

AccessAbility

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by Maria Dibble

It is once again close to that time when Americans get to choose those public officials who will represent them. Yet Americans generally don't turn out in very large numbers to exercise this most precious of rights, especially in a mid-term election.

I've heard so many say, "Why should I vote? Politicians are all the same and it's a waste of my time." Except, they aren't all the same.

As people with disabilities we should really get that message. Some Congressional representatives support many of our issues, such as the Americans with Disabilities Act (ADA); equal employment; Medicaid and other forms of affordable health insurance; ending payment of sub-minimum wage to people with disabilities; and full integration into our communities.

But there are many others who think the ADA shouldn't be enforced, or should be weakened because it's a burden on employers; that we belong in sheltered workshops or other institutions; that Medicaid is too expensive and we should cut it (no matter how many people are harmed), and more.

None of these positions would represent the interests of people with disabilities.

Meaning you, or your family members or friends. You should make your statement to your representatives that says loud and clear what you want and believe.

Our rights are endangered. The Supreme Court is changing, and with those changes could go many of the rights we've taken for granted for decades. The people we elect matter, because they hold the power in their hands to decide which judges sit on the highest court, judges who will decide whether federal agencies will respect and enforce civil rights laws or ignore them (see page 3). The people we elect have the power to save or destroy the Medicaid program's guarantee of adequate medical services. They can pass federal budgets that take food out of the mouths of poor people and deny them affordable housing, or that ensure that the nation's poorest and most vulnerable citizens are not targeted for neglect.

One vote per person is a right guaranteed by our constitution, and no one can take that away from you, though there are some

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who might try. No matter where you live, even if you are in a nursing home, you still have the right to vote. Absentee ballots are available to allow those who can't get to the polls to vote, and they are counted!

History teaches us about the fights for women and African-Americans to get the vote. Many died for that right. In some states today there are laws that seek to disenfranchise many of those who are poor. What are the officials who pass such laws afraid of?

They are afraid of people different from themselves, people of color or those with disabilities, people who, unlike them, do not always have secure or comfortable lives, or who are not automatically treated with respect by the authorities. They hope to deny them the opportunity to cast

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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.

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Continued from the cover . . .

their ballots, or at least make it tougher to do so.

Those officials need to hear from us. We *can* vote, we *will* vote, and no one, *but no one*, will stop us.

Don't miss this precious opportunity to speak out about what has been happening in recent years. If you aren't registered to vote, we can help. If you need assistance to apply for an absentee ballot, we can help. We are nonpartisan. We will not try to influence which party you choose or for whom you vote. It is totally your choice.

Take the power away from the politicians and into your own hands!

PLEASE. Vote even if the weather is bad, even if you have to use your own time off, even if you have to spend hours on the bus to get to the polling place. Also, in these often discouraging times, please remember that the perfect is the enemy of the good. There may never be a perfect candidate for office. But in nearly every race it should be possible to see that one candidate comes closer to representing your views and respecting your needs than the others do.

In our lifetimes, there has never been a more important opportunity for you to make a difference than you will have on November 6, 2018. Please go and make that difference.



BAD WEATHER?

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

courts watch

NFB, et al, v DeVos: Heavens to Betsy!

Betsy DeVos, Trump's Secretary of the federal Department of Education, seems to have embarked on a process to dismantle that agency's investigation and enforcement system for civil rights complaints. She has issued a new "Case Processing Manual" for the department's Office of Civil Rights (OCR) that requires the agency to dismiss complaints of discrimination if they are part of a "pattern" of multiple complaints, or if they come from people or organizations that have previously filed complaints.

In 2009, the National Federation of the Blind (NFB) filed several complaints with the OCR alleging that colleges and universities were providing a type of electronic document reader to students, Amazon's Kindle, that was not accessible to people with visual disabilities. Screen-reader software for computerized devices is a technology that is almost as old as personal computers, and it is available in Kindle. The problem is that Amazon permitted publishers to turn the feature off for specific books, allegedly in order to protect those publishers' revenues that come from commercially available audio versions. Anyone who has used screen reading software will tell you that it's not a particularly enjoyable way to listen to a book, and virtually no sighted person who likes audio books would rather use screen-reading software than hear a voice actor read them. So allowing the Kindle to read the books aloud to blind users was not in fact a significant threat to audio book revenue.

As a result of NFB's complaints, the department sent guidance to thousands of colleges and universities, as well as public schools, clarifying that distributing inaccessible document readers, including Kindles with those restrictions on screen reader software, was illegally discriminatory. If DeVos's changes had been in effect at that time, OCR would have been required to dismiss all of NFB's complaints without investigating them.

Along with NFB, the plaintiffs include the NAACP, and the Council of Parent Attorneys and Advocates. Lest you assume that this only affects lawyers, the new manual would also prohibit the parent of a child with a disability from submitting more than one complaint on behalf of that child. And the new manual removes the right of complainants to appeal a decision that goes against them.

Spokespersons for the Department of Education have claimed that this is intended to improve "efficiency" and conserve limited resources. What it actually seems to be is an effort to summarily dismiss without investigation those complaints that are filed by experienced advocates—i.e., those that are most likely to be upheld. This would essentially eliminate one of the more effective methods by which people can get the federal government to enforce its own civil rights laws, at least in the area of education.

The plaintiffs filed suit in federal district court in Maryland, alleging violations of the federal Administrative Procedure Act (APA). That law requires federal agencies to provide a sound, evidence-based rationale for proposed changes to their rules, and also to publish those changes and request public comment before finalizing them. DeVos's Education Department did neither. In that way, DeVos's actions are similar to those of Seema Verma, Trump's Administrator of the Centers for Medicare and Medicaid Services (CMS), who announced that she would approve Medicaid waivers that included work requirements for Medicaid recipients without providing a valid rationale. Both are examples of the fundamental lawlessness, aimed at people with disabilities and poor people, that has pervaded the federal Executive branch over the past two years. Verma's action was overturned in court (see below), and DeVos's most likely will be too. This fall the voters have an opportunity to overturn this entire pattern of behavior.

Stewart v Azar:

Medicaid – 1, Trump - 0

As we reported last time, several Medicaid recipients sued the federal Department of Health and Human Services (HHS) for approving Kentucky's proposed Medicaid waiver that imposed work requirements on childless adult recipients of Medicaid, the so-called ObamaCare "expansion population". Last time, we erroneously reported that the case was at the federal appeals level. In fact, the suit was filed in federal district court in Washington DC, and the effort to move it to a KY district was denied due to the national implications of the case. On June 29, Judge James Boasberg of the federal district court for the District of Columbia granted summary judgement in favor of those Medicaid recipients, and sent the waiver back to HHS to re-do its review in light of his findings.

We reported that the plaintiffs had very strong arguments for why HHS Secretary Azar did not have authority to waive the provisions of Medicaid that he did. However, Boasberg did not consider most of those arguments. Instead, he pointed out that Azar simply violated the federal Administrative Procedure Act's basic requirement that he consider all of the "important aspects" of how a proposed waiver would affect the state's Medicaid program before granting approval. Azar, the judge said, did not consider what would happen to the



approximately 94,000 people who would be cut off Medicaid by the waiver.

However, on his way to that conclusion Boasberg did spend some time discussing whether the proposed waiver was “likely to assist in promoting Medicaid’s objectives,” a requirement for any waiver of federal Medicaid requirements. While Azar conceded that those objectives included paying for medical and rehabilitation services, he tried to argue that the Affordable Care Act (ACA, or “ObamaCare”) expansion violated the “traditional purposes” of Medicaid, which were to fund health care for “the disabled, the blind, the elderly, and needy families with dependent children.” As the judge pointed out, ObamaCare *changed the law* and its stated purposes to include paying for services for any adult whose income is under 133% of the federal poverty line. What the law used to say is irrelevant; it doesn’t say that anymore, and Azar cannot pretend that it does.

Wonkiness Alert: It’s a bit more complicated than that, of course. The ACA actually added the “expansion population” as an option for states (and actually, it was a US Supreme Court decision that changed the expansion from mandatory, as given in the ACA as passed in 2010, to optional). What the law does not do is allow states that take that option to pick and choose which specific members of that population it will serve. Kentucky, which has a very high poverty rate, chose to serve that group in its Medicaid program. That decision was very popular. However, the current KY governor, who is an ACA opponent, tried to “thread the needle” by submitting a waiver proposal that would effectively cut a huge proportion of that population off of Medicaid without taking the politically risky step of reversing the decision to serve them. The governor threatened that he would take that step if the courts blocked the waiver. As the judge pointed out, whether he would actually be able to do that by himself is not a settled issue.

This case illustrates how that argument can be turned against us.

Boasberg further indulged himself by suggesting that perhaps Azar could have concluded that the cost-cutting effects of the waiver might have been necessary to enable the state to pay for another waiver that created a new program to treat people with substance use disorders. That’s kind of scary because it seems possible that cutting benefits to one group in order to prioritize benefits for another group might actually be allowable. But the judge seemed to want to telegraph that such an argument, if attempted when Azar reconsiders the proposal, would not succeed. He cited a Ninth Circuit decision stating that a “simple benefits cut, which might save money, but has no research or experimental goal, would not satisfy” the requirements to grant a waiver. He also pointed out that Kentucky has provided no evidence that its Medicaid finances are in disarray. He did suggest that it might not be “rational” for the

state to cut the program that receives the highest federal percentage of matching funds of all of the state’s various Medicaid programs (the ObamaCare “expansion” is currently funded with 94% federal dollars in KY, to be reduced to 90% in 2020), even if saving money was really the issue.

Boasberg touched on another important point in his rather playful discussion of things that, while not relevant to the facts on which he based his decision, might come up in future litigation over the KY program. One of the stated purposes of Kentucky’s waiver was to decrease dependency on government programs and therefore improve “health outcomes.” Azar cited research on the “social determinants of health” to show that people who have jobs and are more self-reliant are likely to be healthier. The judge first claimed that a waiver for the purpose of “improving health outcomes” is not actually responsive to the purpose of the Medicaid program, which is to pay for health care and rehabilitative services. Then he quickly demolished Azar’s argument: “The text [of the Medicaid law], however,

quite clearly limits its objectives to helping States furnish rehabilitation and other services that might promote self-care and independence. It does not follow that limiting access to medical assistance would further the same end.”

On this point the judge may have stumbled. Earlier, he pointed out that the “traditional” purposes of the Medicaid law are irrelevant now that the ACA has changed them. But he seems to have missed the point that the ACA also introduced the concept of “value-based payment” (VBP) to Medicaid, an idea that is specifically intended to use Medicaid funds to improve health outcomes. The VBP provisions may have altered the objectives of the Medicaid program as fundamentally as the eligibility expansion did.

Azar could have appealed this ruling. Instead, in late July HHS announced that it would comply with the judge’s order to reconsider Kentucky’s application, complete with another public comment period. Kentucky officials seemed optimistic, and the governor’s threat to drop the expansion population entirely would appear to be on hold. If Azar again approves the application, we have no doubt that the plaintiffs will file suit again in judge Boasberg’s court.

Some disability rights and Medicaid advocates have, like Azar, embraced the “social determinants of health” argument to promote their beliefs. After all, they say, providing better long-term care supports as well as medical services will lead to longer, healthier lives and “bend the cost curve” for Medicaid.

This case illustrates how that argument can be turned against us: If we believe that having a job helps people to be healthier, then that can be used to justify requiring people to have jobs in order to get health care, as it was in the KY waiver. That’s a stark example of what lies at the bottom of the slippery slope whose top is adorned with pronouncements that people who smoke or eat too much should have to pay more for health insurance. (About halfway down that slope would be, as Boasberg suggested, waivers that condition receipt of healthcare on eating more broccoli or enrolling in pilates classes.)

Although the Founders did not see a purpose for government beyond ensuring “life, liberty and the pursuit of happiness” in 1776, in those days a doctor was more likely to kill you than help you. Today just about everyone would concede that you can neither have life nor pursue much happiness without adequate healthcare. Of all of the candidates for so-called “new rights” out there, a right to health care is obviously one of the most appropriate.

Civil rights must not be conditioned on people’s behavior. People—all people, not just people with disabilities, not just the “deserving poor,” but also people who choose to take risks and “live on the edge”—should have access to healthcare, without being required to comply with anyone else’s value judgements in order to get it. Disability rights and Medicaid advocates should be promoting that position.

Sudders v Rotenberg: Now Current in Family Court

In June, a Bristol County, Massachusetts family court judge ruled that opponents of the Judge Rotenberg Center’s “aversive” shock punishment program “failed to demonstrate that there is now a professional consensus that the Level III aversive treatment used at JRC does not conform to the accepted standard of care for treating individuals with intellectual and developmental disabilities.”

As we’ve reported previously (*Accessibility* Summer 2018), the notorious Judge Rotenberg Center in Massachusetts continues to use electric shocks to punish people with disabilities. As we understand it, at present the Center is only permitted to do that because of a court order that the parents of some residents obtained several years ago that both prohibits applying the practice to new residents while “grandfathering in” those who were being shocked at the time the order was issued.

Disability rights advocates have campaigned for many years to have the practice outlawed entirely. So have officials, both elected and appointed, in Massachusetts, though they have been stymied by a member of the MA Legislature whose son resides in the facility and receives the shocks.

The federal Food and Drug Administration (FDA) proposed, in 2016, to issue regulations banning the practice. The proposal received overwhelming support from thousands of people and organizations (including STIC) during the agency’s public comment period. Since then a Change.Org petition started by the Autistic Self Advocacy Network calling for the FDA to issue the ban has collected over 296,000 signatures (as of mid-August). The FDA has not yet finalized the regulation, nor has it moved it off its work docket the way some other federal agencies have done with proposed regulations to benefit people with disabilities under the Trump Administration. The delay was the subject of demonstrations by disability rights activists this past spring. In response, the agency said it is still considering what to do and plans to issue a decision eventually.

The family court case was filed by Massachusetts Health and Human Services Secretary Marylou Sudders in the summer of 2016. There was a 44-day evidentiary hearing, followed by two years of silence, before Judge Katherine Field ruled against her. We have not been able to see any court papers so we don’t know why the case was filed in family court in a different county from where the Center is located, what evidence Sudders submitted, or why the judge made the decision she made.

Any rational person reading the public comments supporting a ban that were submitted to the FDA by a very long list of highly experienced experts in services, including behavioral supports, for people with developmental, cognitive, and mental health disabilities, as well as the much smaller collection of comments submitted in favor of the practice by employees of the Rotenberg center and some of their followers who claim similar expertise, could not fail to see that there is, in fact, an overwhelming “professional consensus” that the practice is not acceptable.

In July Sudders’ office announced that she had asked the Massachusetts Attorney General to appeal the decision. We’ll let you know what happens.

A.T. v Harder: The Harder They Fall

In June, the parties in this suit against the Broome County Sheriff agreed to a final settlement.

The settlement terms are more generous to Sheriff Harder and the Broome County jail than the judge’s preliminary injunction, which we printed last time. For example, the settlement allows the jail to hold a juvenile in solitary for up to 24 hours, while the injunction prohibited disciplinary “keep lock” for longer than four hours.

The settlement allows keep-lock, or solitary confinement, if the juvenile poses an “imminent threat to the safety and security of the facility.” That was always the reason given on paper, and to anyone who asked, for any use of “the box” at the Broome County jail, even when the real reason had nothing to do with security and was only about enabling some overzealous guard to win a power struggle with a child.

However, the settlement also requires that “less restrictive measures” must be tried first. Those may include “crisis intervention, de-escalation, and mitigation.” Mitigation is a good one; it means that, for example, if a guard wants to lock up a teenager for “playing with snow” (an actual example), the guard can, instead, let the kid play with the dang snow. Of course, a guard who would claim that playing with snow is an imminent security threat is also quite capable of lying about whether he tried any less restrictive measures before locking the child up.

There is also a requirement for behavioral support plans, monitored by “mental health” clinicians, for juveniles with disabilities. Those would be clinicians hired by the jail’s medical contractor, which, as we reported last time, has been fined by New York State for its involvement in inmate deaths in five county jails, and which has been accused of failing to provide medical services and falsifying medical records at the Broome facility.



These terms are very easy to violate, and without constant, vigilant monitoring, no one would find out about it. But they are similar to what was agreed-upon with the Onondaga County (Syracuse) jail a couple of years ago. It's been reported that the Onondaga staff have exhibited good "buy-in" to the agreement. Based on what we know about the personalities involved at the Broome County jail, there is reason for concern about how much "buy-in" will happen there. Advocates will have to watch them very closely, and go back to the judge if they find any funny business.

CDPAANYS v Zucker: Anti-Status-Quo-Ante

As we predicted last time, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS), as well as some CDPA providers, sued the New York State Department of Health (DOH) and its commissioner, Howard Zucker, over DOH's requirement that all CDPA marketing materials must be approved in advance.

The case was filed in US District Court and on July 25 the judge issued a confusing order that allegedly preserves the "*status quo ante*." That's Latin for "whatever was happening before," and the term was used by the judge in an obviously mistaken way. There are some pretty heavy technical legal arguments involved, but we'll explain just enough to show how badly flawed the judge's thinking was.

CDPAANYS was seeking an injunction against a state law that required DOH to approve, in advance, any CDPA marketing materials. The law was enacted as part of the state budget that took effect on April first of this year. CDPAANYS sued DOH not much more than a month later. The law was technically in effect but there were no procedures in place to carry it out. The judge argued that if an injunction would alter the "*status quo*," CDPAANYS would be required to meet a higher standard to demonstrate that it would be likely to win the case if it went to trial. The judge acknowledged that in this context, "*status quo*" (which means what is already happening) really means "*status quo ante*"—that is, what was happening before something was changed. Then he

proceeded to define "*status quo ante*" to mean what was happening before the suit was filed, rather than before the law took effect. Of course, CDPAANYS wanted to change the fact that the law was in effect. But in such cases judges almost always understand that "*status quo ante*" means "before the law took effect." CDPAANYS didn't sue DOH to get an injunction blocking its own lawsuit; it sued to get an injunction blocking the law. The judge's interpretation of "*status quo ante*" is utterly ridiculous. It suggests that the rest of his reasoning was similarly muddled.

On the other hand, the primary motive behind all of this is DOH's famous, and oft-repeated, reluctance to get any action on the public record for which it can be held accountable. The law, as written, simply says DOH must approve any marketing materials within 30 days, and any CDPA provider who issues unapproved materials may lose its operating certification. DOH has a very poor history of meeting deadlines for approving written materials. As we've reported, this history would have completely hamstrung the TBI and NHTD waiver regional offices if they had waited for approval before acting. It was reasonable to expect something similar to happen with CDPA materials.

In verbal discussion at a meeting, DOH officials said that they "interpret" the law to mean that materials that don't get a response from DOH within 30 days may be published, but that the CDPA agency will be taking its chances if DOH subsequently finds that the materials were false or misleading. DOH also said it was planning to issue "guidance" that would include these points, and that it would not attempt to enforce the law until the guidance was issued, though it would not guarantee that it would not revoke certification from organizations that did not wait for the guidance before publishing anything. And DOH refused to put any of this in writing, even in the form of a memo summarizing the meeting.

Had DOH been willing to demonstrate good faith by putting its promises in writing, the CDPA providers may well have decided not to sue. Instead, the suit will proceed.

In court DOH will probably have to produce some evidence to support a claim by a DOH official that there have been examples of false advertising by CDPA providers. The agency may also have to prove that it has a compelling interest in regulating only CDPA providers in this way, and not providers of other health-related services for which the state also pays. That might be the most important point in the case. Legal history makes it pretty easy for governments to regulate advertising, but it can be harder for them to do so when it's done in a discriminatory way. We'll keep you informed.

Judge Kavanaugh: A Thoroughly Dangerous Man

Disability rights advocates have numerous concerns about Brett Kavanaugh, President Trump's nominee to fill the US Supreme Court seat vacated by Anthony Kennedy. Kavanaugh is currently a federal Circuit Court judge in the DC circuit.

Those concerns were summarized in a report from the Bazelon Center for Mental Health Law, a broadly respected and authoritative national disability rights organization. We present some of those concerns here, because we believe they are legitimate and very serious. (The report also paints other issues with too broad a brush, criticizing rulings that went badly for people with disabilities for reasons other than the fact that they were disabled, a kind of reasoning that too many overzealous advocates indulge in.)

We also have to report that the Senate has vowed to begin confirmation hearings in early September, before this newsletter will appear, and that there are probably already enough Senate votes, including some Democrats who are running for re-election in conservative states, to confirm him. If he is confirmed, it will be additional evidence that people need to put aside their squeamishness at election time and go to the polls and vote for the people who will do the least harm, instead of sitting at home and waiting for perfect candidates to appear. Had they done that in 2016, this nomination would never have been made.

Affordable Care Act

The most egregious of Kavanaugh's several statements on this law appeared in a dissenting opinion in *Seven-Sky v Holder*, in which he said that even if the Supreme Court found that the Affordable Care Act (ACA, or "ObamaCare") individual mandate to buy insurance was constitutional, the president could override that decision and refuse to enforce the mandate.

If Kavanaugh is able to say something like that in a majority opinion as a Supreme Court justice, it would essentially remove the vital check on presidential power that the Supreme Court provides, and would have far-reaching effects on all kinds of issues, not just the ACA.

Self Determination

Doe ex rel Tarlow v DC was a case involving "surrogate decision making" for people with intellectual disabilities. Although the local law required that surrogates must take into account the wishes and preferences of individuals who have been found legally incompetent to make medical decisions when making those decisions on their behalf, surrogates in the District of Columbia routinely did not consult individuals before approving any and all recommended *elective* surgical procedures for them, including unwanted abortions. A federal district court ruled that the surrogates were violating the law and issued a permanent injunction ordering them to consult with the individuals before making decisions.

The District of Columbia appealed to the DC Circuit and Kavanaugh overturned the injunction. He said that "accepting the wishes of patients who lack (and have always lacked) the mental capacity to make medical decisions does not make logical sense and would cause erroneous medical decisions—with harmful or even deadly consequences to intellectually disabled persons." Clearly he has never heard of supported decision-making, or of New York's Article 17A guardianship law, which can declare people with developmental disabilities incompetent without any presentation of evidence that they have any problem making decisions whatsoever. He may also be ignorant of the fact that some modern guardianship laws in the United States re-

quire guardians to consult with, and give weight to the wishes of, the people for whom they make decisions.

According to Bazelon, Kavanaugh also wrote "that no substantive due process claims were implicated because 'plaintiffs have not shown that consideration of the wishes of a never-competent patient is deeply rooted in this Nation's history and tradition and implicit in the concept of ordered liberty'" (some internal quotation marks removed).

This last bit is astonishing. What, exactly, does "deeply rooted in this Nation's history and tradition" mean? Does it mean that any new ideas about civil rights that arose in, say, the last 50 or 60 years are invalid because they aren't "deeply rooted" enough in our history? What does that say about the 1964 Civil Rights Act, the 1965 Voting Rights Act, and the 1968 Fair Housing Act? How long will the disability rights movement have to struggle and get laws passed in its favor before Judge Kavanaugh would stop overturning them for being only shallowly-rooted?

Agency Authority

Much has been made of Kavanaugh's antipathy to a long-standing legal tradition of courts deferring to "agency expertise" in cases involving the content and enforcement of regulations implementing federal laws. He certainly has ruled against this tradition in ways that would have weakened enforcement of environmental and consumer protection laws.

The problem is, this stuff goes both ways. For example, if that tradition did not exist, the federal Centers for Medicare and Medicaid Services (CMS) would long ago have been forced by federal courts to effectively enforce the provision of Medicaid law that requires states to ensure that Medicaid-funded health services are as readily available to those eligible for them as privately-funded services are to people who can afford them.

As we've said before, advocates for progressive policies need to stop relying on the courts to defend their beliefs, and do a better job of getting progressive politicians elected. And voters need to do a better job of showing up at the polls in each and every election, so they can vote for the best available candidate who will support their views.

Transparency Not Apparent

The ongoing criticism of the New York State Justice Center for the Protection of Individuals with Special Needs was in the news again earlier this summer.

The latest row started in April after it was reported that Christopher Blair, a 34-year-old autistic man, was found dead in his bedroom at the Valley Ridge Center for Intensive Treatment in Norwich. The facility is under the management of Broome Developmental Services. Blair called his mother to say he was having a hard time breathing and going to the bathroom. His

mother, Judy Merkly, says she immediately called the facility staff. He was found dead the next morning.

We have not been able to collect a lot of facts from objective sources. However, a few things are clear.

Valley Ridge is a "secure treatment" center and is only supposed to house people who ex-

hibit dangerously violent behavior or who have committed serious crimes. The man who died was not such a person and should never have been in the facility. Allegedly OPWDD didn't have anywhere else to send him when the developmental center he was living in closed, but that's unlikely to be true. It's possible that his family would not accept placement in any of the available alternatives. The family claims that it didn't know what kind of a facility Valley Ridge was.

The agency did not call 911 at any time to obtain emergency help for the man.

Christopher Blair, a 34-year-old autistic man, was found dead in his bedroom at the Valley Ridge Center

A facility employee, not the person Merklely called, was arrested for falsely recording a bed check on Blair the night before his body was found when no such check was done.

Some OPWDD employees say that it is agency policy to avoid calling for outside help until various other employees have looked into the issue and determined whether it's actually an emergency. An OPWDD spokesperson, Jennifer O'Sullivan, said, "OPWDD staff and providers are instructed to call 911 in cases where an emergency response is needed, and to contact law enforcement in cases of suspected criminal activity."

For the past several years there have been bills in both houses of the NY State legislature to require any "mandatory reporter" who is aware of a serious incident of abuse or neglect to report it to 911, and if criminal activity is suspected, to the local district attorney. The current Assembly version makes willful failure to immediately call 911 for any life-threatening emergency a class-E felony.

There are arguments pro- and con- about the bill. One of the less convincing cons is a claim that ordinary direct-service workers in these facilities are not capable of determining what is and is not an emergency. In fact, all such workers are very thoroughly trained in a variety of paramedical and first aid procedures, as well as versed in medical issues common to people with developmental disabilities, and any of them should easily be able to make sound decisions on what does, and does not, justify a 911 call.

OPWDD, on the other hand, has a long tradition of going to very great lengths to avoid negative publicity about what goes on in its facilities, and the public employee unions that represent the agency's workers have demonstrated willingness to defend bad behavior of any kind and any degree of seriousness, to the utmost limits possible. These facts have led many advocates to be highly suspicious of the agency and its employees.

There are claims that the county district attorney was asked to investigate Blair's death and that such an investigation may have been derailed and taken over by the Justice Center, with the intent to white-wash the incident. We can't verify these claims, although the Justice Center does have a responsibility to investigate such incidents.

Recent court cases have shown that if the Justice Center eventually wishes to prosecute anyone for Blair's death, it will need to step back and let the local district attorney lead the effort. Failure to do so has resulted in decisions that the prosecution was unconstitutional.

On the other hand, there is no reason to believe that local authorities would do a better job. A primary reason for giving the Justice Center prosecutorial authority was because local police and prosecutors typically did not regard residents of institutions to be credible witnesses, or granted too much credence to workers' claims about how difficult and dangerous their jobs were, and often refused to investigate or pursue these kinds of cases.

Meanwhile the Justice Center suffered another legal defeat when, in February, a federal judge granted summary judgement to Disability Rights New York (DRNY) in a case about the Justice Center's refusal to turn over complete, un-redacted information about several of its investigations to that watchdog agency. The Justice Center was ordered to hand over the information immediately (see *AccessAbility*, Summer 2018). And the Center was further humiliated by a report from the state Comptroller, who said the agency refused to provide thousands of documents that the state's financial watchdog said were necessary to conduct an audit.

The Center got a new Executive Director, Denise Miranda, well over a year ago. In June and July of this year she stepped out into the public eye to defend the agency and claim that it has become "more transparent." She cited a new sex crimes investigation unit as an example. But lingering statistics won't go away: As the Associated Press reported on July 6, "the Justice Center has investigated 46,000 allegations and substantiated 16,000 cases of abuse or neglect since 2013. Some 550 people have been arrested because of allegations made to the agency, and another 440 have been barred from ever working with the disabled again in New York State." In other words, out of 16,000 cases of abuse or neglect, there have been fewer than a thousand people arrested or barred from working. Probably a larger number of perpetrators have resigned or been fired without getting onto the "do not hire" registry. (And we should note that "working with the disabled" is not accurate; under federal regulations, nursing facilities evaluating job applicants are not permitted to use information on such registries that are not specifically established for nursing facility workers. There is nothing to stop a fired and disgraced OPWDD employee from getting a job working with severely disabled nursing facility residents.) But this is still a shockingly low number, and in virtually no cases have any middle-management officials been punished for presiding over settings in which these incidents have occurred. And there has been no official word from Miranda or anyone else on whether this new transparency means the Center does not plan to appeal the DRNY case, or intends to give the Comptroller the records he is seeking.





EVV-rybody Dance Now!

Electronic Visit Verification (EVV) is a new federal requirement for some forms of home-delivered services and supports for people with disabilities. It is part of the 21st. Century Cures Act, a law passed in 2016 and signed by President Obama. That law contained some marginally good stuff concerning mental health services (see *AccessAbility* Summer 2017). At the time, though, not many people were paying attention to EVV.

The law required all states to implement EVV by January 1, 2019. This past spring and summer advocates succeeded in getting Congress to pass, and Trump to sign, a law delaying this to January 2020.

So what is EVV? It is a concept in which a worker providing services to a person with a disability in their home or a community location would have his or her claim for attendance and hours worked verified by some electronic system. It's important to note that it is a concept, not a specific standard, method, or technology. At the time the law was passed some people were already doing it, though not necessarily in the best or most flexible way.

Now, we at STIC have a lot of experience in providing these kinds of services. It saddens us to have to say that false reports of attendance and hours worked are, while not common, frequent enough to justify trying to find a better way. Not all of this is deliberate fraud, though some of it is. Whenever and whyever it happens, STIC usually ends up paying workers for work not done, or not authorized, and for which we can't get reimbursed by Medicaid. We have big programs and this costs us many thousands of dollars a year.

As the due date for implementation grew closer, disability advocates began sounding alarms that the requirements would restrict the movements and/or violate the privacy rights of people with disabilities.

The Consumer Directed Personal Assistance Association of New York State published a report of these concerns, from which we have taken some of the material below.

Any EVV system must verify the following:

1. The type of service provided – personal care vs home health
2. Date of service provided
3. Location of the service delivery
4. The individual providing the service
5. The individual receiving the service
6. Time details – service start and end times

It might seem intrusive on people's privacy to have to electronically verify that a service recipient and his or her worker were both present in some specific community location for some specific time period. And indeed it is.

However, recording where and when work was done has always been part of the system; it is an absolutely necessary component to ensure that only work that complies with regulations governing these services is done. The only thing changing here is that, theoretically, it will be possible to use something like GPS to verify that people were where they said they were when they said they were there. We don't presume that most disability advocates want to preserve a paper-based system's inability to detect lying about that, but probably some of them do.

On the other hand, the federal government's starry-eyed notion that some such system can definitively prevent fraud is also not ... er ... verifiable. For example, we are aware of one case in which a homecare worker arrived in a car, on time, on the street outside the apartment of the person she was supposed to serve.

She sat there, in the car, playing with her cell phone, for the entire work period, then drove away, without providing any services. A GPS-based system would not have detected that fraud.

Another way to do this might be to require the worker to call in using the service recipient's phone at the beginning and end of the shift. Sadly, again, we have to report that sometimes workers and the people they serve collude in committing fraud, whether by choice or coercion. Neither a phone-based nor a GPS-based system would prevent a worker from calling in at the beginning of a shift, leaving and doing whatever, and then returning and calling in again at the end of the shift. If you think people can't be that evil, you really, really should think again.

EVV also has benefits for conscientious workers. A good system would be simpler and faster than our current paper-based systems, which require workers to fill out rather complicated time sheets, on which they sometimes make innocent mistakes, and then physically deliver them to our office before a sometimes hard-to-meet deadline.

EVV also has benefits for the people who use the services. A good system can require a participant to verify, also electronically, a worker's claim for hours worked at a convenient later time when the worker is not present to potentially coerce him or her.

A significant problem is that unless the system offers a variety of ways to input information, it can force service recipients, workers, or the agency to spend money to provide compliant devices. Although cell phones are ubiquitous, not everybody has a "smart phone." Also, in our region of the state there are many areas where there is no reliable cell signal. Conceivably an agency might have to purchase special

GPS-based apps that can record data that would have to be uploaded later when a signal is available.

Some of the early systems for doing this required service recipients to provide a fixed schedule of hours and locations, and also only accepted shift start and end times in 15-minute intervals. Some vendors have come to understand that consumer-directed services do not have fixed schedules, and that agencies cannot be put in the position of paying for unauthorized time because the system operates on a 15-minute clock. So we don't think that this is going to be an issue now.

Still, there may not be a single system that satisfies everybody in every situation, and all of these systems will be very expensive to purchase. We will only be able to buy one.

We would like to assure you that we are carefully investigating the options and we certainly want to have a system that enables people to travel anywhere in the community with their workers, and which does not put them to significant expense. We will also provide thorough training to everyone on the system we eventually buy. And we'll keep you updated on our progress.

Veterans Reexaminations Re-Examined

In July the federal Veterans Administration's Inspector General reported that the agency had unnecessarily forced thousands of disabled veterans to undergo medical reexaminations to verify their disabilities.

According to the report, which covered a six-month period in 2017, 19,800 mandated reviews out of 53,500, or 37%, were not necessary or appropriate. These reviews are intended to save money by getting people who don't actually have permanent disabilities off the benefit rolls, but the agency ended up wasting more than \$10 million on these inappropriate reviews. The reviews also diverted agency employees from helping veterans to receive benefits, contributing to the agency's woeful history of delays.

The errors were attributed to poor training for workers. A common error was failure to understand that a previously-verified disability was permanent. That's a very old story in the disability community. So old and so often repeated that it is difficult to accept any rationale for it except that

wrong decisions to deny services, if not detected, save money just like right decisions do, and the pressure to save money often trumps every other motivation in government agencies—unless citizens show up at the polls on election day and vote for officials who care more about doing the right thing than about cutting taxes for rich people.

A National Disability Rights Agenda

On July 24, disability rights activists held a rally and march on the Capitol in Washington DC to call attention to the National Council on Independent Living (NCIL)'s disability rights agenda. The organization expected about 1000 people to participate, and provided a schedule of speakers, all of them Democrats. We were unable to find any news reports of the event at press time in mid-August, so we can't report how successful the event was.

The agenda covers dozens of topics across all sectors of American life. It is an excellent survey of all of the ways in which federal government policies affect people with disabilities, as well as a list of many pieces of proposed legislation that might be of benefit. An article analyzing each of them objectively may be a project for a later issue of *AccessAbility*. In the meantime, we urge you to read it for yourself and consider what effect getting involved in the coming election might have on these issues.

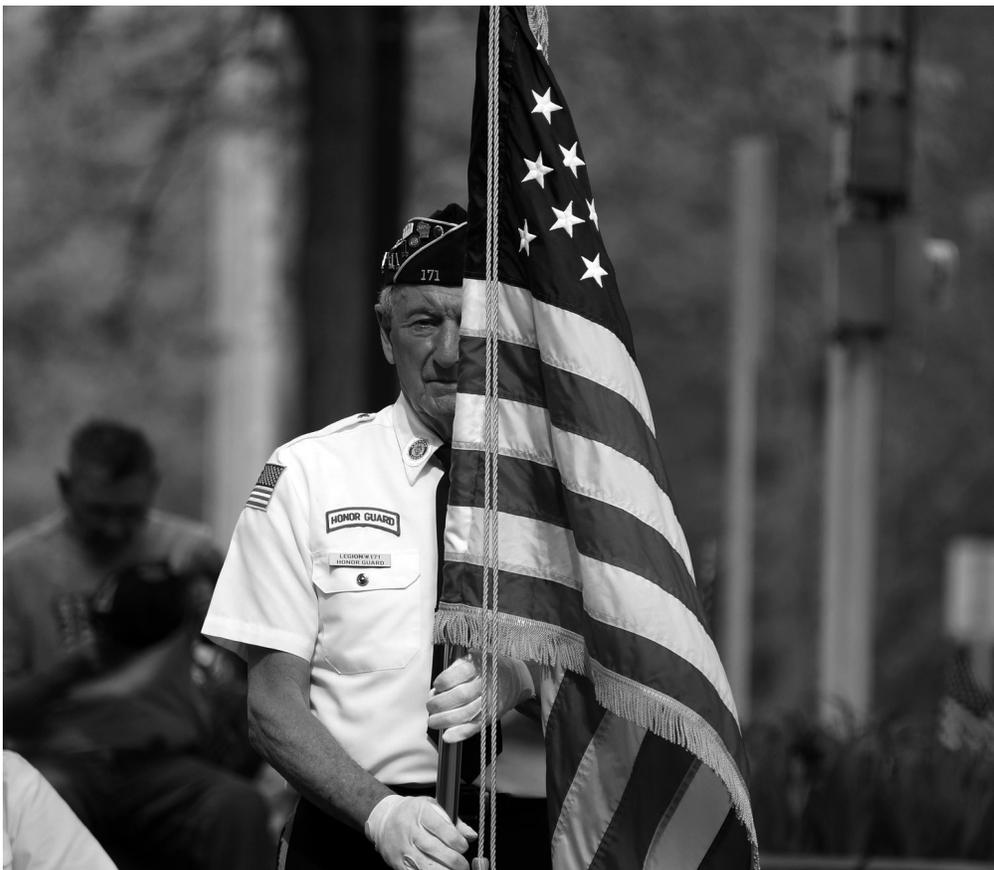
(Please note that NCIL represents federally-funded Centers for Independent Living (CILs). STIC is a CIL, but it is not federally-funded. Most of the agenda's recommendations concerning funding and other things for CILs do not apply to STIC.)

A plain-text version (easiest for people with visual disabilities) can be found here:

<https://www.ncil.org/wp-content/uploads/2018/06/Policy-Priorities-July-2018.txt>

Links to PDF and Word versions are also available at:

<https://www.ncil.org/press-room/>



STIC NEWS



In June, the City of Binghamton converted the red-green stoplight at the corner of East Frederick Street and Broad Avenue, where STIC's main office is located, to a red-yellow flasher, making it impossible for some people with disabilities to navigate crossings safely.

We contacted the City of Binghamton to advocate for them to restore the full stoplight, and expressed the following concerns:

There is a great deal of traffic in this area, including a high volume of pedestrians with various types of disabilities, due to STIC's location at this corner. Vehicle traffic is heavy, and parked cars on Broad Ave. near the intersection make it hard for drivers coming out of Frederick St. to see oncoming vehicles. Many people with disabilities move slowly, some using canes, crutches, walkers or wheelchairs, creating a highly dangerous area to cross to catch the bus, visit STIC, etc. Travel for those

who are blind or visually impaired was also much more problematic, making it much harder for these people to know when they could cross safely.

Additionally, students attending East Middle School might need to cross at the corners, when walking to or returning home from school, creating another potentially dangerous scenario.

We urged others who complained to us to submit their issues and concerns to the city, so they would understand the seriousness of the points raised. I also sent an email with the above information, and an official quickly responded with their willingness to meet.

Individuals from the Traffic Board, a City Council member, a consultant, and others stopped by to observe the light, and to speak to STIC employees. They told us that this was only a trial, and that the change might not be permanent. They said that they were trying to assess several lights in the city to

determine if they were functioning in the best and safest ways possible.

They said they honestly weren't aware that STIC was located at this corner, or how the people who come here would be affected. Once we painted the full picture, they were very willing to recommend to the city that the light be returned to its former status. It was an extremely productive meeting.

Two days later, the light was back to normal.

This is a good example of how, when reasonable people have all of the information on an issue, they will usually do the right thing for those involved. It also demonstrates that advocacy works and that it can be an effective tool for fostering change.

From our staff and the people we serve, many thanks to the City of Binghamton Traffic Board and others from the City of Binghamton who were willing to listen and to respond quickly to the situation.

Anniversary WALTZ

by Maria Dibble



Thirty-five years sounds like a long time, but it seems to have gone by in the blink of an eye. I began working for STIC on June 27, 1983, and here I am in 2018, still loving my job, still challenging those that would deny us our independence, still fighting the good fight, and still cheering on STIC.

Coral was the color, and tropical island was the theme, as STIC celebrated its 35th. anniversary on July 26, the same date as the Americans with Disabilities Act (ADA)'s 28th. birthday, which was no accident.

We dreaded that all of our efforts to plan, prepare, and set up would be drowned out by rain, since that was the weather for most of the week, as it has been for much of the summer, but our luck held, and the day dawned with a promise of sun and high temperatures.

And what does one do when the sun is out and the temperature is warm? Why, get dunked in a dunk tank of course. And that's exactly what some of the almost 300 attendees to our event did.

We had a visit from Animal Adventure who brought a turtle, rabbit, alligator, snake and more, which children and adults (including myself) very much enjoyed.

A unicyclist could be seen wheeling around the premises juggling balls and other items, never missing a beat in his travels.

Children and adults had their faces and arms painted in interesting designs, prompting many to take pictures of their artwork.

Our Xscapes tent was set up in the parking lot, where people could get an idea of what an Xscapes escape room actually is, the game being a tropical island theme called, "Immunity Quest". An escape room is a game where you find clues and solve puzzles, to "escape" in the metaphorical sense, from a room, though no one is actually locked in. Each room is a different theme, our latest being *The Twilight Zone*. Sorry; just had to throw in that plug.

There were games, stories told in sign language, informational tables, displays of adapted bicycles and assistive technology, hot dogs to eat and cooling slushies to drink and much more.

There was a wheelchair obstacle course, demonstrating why a small bump can seem like a cliff or a narrow doorway an insurmountable barrier to a wheelchair user.

At noon we held a well-attended press conference where Assembly Members Donna Lupardo and Clifford Crouch, County Executive Jason Garnar, and Binghamton Mayor Richard David all spoke, each bringing a proc-

lamation celebrating our anniversary and our accomplishments and speaking many kind words for the occasion. I also reminisced a bit while STIC staff snapped photos and seemed to be having a great time.

Unfortunately, we didn't get as many participants as at other events, because it was the first (and I believe only) nice day of the week and many took advantage of the passes for children with disabilities to attend the Broome County Fair. I hope they enjoyed themselves as much as we did at STIC that day.

You can see in this photo that I was certainly having fun.

I know I won't be here for all of the next 35 years, but I've been honored and privileged to lead STIC in the first three decades and a half, and I look forward to being around for another march of years.



Twilight Zone: Binghamton's Rod Serling Experience Opens that Floating Door

by Bill Bartlow

Since its opening on June 15 the Twilight Zone escape room has been a stellar attraction with an amazing number of teams taking the challenge of solving its puzzles. In fact, before the end of the month we had 146 people enter "The Zone". It is totally appropriate that the only CBS-approved Twilight Zone escape room in the country should be located in Binghamton, Rod Serling's hometown. Many area residents are avid fans of the Twilight Zone series and are excited to enter the dimensions of sight, sound and mind that constitute the Zone experience.

Our TZ room is not only entertaining but also informative, giving the players insight into Rod's life and the prolific creativity of this American icon and legend. On August 3 and 4 the Rod Serling Memorial Foundation held Serling Fest 2018 at the Forum Theater and the DoubleTree hotel in Binghamton. Close to 200 Rod Serling super fans and experts assembled here. We at STIC opened our TZ escape room for four days to accommodate the attendees. It was most gratifying to hear the accolades of this group who knew so much about Rod and his accomplishments. That was the "acid test" confirming that we had done the job of honoring Rod appropriately while providing a fun and challenging adventure to the community. The Twilight Zone escape room, along with our other two rooms, Valley of the Kings and Pulse, are fundraisers with all proceeds dedicated to the Southern Tier Independence Center's mission of assisting people with disabilities to realize fulfilling lives and sustain independence.

For more information visit our website:

www.Xscapes-stic.com

Or link through the STIC website: stic-cil.org



With Andrew Polak, President of the Rod Serling Memorial Foundation looking on approvingly, Anne Serling, Rod's daughter, cuts the ribbon opening "Twilight Zone: Binghamton's Rod Serling Experience". Beside Anne are (L-R) Maria Dibble Executive Director of STIC, Rich David Mayor of Binghamton, & Donna Lupardo NYS Assembly member.

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FREE CONFERENCE

Building Networks and Opportunities:
Social Capital and Community Building

Featuring: Al Condeluci, Ph.D.

Thursday, October 11, 2018

8:30 am — 3:00 pm

**Southern Tier Independence Center
Binghamton, NY**

Studies show convincingly that people who have important relationships in their lives are healthier, happier, safer, advance more quickly, and achieve more in life. They also show that vulnerable people, including people over the age of 60, people with disabilities, and economically disadvantaged people have less social capital. Join us to learn about social capital and ways to help build relationships for our most vulnerable population.

Agenda

8:30 – Registration and Light Refreshments

9:00 – Social Capital and Cultural Shifting

12:00 – Lunch (provided)

1:00 – Strategies and Actions for Relationship Building and Social Capital

Social Capital and Cultural Shifting

This session will explore the process of community building and how this effort can help create social capital and community inclusion. As we think about the things that influence our culture and services, a clear macroscopic agenda must be evident. The key to community building is social capital, thus, we will examine the impact of relationships and look at the challenge of supporting people to find their fit in the broader community. Emphasis will be on people with developmental disabilities, though

this approach can work with anyone in your home or community.

Strategies and Actions for Relationship Building and Social Capital

The afternoon session will be an advanced focus on ways and means to more social capital and relationship building, especially for people with developmental disabilities. The challenge of diversity inclusion is front and center in organizations and agencies today. This afternoon session will take a cultural look at this challenge and rather than thinking about deficits that individuals have, attention will be turned to understanding culture and community (with emphasis on relationship building). We will examine the four key steps to community building in an interactive way, and the segment offers clear and distinct take-away strategies that you can use with the people you care for and serve.

Register for this FREE conference at ecdc-stic.com/registration by October 4.

Questions? Call ECDC at:
(607) 724-2111

Parking is available on the streets surrounding STIC and in STIC's E. Frederick St. and Ely St. lots.

If a special accommodation, such as a sign language interpreter, is needed, please let us know by October 4.

About Al Condeluci

He has been an advocate, a catalyst for building community capacities, and leader in understanding social culture since 1970. Dr. Condeluci received his Bachelors Degree in Psychology from Youngstown State University, his Masters in Social Work and Ph.D. in Education from the University of Pittsburgh. Since 1973, he has worked as an attendant, caseworker, advocate, planner, program director and now, CEO of his organization, Community Living and Support Services (CLASS). CLASS has created a family of corporations and is dedicated to its mission—working toward a community where each belongs. CLASS, under his leadership, has grown to become the third largest disability specific agency in Southwestern PA. CLASS was listed in the 50 “Best Places to Work” in Allegheny County, PA in 2007 and 2011.

Along with his work at CLASS, Dr. Condeluci is associated with the University of Pittsburgh's School of Social Work and School of Health and Rehabilitation Science and Robert Morris University Graduate School of Business. In these academic roles he teaches, supervises students, and serves as advisor and consultant. He has emerged as a national leader and consultant on human services and community issues. He speaks annually to national and international audiences reaching some 15,000 people each year. His books have won praises and awards for their thoughtful approach to culture and community and are now used at many colleges, universities and in-service settings.



ASAC Thanks You!

by Sue Hoyt

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

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

Nalit Associates, Molburn, NJ – owners of the Northgate Plaza on Upper Front St. in Binghamton, NY, especially Harvey Sanford, the maintenance / caretaker of the property:

Thank you for fixing the handicapped spaces in the large lot (by Rite Aid) as well as the lot by Creature Comforts to bring them into ADA compliance. It is greatly appreciated.

United Health Services, 10-42 Mitchell Ave., Binghamton / John Carrigg, President and CEO

Thank you for fixing the height of the restroom's accessories at Wilson Hospital / Decker Center and at the Vestal walk-in to make them more accessible for all people.



STIC HELP

Care Management: Tiers and Tears

We know that many people have been upset about some changes related to the conversion from Medicaid Service Coordination to Health Home Care Management for people served by OPWDD.

During this “year of transition”, the Care Managers who work at STIC are still employees of STIC, but they are operating under rules imposed on Prime Care Care Management by OPWDD. (Those who used to work for Catholic Charities of Broome County are no longer employees of that agency; although they still work in a Catholic Charities office, they are Prime Care employees now. Care Managers at AIM in Elmira are still AIM employees, but operate under Prime Care rules.) Although we agree with many of your concerns, we at STIC do not have authority to change the rules.

Here is some of what is happening:

The rates that OPWDD pays for Care Management are based on categories of “needs”, known as “tiers”. Each Care Management recipient has been assigned to one of those tiers. OPWDD also imposes strict caseload limits—the number of people each Care Manager can serve—based on which tier you are in. The tiers are numbered 1 through 4, with Tier 4 being the high-needs category. The higher the needs, the smaller the caseload. This is a new thing that came with the Health Home system.

Now, to be clear: Although OPWDD has always told people that they can “choose their Service Coordinator”, that has always been a misleading promise. There have always been caseload limits, so it should be easy to understand that not everybody could choose the same, very popular, Service Coordinator. However, there were no mandatory rate tiers under

the old system, so in many cases people who didn't have strong preferences for a particular Service Coordinator might voluntarily agree to move to a different one so that someone with such a preference could be satisfied.

The tiers make that sort of thing much more difficult now. If you qualify for Tier 4, then your Care Manager is required by OPWDD to have a very small caseload. It turns out that quite a few people qualify for that tier—more than we were originally led to expect—so there are a lot of Care Managers with small caseloads and relatively few with larger ones. It simply is not possible to shift people around very much.

We have asked OPWDD to allow people in Tier 4 who don't feel that they need a great deal of service to choose to be in a lower tier. This would provide more flexibility for shifting people between Care Managers. OPWDD has refused to do this.

So what can you do?

We suggest you contact OPWDD Acting Commissioner Kerry Delany and tell her of your concerns, and copy in Senator Fred Akshar and your New York State Assemblyperson. How to contact legislators depends on whether the legislature is in session or not. You want to reach them where they are. Websites for legislators are easy to find on the internet.

To contact Kerry Delany:

Email:

Commissioners.Correspondence.Unit@opwdd.ny.gov

Mail:

NYSOPWDD

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Albany, New York 12229



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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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 135 E. Frederick St.
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Address _____

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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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