Everyone means everyone, especially family members and aides who spend a lot of time with the children. We know that family members are sometimes uncooperative, and there may not be much that can be done about that. But that’s not an excuse for excluding aides from meetings in which behavior plans are developed. All of the people who are paid to work with the child have to participate in that process, and everyone needs to fully understand the plan and how to follow it. Please, don’t be uncooperative about clearing aides’ schedules so they can participate in planning and get additional training.

A related question concerns how to help children who have not been formally “classified” as having disabilities, and who therefore do not have a lot of extra resources directed toward them.

A child who has ongoing significant issues with anxiety is nearly always “classifiable,” and although people are reluctant to have children “labeled,” in these cases the benefits almost always outweigh the downside. But schools are already required to provide an environment that promotes positive behavior, and addresses individual needs, for all students, not just those who are classified as needing special education services. Nothing is stopping schools from adopting collaborative approaches to supporting any child who has significant issues with anxiety, whether she is “classified” or not. Just do it.

We provided a lot of informational resources to conference attendees. Here they are:

Behavior Assessment, Plans, and Positive Supports explains the use of behavior as communication, challenging behavior, Functional Behavioral Assessments (FBA), Behavior Intervention Plans (BIP), and Positive Behavior Supports. This is a parent-friendly web page that answers many questions a parent may have. www.parentcenterhub.org/repository/behavassess/#assess

Behavior Doctor webpage, created by Dr. Laura Riffel. Behavior Doctor seminars provide training and educational materials to help professionals, educators, and family members communicate more effectively with people of differing ability levels.

www.behaviordocor.org

The Center on the Social and Emotional Foundations for Early Learning (CSEFEL) is focused on promoting social and emotional development and school readiness of young children birth to age 5.

www.csefel.vanderbilt.edu

Early Childhood Direction Center (ECDC) assists families and professionals working with children ages birth - 5 who have disabilities.

www.ecdc-stic.com

The New York State Education Department (NYSED) provides information to

parents and professionals to create an educational system that yields the most highly educated people in the world.

www.nysed.gov

NYSED Special Education News and Notes provides the latest updates to NYS Special Education policies.

www.p12.nysed.gov/specialed/publications/2016-memos/news-and-notes.html

PACER Center enhances quality of life and expands opportunities for children, youth, and young adults with all disabilities and their families so each person can reach his or her highest potential. PACER operates on the principles of parents helping parents, supporting families, promoting a safe environment for all children, and working in collaboration with others.

www.pacer.org

Parent Technical Assistance Center (PTAC) assists families of children ages 3 - 21, with disabilities, in navigating the special education world.

www.ptac-stic.com

Positive Behavioral Interventions and Supports (PBIS) website is established by the US Department of Education’s Office of Special Education Programs (OSEP) to define, develop, implement, and evaluate a multi-tiered approach to technical assistance that improves the capacity of states, districts, and schools to establish, scale-up, and sustain the PBIS framework. Emphasis is given to the impact of implementing PBIS on social, emotional, and academic outcomes for students with disabilities.

www.pbis.org/family

PBISWorld.com is a comprehensive and easy-to-use tier 1 through tier 3 PBIS (positive interventions and supports) tool and resource that includes data tracking.

www.pbisworld.com

Regional Special Education Technical Assistance & Support Center provides direct technical assistance and professional development to improve instructional practices and outcomes for students with disabilities.

www.p12.nysed.gov/specialed/techassist/rsetasc/home.html

Southern Tier Independence Center (STIC) offers many services and programs to assist families and individuals with disabilities.

www.stic-cil.org

What to Do (and Not Do) When Children are Anxious: This article provides tips and techniques to use with children who are anxious.

<http://childmind.org/article/what-to-do-and-not-do-when-children-are-anxious/>

New Nursing Home Regulations

To be clear: STIC's position is that nobody "needs," in the medical sense, to live permanently in a nursing facility. Some of the better facilities that offer high-quality short-term post-acute rehabilitation services have their uses, though. And, sadly, the ongoing failure of various homecare-type programs, including Medicaid waivers, to ensure adequate coverage and especially backup when attendants don't show up, does make the facilities necessary for some people who do not have friends or family members who are able to help them. This problem can't be fixed by adding more kinds of homecare programs. It can only be fixed by raising the rates paid to homecare providers, and requiring those providers to pass through those raises to the workers, so we can recruit and retain more people to do this essential work.

So better quality control in nursing facilities is an important concern of ours. The federal Centers for Medicare and Medicaid Services (CMS) recently finished a big project to modernize regulations for nursing facilities. Much of what they did was to make the regulations easier to understand. For example, person-centered planning has been required for a while, but the new regulations bring all the rules together in one place and make them easier to follow.

The person centered planning regulations do include a requirement to review service plans quarterly, and these service plans must address whether the person would like to leave the facility and move back into the community.

Probably the most important change is that nursing facilities can no longer make residents sign contracts that require them to accept binding arbitration as a condition of admission. Nursing facilities frequently use these contracts to prevent residents from filing lawsuits in cases of abuse or neglect. The new rules only allow binding arbitration if a resident voluntarily agrees to it after something happens that triggers a complaint.

CMS has beefed up its enforcement policies; it now requires monetary penalties for more kinds of problems. However, it is up to state governments to actually monitor nursing facilities and impose those penalties. Many states have poor track records on this, including New York. Unfortunately, CMS does not seem to have done anything to increase its own activities to monitor states.

There are new provisions regarding personal hygiene and toileting. Most nursing facilities—at least, for Medicaid recipients—neglect residents' personal hygiene and don't provide enough assistance with toileting. It is very common for residents to go a week or longer between showers or shaves. And the facilities rarely have enough staff to help people who can't walk on their own get to a toilet, so people are forced to wear diapers even though they are not medically "incontinent."

The explanatory text for the regulations says that CMS expects that nursing facilities will make all practicable efforts to prevent people from becoming incontinent, and that includes providing assistance to use the toilet.

The actual regulations themselves contain a new definition of "neglect": "the failure of the facility, its employees or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish or emotional distress." And there are reporting requirements for any allegation of "neglect." Failing to comply with a person's hygiene maintenance requirements could certainly cause "emotional distress" and would likely be actionable neglect, if anyone reports it.

We urge people who live in nursing facilities and their friends and families to take these changes seriously. Anyone who lives in a nursing facility should be asked whether they want to leave, and be told how they can

get help to do so if they wish, every three months. If they aren't asked, complain. Nobody in a nursing facility who can use a toilet, and can ask for help to get to one, should have to wear a soiled diaper. If that's happening, file a charge of neglect. Nobody in a nursing facility should have to go longer without a shower, a shave, hair washing, or any other personal hygiene service longer than they would if they were at home. If they do, file a charge of neglect.

And if the New York State Department of Health doesn't follow up on complaints and get changes made promptly, file a complaint with CMS.

COMMUNITY PROGRAMS

Alternative Format Documents Now Available to Residents of New York State

As a result of a legal settlement, New York State has announced a new program that will mail official government documents in alternate formats to people with disabilities. Available formats include braille, audio disc, "data disc" (an electronic document purported to be accessible to screen readers—if the people who created it know what they're doing, which is not guaranteed; see *AccessAbility* Fall 2016), and large print.

The accessible documents are provided in addition to the standard print mailings, so that family members and caregivers can read along or provide additional assistance as needed.

You can request the alternate formats on the website, or through your "caseworker" if you have one. You can also contact the project by email or phone:

www.accessibilitycompliance.org
info@accessibilitycompliance.org
(888) 771-5331



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