

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

# AccessAbility

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## GROWING UP & MOVING OUT

*by Maria Dibble*

STIC, as an active member of the New York Association on Independent Living (NYAIL), is strongly advocating this year to create an Office on Community Living (OCL). It will, among other things, merge the state Office for Aging with the Independent Living network, which is currently administered by ACCESS-VR, an agency in the State Education Department (SED). The concept somewhat mirrors the approach taken by the federal government, which recently created an Administration for Community Living (ACL) and moved federally-funded Independent Living Centers (ILCs), the Administration on Intellectual and Developmental Disabilities, and other aging and disability programs under the new umbrella.

The Governor has proposed legislation that would allow for a dialog between the aging and disability communities and gather testimony from advocates and consumers, as well as other interested parties. At the end of 2015, recommendations would be made to the Governor that could result in more comprehensive legislation by April of 2016 to establish the new OCL.

OCL would potentially eliminate the service silos that rigidly separate seniors from people with

disabilities, somehow ignoring along the way that as we age, all of us will likely experience arthritis and other disabling conditions, blurring the lines between the two groups. Even more appealing: other programs would eventually also become a part of OCL, such as Access to Home, which pays for ramps, bathroom modifications, and other accessibility improvements in qualified people's homes; the TRAIID Project, which helps people learn about and try out assistive technology and borrow equipment; and other aging and disability entities. If we were collected under one roof, the eligibility and regulatory barriers between programs could be removed, creating tremendous potential for networking on new projects, all of which would directly benefit people with disabilities in our local communities.

Part of that barrier removal process will be creation of a "No Wrong Door" system to provide information about and access to services, of which ILCs and local aging services providers will be a part. The goal is that no matter what your disability or age, and no matter where you first contact the service system, whether through state or county agencies such as OPWDD, ACCESS-VR, OMH, the Broome Office for Aging, or their subcontractors, including ILCs like

STIC, Action for Older Persons, etc., you will receive the same information about what's available to you, so you can determine which services/programs would best meet your needs. It will be highly beneficial to people with disabilities, since they won't be shuffled from one agency to another to gather all the information they want. It is a model that has been long in coming, and STIC looks forward to being part of the process. The Governor has proposed additional funds for the project for the next fiscal year, so hopefully concrete results will be coming soon.

ILCs are excited about moving to an OCL for another reason. Being located under ACCESS-VR has not been a positive experience. ACCESS-VR stands for "Adult Career and Continuing Education Services-Vocational Rehabilitation," and that agency is focused on basically two issues, employment and education—as it should be. ILCs, on the other hand, have a much broader mission: to do whatever it takes to provide assistance or skills to people with disabilities to enable them to participate fully

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## Authorship

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

in all aspects of community life, and whatever it takes to make our communities as welcoming as possible to them.

It is an accident of history that ILCs are "under" ACCES-VR. When the first federally-funded ILCs were created, they were under the federal Vocational Rehabilitation Administration, and it seemed logical to assign centers in NY, including those that came along later and received only state funds, to the state VR agency. The logic was superficial; nobody who made these decisions at the time thought ILCs actually were supposed to be vocational or educational programs.

But for many years now, ACCES-VR administrators have tried to use ILCs to further their own narrow goals, ignoring the local character of the agencies and their broad purposes. We do offer valuable education- and employment-related programs, of which we are very proud, but it isn't all we do, and never has been.

Thirty-some years ago, nobody understood our potential as transformative organizations. But now we have grown up, so to speak, and it is time for us to leave the nest. Being part of a larger orbit of aging and disability organizations would be ideal for ILCs, since we serve children, adults in the prime of life, and senior citizens, who have all types of disabilities. We offer a wide range of services, from peer support to advocacy, housing and benefits advisement, employment options and education advocacy, consumer-directed personal care, technology assistance, and much more. The breadth of our services is limited only by financial resources and our imaginations. We have worked diligently to make ourselves the "go-to" agencies on disability issues and this move would open up myriad opportunities for both disability and aging agencies.

This year ACCES-VR has added a new twist to its efforts to rein in ILCs. They have said that if we don't want our contracts to be put out to competitive bidding this fall, we must accept several new, and expensive, data collection requirements, as well as restrictions on the kinds of services we can provide under those contracts.

We at STIC support accountability for quality, but we have irreconcilable differences with ACCES-VR on what "quality" means. ILCs are not rehabilitation agencies. The Independent Living Philosophy clearly states that people with disabilities are responsible for themselves and their achievements, not ILCs. But many years ago, it was STIC that provided the ideas that led to ILCs being required by ACCES-VR to specify systems advocacy goals and report outcomes for them. I'm proud of these achievements and have always welcomed the opportunity to showcase them wherever possible. I believe we must collect data and report on how we spend the money, but this should not be make-work; rather, it should be narrowly targeted to help improve our understanding of the needs of our communities, and demonstrate our value as systems change agents. There are so many possibilities! Numbers and data can be tools rather than a burden, but they must be approached in a spirit of mutual cooperation and a desire for mutual benefits.

I don't believe that ACCES-VR, if challenged legally, will be allowed to hold a grant competition for ILCs. I think, based on conversations with officials in the NYS Comptroller's office, that we should continue to be what is called "sole-sourced," meaning no competitive bids. It has been this way for 30+ years, except when new ILCs were formed, and it has worked well.

It is unlikely that we would lose our contract if we had to compete for it. But putting these contracts out to bid will waste a huge amount of time that will be spent on preparing for the bidding process and submitting a proposal. All of us have more useful ways to spend our limited resources, and none of us want a legal battle that drags on forever and benefits no one in the end.

But it's not just about our time or work load. There are other important reasons to sole-source independent living centers, reasons that directly affect you, who rely on our services. Centers are distinct local grassroots organizations of people who take an active role in making their communities more accessible to and inclusive of people with disabilities. By law our controlling boards

## *In Memoriam*

### Lucy Gwin

Lucy Gwin, tireless editor of *Mouth* magazine, crusader against corrupt rehabilitation agencies, institutional settings, and do-gooders everywhere, passed away on October 30, 2014. She was 71.

Lucy came out of the advertising world, and got her start as a disability rights advocate in Rochester, NY after surviving a traumatic brain injury and the scorn of those who got paid big bucks to "treat" her for it. She had a profound influence on your editor's writing style.

*Mouth* ceased publication in 2010, but neither it, nor Lucy, will ever be forgotten.

must be at least 51% people with disabilities. ILCs are not cookie-cutter interchangeable sub-contractors. The Independent Living Philosophy is a unique way of working that arises out of the aspirations and experience of those active people. They are your guarantee that we will never take a paternalistic or overprotective view of you. Our peer support model combines direct services with advocacy to both meet the individual needs of people with disabilities and push for changes to outdated or discriminatory regulations, laws and practices.

We get very good results, because our ability to successfully connect people to all the different kinds of services they need, and to work cooperatively with other organizations and officials on systems advocacy issues, has been gained over decades of building relationships and expertise within our local community and across the state. A generic social service organization, even if it had a board of directors controlled by people with disabilities (how many of those are there, exactly?), would be

starting from scratch and would take years to come up to speed.

Do we bid out schools or hospitals every three to five years? What about Urban Leagues or Rape Crisis Centers? Of course we don't. It makes no sense. We would lose way too much in expertise, knowledge, and dedication, and the affected systems would be a mess. It would truly be disastrous to the people we serve and the communities in which we work.

The money we get through ACCES-VR is not a contract to provide specific products or services. It is a general operating grant to establish and maintain an Independent Living Center. ILCs provide a lot of different programs and services, using funds from other state and federal agencies. Those agencies rarely pay the full cost for those services; they almost always require additional support from us, which can only come from the ACCES-VR grant. This is one of the main reasons why that grant exists. It is the root of how our philosophy is funded. From that root trees have grown. IL funds generate other money and

resources. That is how it was designed to be and how it should remain. STIC is one of the most successful ILCs in the state at diversifying revenue. But that is only possible because we have a general-purpose funding source behind us.

The state law that established ILCs and state agency oversight of them also provides for this general-operating money. ACCES-VR has authority to regulate and oversee us, but it does not have legal authority to redefine our purpose, or the purpose of the funds we receive.

ILCs exist to challenge the status quo and fight for consumer rights, even when it annoys our funding sources or goes against popular opinion. ILCs have the courage of their convictions, and it shows in the types and quality of services we provide. Sole-sourcing is really the only way to ensure that this kind of program can continue. And combining disability support services under one roof without regard to age or diagnosis is the best way to ensure that the things we fight for can be achieved and maintained. Stay tuned: a new era is dawning.

## News & Analysis

### That Old Familiar Tune

Some of Governor Cuomo's disability-related budget proposals for fiscal year 2015-16 are so familiar that we could just reprint much of last year's article. We aren't quite that lazy, though.

There is no deficit expected this year, but long-range projections appear to require NY to keep overall spending growth under 2% to prevent deficits in future years. Meanwhile, Cuomo's front burner is cooking up more property tax cuts and tax give-aways for busi-

nesses. The extra up-front money the state will have to plow into the OPWDD system over the next five years to keep people from dropping through the cracks as NY phases in compliance with the new federal HCBS regulations is way back on that tiny little burner in the corner.

Anyway, the cuts proposed are the same red herrings that keep getting thrown back by the legislature, and one, the annual effort to eliminate "prescriber prevails" for prescription drugs paid for by Medicaid, has already landed, wet and flopping, back on Cuomo's

desk. There is also another attempt to end the "spousal refusal" option that lets family income be disregarded in order to enable someone to get Medicaid-funded community services and stay out of an institution. We're tired of explaining these things every year. The NYAIL Agenda (page 8) covers them; for more, check out *AccessAbility* Spring 2014 (spousal refusal), or Spring 2013 (prescriber prevails).

And, as has happened eleven years in a row, there is no proposed increase for the general operating grants that Independent Living Centers like STIC use to maintain and help diversify services. Increases in healthcare benefit costs alone have reduced the value of those grants by more than half over the past dozen years. However, unlike last year, some legislators have responded favorably to requests to increase those funds, so something may be worked out. See the NYAIL Agenda (page 8), for more.

In fact, this year's Agenda covers just about everything of interest in the Governor's package pretty well, so why repeat it? Go to page 8 and read all about it.



## Assisted Suicide Comes to NY?

Assemblymember Linda Rosenthal (D, Working Families-Manhattan) has introduced a bill in the NY State Assembly to permit assisted suicide (A.2129).

The disability rights community opposes assisted suicide because of the tremendous potential for abuse. Assisted suicide is cheap compared to the cost of medical treatment or support services to keep people with disabilities alive. The estimated average cost for assisted suicide is \$300. This creates plenty of incentive for people concerned about health care spending to encourage people with disabilities to off themselves.

Rosenthal's bill has the following loopholes that would permit abuse:

### A Fate Worse than Death

One reason why people who aren't actually dying may ask for assisted suicide is chronic pain. They aren't fooled by so-called "holistic approaches" to "living with pain". The fact is, modern medicine could completely eliminate a lot of pain if we took the legal barriers away. If politicians really want to end suffering, they should pass a law to:

- Require insurance companies to pay for any and all diagnostic procedures to find out what's going on immediately when a person makes a credible report of severe pain, instead of making them wait to see if the pain goes away, or to undergo "treatments", such as physical therapy, that actually make the condition worse, before they pay for MRIs or CAT scans.
- Require doctors to offer anesthesia whenever it might help, not just when it's absolutely necessary to keep people from screaming and flailing around, and require insurance companies to pay for it for any diagnostic or treatment procedures that cause intense pain, for people who have a good history of tolerating it.
- End restrictions that keep women who have severe dysmenorrhea from getting real treatment, including surgery or effective pain meds, if they want it, instead of excuses and condescension.
- End the assumption that it is better for people to suffer than to be addicted to a carefully monitored permanent regimen of pain medications that enable them to function.

Elderly people and people with disabilities suffer high levels of abuse from "caregivers." The bill would not prevent caregivers from coercing people to agree to assisted suicide. Coercion can be quite subtle. People with a lot of needs often feel that they may be a "burden" to others, and it is not difficult for a person with an agenda to feed into those worries and promote the idea of "ending it all" as a favor to loved ones. Under this bill, caregivers can be a witness to the person's written requests, pick up the lethal drug from the pharmacy, and even administer it. The bill does not require the death to occur in a setting that is objectively monitored by responsible authorities. Although the bill specifically prescribes criminal penalties for coercion, there is no way to find out if coercion actually occurred in most cases. Coercion would be virtually impossible to prove in court, and it would be extremely rare for prosecutors to even try.

Assisted suicide would only be available to people who, in the judgment of their doctor, have less than 6 months to live. However, these predictions are usually made on the basis of statistical averages, not the specific characteristics of a person. What they mean is that, out of all the people who have had this diagnosis and exhibited these symptoms, more than 50% were dead within 6 months. Many died sooner, and many lived longer, sometimes much longer. And some did not die from the condition at all, even if it was correctly diagnosed, which it may not have been.

If the doctor whom the person asks for a lethal prescription thinks the person may not be able to make an informed decision, s/he is supposed to refer the person to a psychologist or psychiatrist for evaluation. Ordinarily an expressed desire, with a plan, to commit suicide is regarded by mental health practitioners as evidence of a mental health disorder. Why shouldn't the law mandate a psych eval for everybody who asks to die?

The bill is unnecessary to address the alleged problem of people having to linger through unpleasant deaths. In NY, people who are dying already have the legal right to refuse food, water, and medical treatment, and they can request palliative pain medication and sedation up to the point of unconsciousness. As for chronic pain, there's a lot more that could be done to keep people from wanting to die. See the sidebar.

Rosenthal's bill has an especially nasty provision. Although hospitals, medical groups, and other organizations that employ doctors, either directly or as independent con-

tractors, could forbid them to participate in assisted suicide, such doctors would be allowed to whip out a handy contract for the patient to sign that says the patient hired the doctor specifically to write the prescription, and the doctor won't be working under the employer when s/he does so.

At press time there was no companion bill in the Senate and chances of passage seemed slim. However, these bills keep coming up, and eventually getting passed, in other states. People with disabilities here need to stay vigilant and make sure that well-meaning left-leaning and moderate politicians understand the flaws in their thinking.

### AH-HA!

As we've reported (*AccessAbility*, Summer '14, Fall '14), NY has committed to adding a Community First Choice (CFC) option to its Medicaid system. CFC is part of Obama-Care; it lets a state expand homecare services to people who aren't otherwise eligible for them. In NY, that includes people who don't qualify for various Medicaid waiver programs, or who can't use the CDPA program because they aren't fully "self directing" and have no family to represent them. To make this work affordably, the state must agree that people who provide CFC services don't have to be licensed nurses. That means amending the state's Nurse Practice Act (NPA).

Last year, politicians who had promised disability activists that the NPA would be changed reneged. However, a workgroup of state agency bureaucrats, nurses, and others was convened to hammer out what tasks CFC "Advanced Home Health Aides" (AHHAs) might be permitted to perform if the NPA was amended. At press time that workgroup was still meeting.

Meanwhile, Cuomo's package of budget and program bills for 2015-16 again contains language to modify the NPA. It is very similar to last year's bill, and it will require the Department of Health and the State Education Department (which regulates medical licensing) to take into account the workgroup's recommendations when they develop regulations for the program.

The bill lets the aides administer medication that is pre-packaged or measured, and limits other aide tasks to those that a Licensed Practical Nurse can perform. It requires aides to be supervised by registered nurses, who must decide what specific tasks, from

among those that the regulations permit, they can perform for specific individuals. It also has extensive training and experience requirements for AHHAs.

This version of the bill specifically directs the regulatory agencies to decide if the aides can administer injections or “controlled” drugs such as opiates. It also requires that AHHAs be placed on the public registry of homecare workers.

The law takes effect on October 1, 2015, and the regulations are “required” to be in place by then, but no one believes that is realistically possible. No services under the law would be permitted to be delivered until those regs are finalized.

Advocates are mostly pleased with the bill, but object to a requirement that AHHAs must work a full year as Certified Home Health Aides (CHHAs) before they can perform AHHA duties. Many people who are qualified as CHHAs have only worked as Personal Care Attendants, a less technical form of homecare. This rule would senselessly reduce the pool of available workers.

## Left Behind!

Many right-wingers in Congress seem enraptured by the opportunity to reduce expectations for children with disabilities offered by the Second Coming of “No Child Left Behind” (also known as the federal Elementary and Secondary School Act, ESEA, which must be re-authorized). This fits with their belief that the feds have been acting as Big Brother, overriding local prerogatives and imposing unfunded mandates on schools.

What’s really at issue is whether children with disabilities, and the schools that teach them, will be held to the same achievement standards that apply to nondisabled children.

The Individuals with Disabilities Education Act (IDEA) requires schools to have individualized education plans that explain how children with disabilities will be assisted to learn. ESEA is about holding schools accountable for what children learn, including those with disabilities.

Today, ESEA lets schools use “alternative standards for students with the most significant cognitive disabilities,” and “modified standards” for other students with disabilities. “Most significant” imposes a limit on how many children can be included in the “alternative” group. There is no limit on “modified” standards, and that’s a problem.

However, when schools report to the feds on their performance, ESEA says they can only in-

clude the grades of 1% of students working on “alternate” standards, and of 2% of those working on “modified” standards. The assumption is that these different standards will be lower than those applied to most students, so that the grades of these groups will be higher than those of most students, and therefore they would skew the results in favor of the schools if they were allowed to report all of those grades. The people who wrote the law thought that these tight limits would create an incentive for schools to increase the number of students with disabilities who are taught the same things, and take the same tests, as nondisabled students. At press time we didn’t have any data on whether that assumption has panned out.

Here is the most important thing to understand about all of this. ***Most disabilities do not affect how much, or how fast, a child can learn at all.*** Under IDEA, students with disabilities can be classified into one of 13 categories (if they have disabilities that fit into more than one, then they are classified under “multiple disabilities”). Giving the benefit of the doubt to schools, only the following IDEA categories potentially affect what children can learn: autism, developmental delay, intellectual disability (ID), “multiple disabilities,” and traumatic brain injury. Of all of those, only ID is guaranteed to limit learning to some extent. National data from 2010 show that out of 5.8 million students classified under one of these categories, fewer than 1.1 million were in categories that could limit learning for some children, and fewer than half a million had ID. If the other 4.7 million weren’t learning at the same rate as nondisabled children, it wasn’t due to their disabilities; it was because the schools failed to meet the legal requirements of IDEA to provide adequate supports so they could learn.

Let’s stop here for a minute. One of those categories is “specific learning disability,” and it accounts for about 50% of all students with IDEA-classified disabilities. This category includes things like dyslexia and attention-deficit disorder. Despite the name, these disabilities have nothing to do with how much or how quickly a person can learn. They are information-processing issues, and we have known for at least 25 years how to provide supports and accommodations to enable children with these disabilities to keep up with the academic achievements of their nondisabled peers. There is no excuse for any school that doesn’t do that.

ESEA’s No Child Left Behind incarnation is controversial for many reasons. But most disability advocates applaud its rules for students with disabilities, because it holds schools to much higher standards than IDEA does. IDEA defines ID as “significantly subaverage general intellectual

functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child’s educational performance.” Schools use varying IQ scores between 70 and 80 as “cut-off” measures for this (OP-WDD uses IQs under 70). The incidence of IQs below 50 is about 1 in 1000, or one tenth of one percent. Lots of people with IQs between 50 and 80 can master basic reading and math. So among that half-million students with ID in 2010, probably fewer than 1000 would be unable to learn to read, at least at a basic level, if taught properly. Let’s tack on another 10,000 from the other categories that might limit learning. 11,000 out of 5.8 million is one one-hundredth of one percent of students classified as having disabilities who probably can’t learn to read. There were roughly 48.3 million public school students in 2010. 11,000 as a percentage of 48.3 million is vanishingly small. But it’s not just about basic reading and arithmetic, so let’s say that half a million students with disabilities would not be able to learn what an average nondisabled student can learn. That’s 1%. That’s what ESEA is talking about. These are not unreasonable requirements at all.

Senator Lamar Alexander (R-TN) is the principal name behind the current bill to reauthorize IDEA (he was Secretary of Education under Bush I). His bill would completely eliminate any limits on how many “alternative” or “modified” standards-based test scores schools could report to the feds. Those reports affect whether school districts have to spend money to improve low-quality schools, and how much of that money they can get from the feds.

Advocates say that this bill also would “make it easier for school districts to overrule parents and place their children with disabilities on track to receive a lower quality education.” Senator Bob Casey (D-PA) has introduced a separate bill, which he reportedly hopes will end up as part of ESEA, that would require states to have specific rules explaining how students with disabilities will be assigned to the lower standards groups. It would also require informed written consent from parents of these children, who would have to be told that accepting lower standards may mean their kids won’t get a regular high school diploma.

At press time Alexander’s bill was moving quickly through the Senate. By the time you read this, they may have already voted on it. A bill with similar language on standards and accountability for students with disabilities was reported out of a House committee and awaits a floor vote. Obama has made veto noises. We’ll keep you informed.

# On the Federal Tip

As spring approaches, a young lame-duck President's heart turns lightly to thoughts of legacy, and various Congressional roosters climb up on the fence and strut and squawk in the air that is slowly being warmed by the approaching elections. So we have a few things to talk about on the federal level. Obama isn't likely to get anything he wants from Congress, and Congress isn't going to override any presidential vetoes. But still, it's interesting...

## Fannie May or May Not

Fannie Mae and Freddie Mac, the two federal mortgage-assistance programs that were caught with their... er, fannies exposed during the mortgage-backed securities implosion a few years back, are supposed to give a portion of their funding to the National Housing Trust Fund (NHTF). The NHTF was established by Congress in 2008 to make money available for housing for very-low-income people, including people with disabilities. In fact, it's never been funded. But now, those two agencies have gotten back on their feet and are ready to start contributing to the fund. So, naturally, some members of the House majority have introduced a bill to block it, lest the Obama Administration be seen to be accomplishing something good. The bill is HR 674.

## Who Cares?

The National Family Caregiver Support Program provides information, counseling, respite services, and "supplemental services" to caregivers for people with disabilities. Unfortunately, the current program excludes parents of adult children with most types of disabilities who are under the age of 60. It only covers grandparents of such people. Surprisingly, there is a bipartisan effort in the Senate to reauthorize the program and extend it to parents of younger adult children with disabilities. This bill is S. 192.

## Take the Good with the Bad

Obama's proposed 2016 budget (which would take effect in October 2015) contains both good and bad things for people with disabilities.

Both are combined in proposals related to Social Security

Disability Insurance (SSDI), an income stipend for working-age people who have held jobs but can no longer do so because of an acquired disability.

The payroll tax that funds the federal Social Security program gets broken up into a percentage for the standard Social Security benefit that retirees get, and a (much smaller) percentage for SSDI. As a result, although the standard Social Security trust fund is solvent until 2033 at least, the SSDI trust fund will run out of money next year, after which people would only be able to get 80% of their current (quite small) SSDI checks. Obama wants to adjust these percentages so that both funds stay in the black until 2033. It doesn't involve increasing the total payroll tax; just changing where parts of it go.

However, he also wants to deduct from these SSDI checks any federal or state unemployment benefits that people receive. For example, if you get \$1000 a month from SSDI but begin receiving \$200 monthly from unemployment, your SSDI check would be cut to \$800. This is an unfair bit of penny-pinching. There's a complex formula by which people on SSDI can continue to get those checks if they work a little bit at part-time jobs. Their incomes have to remain below the "substantial gainful activity" cut-off. This lets people who are recovering from a long-term disabling injury slowly gain stamina so that they can eventually return to full-time work, without jeopardizing their incomes in the process. If you had one of these little jobs and lost it through no fault of your own, you might get a (very small) unemployment benefit. Since you're allowed to have the tiny bit of extra employment income without losing your SSDI, why shouldn't you be allowed to keep what is likely to be an even tinier unemployment benefit as well?

The Social Security Administration has been plagued by funding cuts in recent years. As a result there's a huge backlog of people waiting to get their applications for SSDI approved. Obama wants funds to hire more administrative law judges to get appeals of denials processed faster.

On the other hand, he also wants to put more money into the program that periodically reviews the eligibility of SSDI recipients, because it's also backlogged. Eliminating that backlog will mean more people whose disabilities have improved enough for them to go back to work will lose their SSDI, which will save the government a projected \$9 for every dollar spent on the reviews. That's painful, but fair.

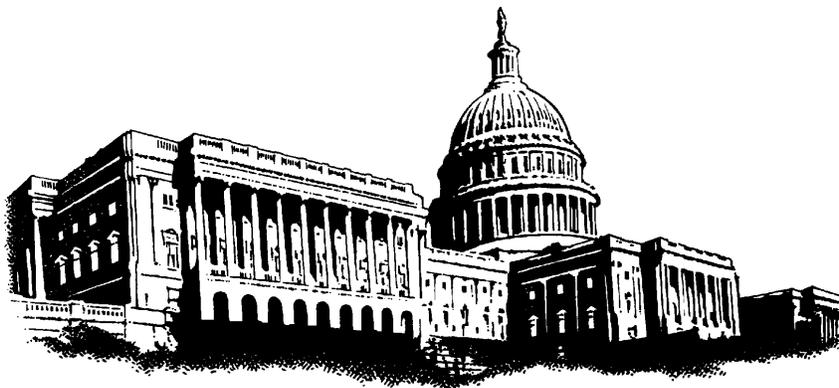
## It's about TIME

On January 7, 2015, Congressman Gregg Harper (R-MS) introduced HR. 188, the Transitioning to Integrated and Meaningful Employment (TIME) Act. It would phase out "special wage certificates" under the Fair Labor Standards Act of 1938, which let employers pay people with disabilities less than minimum wage. New certificates would not be allowed as soon as the bill is enacted. Employers that already have certificates would have them "transitioned" away within three years. The same bill was introduced in 2013 under a different name, but got no action. At press time, the bill had been referred to the House Committee on Education and the Workforce.

## Want Some Candy?

Obama's budget requests increases for several disability programs, including more money for state vocational rehabilitation agencies, early intervention services, personal assistance services for elderly people,

a new program to promote best practices in school-to-life transition for young adults with developmental disabilities, and more Section 8 housing slots targeted for people with disabilities. Most of these increases are modest, but at least they are going in the right direction—where they will likely be stopped dead in their tracks by Congress.





## Abel Sues Cain

Disability Rights New York (DRNY) filed suit in federal court against the New York State Justice Center for the Protection of People with Special Needs in January 2015, claiming the Center has refused to provide required information about cases of abuse and neglect to the federally-funded protection and advocacy (P&A) agency.

DRNY inherited the P&A functions of the old NYS Commission on Quality of Care (CQC), at the same time that the rest of the CQC's functions were moved to the Justice Center. These changes were made in the wake of the abuse scandal involving OPWDD facilities and subcontractors, and charges by the federal government that NY's P&A programs were not sufficiently independent from the state.

Many disability advocates supported DRNY's take-over of P&A, while at the same time criticizing the Justice Center for hiring employees of OPWDD who apparently had not detected, reported, or responded to abuses at that agency.

We have not yet seen the formal complaint submitted by DRNY; we hope to analyze it for an upcoming issue of *AccessAbility*. In the meantime, the organization's press release pretty much says it all:

“This national Protection & Advocacy System was created by Congress as a direct result of the horrific conditions that were uncovered in the 1970s at the Willowbrook State School and left un-remedied by New York State.

Pursuant to two federal statutes, the Protection and Advocacy for Individuals with Mental Illness Act and the Developmental Disabilities Assistance and Bill of Rights Act, DRNY is specifically authorized to obtain records of abuse and neglect investigations conducted by state agencies, like the Justice Center, to ensure that people with disabilities are indeed protected from abuse and neglect. However, the Justice Center has been consistently refusing to provide DRNY with full access to records and reports regarding the abuse and neglect of several individuals, one of which resulted in death....

Timothy A. Clune, Executive Director of DRNY, said “New York State has a well-documented history of failing to adequately investigate serious allegations of abuse and neglect against people with disabilities. The Justice Center was created to remedy this deplorable situation. It is deeply disturbing that the Justice Center is intentionally obstructing DRNY's efforts to fulfill our important federal oversight mandate.”

### *Armstrong v Exceptional Child Center, Inc.:* How Much is Enough?

As disability advocates have both hoped and dreaded, the US Supreme Court is considering whether people can sue state governments to enforce the federal Medicaid law Section 1902(a)30(A) requirement that states must pay Medicaid service fees that are “sufficient” to ensure that services are adequately available to people who need them.

We've covered the issue before, when it came up in a suit filed by Medicaid recipients and providers against the state of California known as *Douglas v Independent Living Center* (see *AccessAbility* Spring 2011, Fall 2011, Fall 2012).

This case involves rates set by the state of Idaho to pay for residential habilitation services for people with developmental disabilities under a Medicaid Home and Community Based Services (HCBS) waiver. Unlike *Douglas*, only Medicaid service providers, not recipients, sued the state, and nobody is claiming that anyone has been denied services due to Idaho's rates. In fact, the providers concede that there aren't even any waiting lists for waiver services. It seems that they simply want more money. This is a sad, sad reason for asking the Supreme Court to potentially find that the Medicaid “sufficient payment” rule can't be enforced.

The case is deeply technical, which Supreme Court geeks love. This geek can only summarize it here. But it is the sort of dry, mechanical argument that gives cover to those who want to engage in the messy human business of destroying the social safety net that keeps less fortunate people alive.

In *Douglas*, Medicaid providers and recipients sued CA, charging that new Medicaid rates being rolled out by the state were making services too scarce. A federal district court ruled that CA had to use a rate setting method that ensures that rates bear “some reasonable relationship” to the cost of providing services. CA appealed, and the Ninth Circuit upheld the lower court. CA took it to the Supremes. Mean-

while, the federal Centers for Medicare and Medicaid Services (CMS) first disapproved, then approved, most of CA's rate cuts, apparently because Obama felt pressure to ease up on states facing massive budget deficits during the Great Recession. Part of CA's argument was that people have no right to sue a state to enforce federal Medicaid law. The Supremes agreed to decide the case but changed their minds after CMS approved CA's rates. So the question of whether anybody can sue over this type of thing remained unresolved.

How does that argument go? If you want to sue, you need a “cause of action.” If a state doesn't do what a federal law says it should do, is that enough? After all, the “Supremacy Clause” of the US constitution says, “This Constitution, and the Laws of the United States which shall be made in Pursuance thereof ... shall be the supreme Law of the Land; and the Judges in every State shall be bound thereby, any Thing in the Constitution or Laws of any State to the Contrary notwithstanding.” People who benefit from Medicaid say yes, that's reason enough to file suit. People who have to pay for Medicaid services don't like this. For over 30 years, right-wing Supreme Court Justices have been helping them by narrowing the definition of cause of action. The Supremacy Clause, they say, just means that if the feds make a law, the terms of that law override state law if they are in conflict. If the federal law says, “Medicaid-funded service providers can sue a state because they think its Medicaid rates are too low,” or if it says, specifically, that people who are eligible for Medicaid services have a legal right to get those services, then the Supremacy Clause backs that up. But if the federal law doesn't specifically create a right, or require a specific procedure, or indicate that people can sue, then that is also “supreme” law, and there is no conflict with the state, so there is no cause of action. The Medicaid law doesn't say any of that stuff with regard to Section 30(A).

Yet a federal court ordered CA to follow a specific rate-setting procedure. If that order stands, then, because court rulings have the force of law, there *is* federal law that conflicts with what the state wants to do. But, says Idaho, that order should never have been issued because the people who started this fight had no standing to sue in the first place. So now the Supremes have to settle this. Be afraid. Be very afraid.

At bottom, this is a dispute about the politics of government spending. Must states rationally consider facts, such as how much it actually costs to deliver services? Or can they simply say that budgeting is a political matter between

the state legislature and the governor, and let people who are rich enough to make campaign contributions, and who don't want their taxes raised, control the process?

If an "agency expert" such as CMS regulates how states must comply with a federal law, then people who don't like what the state does have another avenue; they can sue the "expert" under the federal Administrative Procedure Act to get the agency to force the state to do something different. CMS says it is working on regulations to define procedures for complying with Section 30(A), and has argued that people should wait for them to be finalized before going to court. But CMS used weasel words when it proposed the regulations in May 2011; they said the rule "does not focus on one particular data element, such as the relationship of provider payment rates to provider costs, but recognizes that access to covered services is affected by multiple factors. Though cost may be one consideration affecting access to care, there are other factors such as local market conditions, variable provider costs, administrative burden for providers, and demographic differences." And they still haven't released a final rule, almost 4 years later.

We agree that "administrative burden for providers" is a factor; we could provide more services if we didn't have to maintain a department of several people whose only jobs are to fill out, and check, and re-check, all the paperwork to avoid being forced to give money back to auditors. But no state lawyer is going to let any state government streamline those requirements; "CYA" is the name of their game. And that goes double for NY, which has been under a justified cloud of suspicion for its bogus OPWDD rate-setting process.

In truth, CMS seems to be trying to finesse the issue; they are providing loopholes big enough to drive a Brinks truck full of campaign contributions through, while claiming to create a rational "system". Apparently they

are pleasing no one, and that's why the final rule has been held up.

Meanwhile, the same Supremes who changed their minds on *Douglas* and sent the case back to the lower courts, instead of confronting the cause of action issue, are still there. That decision was 5-to-4; Alito, Roberts, Scalia, and Thomas predictably dissented, saying they could have settled it then and there: no standing to sue. This at least suggests that the Court will rule 5-to-4 in favor of the Medicaid providers. But Kennedy is a swing vote, and the Gang of Four may have gotten to him. So stay tuned.

## NYAIL 2015 Agenda

(abridged, from NYAIL)

The New York Association on Independent Living (NYAIL) is dedicated to removing barriers to full community integration of people with disabilities of all ages. NYAIL represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs are controlled and primarily staffed by people with disabilities. They provide community-based services and supports, including peer counseling, independent living skills training, individual and systems advocacy, and assistance with negotiating complex service systems to obtain health and long-term care, housing, education, employment, and other services that empower people with disabilities to live independent, fully-integrated lives in their communities.

NYAIL is pleased that Governor Cuomo continues taking steps toward full *Olmstead* implementation in NY. Most recently, he created the Employment First Initiative, which seeks to increase competitive, integrated employment options for people with disabilities. The *Olmstead* implementation process began in October 2013 when Cuomo issued NY's long-awaited *Olmstead* Implementation Plan, detailing how the State will comply with the Supreme Court's *Olmstead v LC* decision to ensure people with disabilities receive services and supports in the most integrated setting appropriate to their needs. The State is also implementing the Community First Choice Option and the Balancing Incentive Program. These programs, part of the Affordable Care Act, can create new opportunities for people with all types of disabilities to live in the community with services and supports. NYAIL's 2015 agenda supports *Olmstead* implementation by addressing barriers to community living and ensuring individual rights.

## RESPONSE TO THE GOVERNOR'S BUDGET PROPOSALS

### Independent Living Centers

**NYAIL urges the Governor to increase base funding for ILCs to \$18 million. This much-needed increase of only \$5.6 million is long overdue and essential to sustaining IL services.**

ILCs are essential community-based advocacy and service organizations that help ensure people with disabilities have services and supports to live independently in their communities. The Executive Budget proposes level funding for ILCs at \$12.361 million. ILCs have received flat state funding for the past 11 years, while demand for services and the cost to provide them have increased dramatically. In 2012/13, ILCs in NY served 87,592 people with disabilities, family members and others, an increase of over 19,000 in 10 years.

Flat funding for 11 years, steadily rising costs of doing business, and increasing demand for services have made it impossible for centers to adequately meet the needs of the communities we were created to serve. Recent data by the IL network shows that people with disabilities are waiting longer to get the IL services they request. Also, ILCs are being forced to lay off staff—many of whom are people with disabilities. Yet Governor Cuomo has just created the Employment First Commission to make competitive, integrated employment the first option among supports and services for people with disabilities.

Adequate ILC funding is essential to successful *Olmstead* implementation in NY and would save more Medicaid dollars. NY's *Olmstead* plan commits to reducing the long-term-stay nursing facility population by 10% across 5 years. ACCES-VR data show that ILCs' work to transition and divert people with disabilities from costly institutional placements **saved NY over \$1.7 billion since 2001. ILC transition and diversion activities save more than \$9 for every state dollar invested in ILCs.** NY has an unprecedented opportunity to use ILCs to assist in implementing *Olmstead* and the Medicaid Redesign Team (MRT)'s reforms affecting people with disabilities, including the implementation of the Community First Choice Option and the Balancing Incentive Program. **NYAIL urges the State to increase IL funding to \$18 million.**

### Health/Medicaid

**New York must authorize an exemption to the Nurse Practice Act for advanced**

**home health aides as proposed in the Executive Budget. This change is critical for full implementation of the Community First Choice Option (CFC), a Medicaid program that offers incentives for community-based provision of long-term services and supports.**

NY submitted a proposed State Plan Amendment to the Centers for Medicare and Medicaid Services (CMS) in December 2013 to implement CFC, but without an exemption to the Nurse Practice Act (NPA), CFC will not reach the scope and vision intended for the program. The amendment is necessary for non-licensed professionals, who will be trained and certified as “advanced aides,” to assist with health-related tasks that would otherwise require a Licensed Practical Nurse. Such tasks are likely to include catheter care, medication administration (including insulin), handling feeding tubes, and other duties required by an individual’s person-centered plan. If the NPA is not changed, CFC will, at best, look like a broadened Consumer Directed Personal Assistance program (CDPA), which currently only serves approximately 10,000 Medicaid recipients in NYS. CFC’s purpose is to eradicate the silos and provide a comprehensive long-term services and supports system for all people as an alternative to institutional placement, regardless of age, diagnosis, or severity of disability.

The enhanced federal 6% Medicaid increase for CFC should be used to promote independent living in NY. **NYAIL supports the proposal to allow NYS to use these monies for initiatives that realize the goals of the State’s Olmstead Plan.** People with disabilities should be involved in developing the allocation plan, and the Most Integrated Setting Coordinating Council (MISCC), created in 2002 to guide NY’s *Olmstead* efforts, should have final approval. NYAIL urges NY to invest CFC funds toward further increasing the ILC network’s base funding, given their unique role in *Olmstead* implementation efforts and increased demand for services.

**NYAIL thoroughly supports creating an Office of Community Living.** The disability rights community has long advocated for a state-level structure that brings together aging and disability services in a way that helps eliminate silos and promotes the “community first” philosophy. The approach outlined in this year’s budget will result in better coordination of services and maximized use of resources to help keep individuals living and engaged in their communities. The ILCs, which are the leading cross-disability providers of

services and represent, through lived experience, people with all types of disabilities of all ages, must be included in this process.

**NYAIL supports the funding to sustain NY’s No Wrong Door system**, which includes \$8.2 million in 2015-16 and \$18.1 million in 2016-17. The intent of No Wrong Door is to bring together the federally funded Area Agencies on Aging and ILC networks to create a true single point of entry system for accessing long-term services and supports. The development of a No Wrong Door system that encompasses aging and disability service providers is required as part of NY’s Balancing Incentive Program, and serves as the foundation for the proposed Office of Community Living. Additional funding should be contingent on a set of uniform standards that ensures accountability and consistency across the state.

**NYAIL strongly opposes prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that person to obtain Medicaid.** This proposal will eliminate the longstanding right of “spousal/parental refusal” for vulnerable populations such as severely ill children and low-income seniors. As proposed, the refusal will only be honored, and Medicaid granted, if a parent lives apart from their child or if a spouse lives apart or divorces the potential Medicaid recipient. NYAIL opposes denying Medicaid to these vulnerable populations. If this proposal is enacted it will force low-income people to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias.

**NYAIL strongly opposes eliminating Prescriber Prevails.** This proposal would repeal the state legislature’s restoration of “prescriber prevails” for several classes of drugs in fee-for-service Medicaid. A prescriber, with clinical expertise and knowledge of individual patients, should be able to override a Medicaid-preferred drug. Because people can have very different responses to different drugs in the same class, prescribers are in the best position to make decisions about what drug therapies best serve their patients. NYAIL urges NY to recognize the importance of specific prescription drug combinations and protect Prescriber Prevails.

**NYAIL supports a Mobility Management Pilot program.** Lack of transportation for people with disabilities in rural areas requires

immediate attention. NYAIL supports Gov. Cuomo’s plan to assess the mobility and transportation needs of people with disabilities with a goal of creating a project to coordinate medical and non-medical transportation services, to enhance community integration. However, NY must ensure that this program does not limit choice for people with disabilities, or create further silos. The IL community should be central to this assessment.

Given Governor Cuomo’s Employment First Initiative, it is crucial that NY address the lack of affordable, accessible transportation. The MRT identified transportation as a key factor for people as they transition off benefits and into jobs. Transportation is one of the greatest barriers to people with disabilities living independently in the community, especially in rural areas, which lack public transportation. We urge that any pilot project focuses on these areas.

*NY must commit to ensuring that these vital services aren’t interrupted.*

#### **Additional Recommendations**

**NY must ensure that CDPA services are not interrupted due to federal labor law changes.**

The US Department of Labor (DOL)’s Fair Labor Standards Act Companionship Exemption, which would require that attendants be paid for travel time, and time-and-a-half for hours worked over 40 per week, was recently overturned by the courts. This rule did not come with additional federal funding to ensure that attendants could actually be paid more for overtime, and as a result, fiscal intermediaries would be forced to cap hours at 40, putting people at risk of unnecessary institutionalization. These court decisions are being appealed by DOL and the rule could be back in effect as soon as 6 months from now. While the Governor’s office had committed to use Balancing Incentive Payment monies as temporary funding to ensure that attendants would be paid more for overtime, there is no permanent mechanism to pay for this if the appeal is successful. NY must commit to ensuring that these vital services aren’t interrupted.

**NY must fund a living wage for consumer-directed personal attendants.**

The state has established and funded a living wage for some attendants working in traditional homecare. Unfortunately, other attendants—including those in the consumer-

directed model—have had their wages held flat for years due to Medicaid rate cuts and roll-out of managed care. Without adequate wages, people with disabilities can't attract and retain workers, and in some cases will be forced into institutions, which are more costly than home and community settings, but guaranteed to be funded. NY must fund a living wage for CDPA attendants.

## RESPONSE TO THE JP MORGAN CHASE SETTLEMENT PLAN

NYAIL is pleased that Governor Cuomo is committing nearly \$440 million for housing programs, including those for vulnerable populations. However, his allocation plan has major gaps. The lack of affordable, accessible, integrated housing is the biggest barrier to people with disabilities and older adults living independently in the community. NY's *Olmstead* compliance efforts can't be successful unless the dearth of housing options for people with all disabilities is addressed. These settlement funds present that opportunity. NYAIL specifically urges adoption of the following strategies as part of the JP Morgan Chase allocation plan to increase affordable, accessible, and integrated housing and we support the Governor's *Olmstead* commitment to reduce the long-stay nursing home facility population by 10% over the next 5 years.

### 1. A portion of these funds should go to Access to Home.

The proposed plan earmarks \$19.6 million for veterans to get home modifications through their own Access to Home program. While NYAIL supports this, it creates a huge inequity, as the rest of the Access to Home program is funded with a \$1 million re-appropriation, which is woefully insufficient to meet the need. The 2012-13 budget cut this program by 75% and it has yet to be returned to its previous level of \$4 million, an amount already proven inadequate.

Access to Home, through the NYS Division of Homes and Community Renewal (DHCR), provides funds for home modifications so people with disabilities and older New Yorkers can remain in their homes and out of costly institutions. For many people, adding a ramp to the front door makes the difference between being able to leave the house and being homebound. As people transition back into the community, the need for accessible housing will only grow. The MRT acknowledged the crucial role this program plays and committed to a modest increase through the supportive

housing allocation fund last year, but it is still severely underfunded.

### 2. Increase access to housing rental subsidies for people with disabilities who are institutionalized or at risk of institutionalization due to lack of affordable, accessible, integrated housing.

The proposed plan commits approximately \$166 million to increasing existing supportive housing programs for seniors, veterans, victims of domestic violence, and formerly incarcerated and homeless people. The plan funds a housing model that for the targeted population is not the most integrated setting and not the type of housing they would choose. There are many people with physical disabilities living in institutions strictly due to lack of housing; they could transition if provided a housing subsidy. NY should use JP Morgan settlement funds to support a housing subsidy program for people with disabilities who are institutionalized or at risk of unnecessary institutionalization due to lack of affordable, accessible, and integrated housing.

### 3. NYAIL supports funding for the Residential Emergency Services to Offer Home Repairs to the Elderly (RESTORE) program, and recommends more funding to expand eligibility to people with disabilities.

RESTORE pays for emergency repairs to eliminate hazardous conditions in homes owned by older New Yorkers who can't afford to make the repairs in a timely fashion. Eligibility is limited to homeowners age 60 or older whose income doesn't exceed 80% of the area median income. NY should expand eligibility to include people with disabilities who need home repairs to ensure that they can maintain full independence in the community.

## PUBLIC POLICY PRIORITIES

### Housing

- Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law. A.3059 (Weprin).

Landlords often reject tenants with rental subsidies, such as Section 8 and subsidies tied to the NHTD and TBI Medicaid waivers. Many people with disabilities rely on subsidies and other assistance programs to live independently in the community.

- Incorporate inclusive home design/visitability features in new residential housing that receives financial aid for construction from federal, state, county, or local governments.

Most existing housing was not built to meet the needs of people with disabilities, including disabilities acquired as one ages. Housing built with basic accessibility features—known as “inclusive design” or “visitability”—is less expensive than renovating existing structures and allows friends and family members with disabilities to visit.

- A tax credit for purchase, construction, or retrofitting a principal residence to achieve universal visitability pursuant to standards adopted by DHCR. A.1276 (Lavine) and S.2967 (DeFrancisco).

This bill complements NYAIL's Visitability bill by offering incentives to homeowners to include visitable standards when constructing or retrofitting their homes. Most people don't consider this when building homes, but as people age or become disabled, these features are highly desirable.

### Civil Rights

- Incorporate ADA Title II into NYS Human Rights Law. A.136 (Paulin) and S.1405 (Marcellino).

- Waive the State's sovereign immunity to claims under the ADA and Section 504.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act provide comprehensive protection for the civil rights of people with disabilities under federal law. Under the 1999 US Supreme Court *Olmstead* decision, people with disabilities are entitled to receive services and supports in the community and avoid unwanted placement in nursing facilities and other institutions. ADA Title II provides protections against discrimination due to disability in services provided by public entities, including state and local governments. In 2009 and 2010 NY's legislature passed a bill to incorporate Title II into state law, but Governor Paterson vetoed it. This bill would require public entities to make reasonable accommodations, including in the provision of services, programs and activities, and people with disabilities would gain critical access to the enforcement mechanisms of the State Division of Human Rights. More than 30 other states have incorporated Title II into state law with no increased costs reported.

### Employment

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

Working-age New Yorkers with disabilities have a 34.5% employment rate (*Disability*

*Matters*, Center for Independence of the Disabled in New York, 2011). The poverty rate for people with disabilities in NY is 17% higher than for nondisabled New Yorkers. This tax credit would be an incentive for small businesses to hire people with disabilities, increasing their self-sufficiency.

- Add disability-owned businesses to the Minority and Women Business Enterprise (MWBE) program. A.2910 (Weprin) and S.2342 (Marcellino).

NY needs to encourage self-employment by including New Yorkers with disabilities in the state procurement program. Businesses could be certified in the Minority and Women Business Enterprise process under a “disability” minority classification. This would not increase the current percentage, but would allow participation in the program.

## TRANSPORTATION

- Cap paratransit fares at the same level as the base public transit fares for nondisabled people.
- Require transportation providers, such as taxis and limousines, to buy accessible vehicles.

Limited availability of accessible transportation is a major barrier for people with disabilities throughout the state, often leading to unemployment, inability to access medical care, lack of access to voting sites, and isolation from friends, family, and full community participation. Many people with disabilities rely heavily on paratransit services but public transit budget woes have led to an increase in their cost. Transit fares that are higher for people with disabilities than nondisabled citizens are discriminatory. Increased availability of accessible transportation will result in considerable savings to the state Medicaid program, as the cost of paying for ambulettes to transport wheelchair users to medical appointments will decrease significantly.

- Establish a visor communication card for people who are deaf and hard-of-hearing.

This bill would provide all deaf or hard-of-hearing drivers with a visor communication card that explains procedures to assist deaf or hard-of-hearing drivers during traffic stops. The Department of Motor Vehicles would provide the card after payment of standard auto registration fees.



# STIC NEWS

## MFP – Money Follows the Person

by Dacia Legge

As we wait for our official name change, the expanded MFP project is underway and referrals are coming in from all over the twelve-county region we serve and oversee. STIC is excited about our partnership with AIM in Corning, ATI in Cortland, and CCFI in Oneonta as we serve Allegheny, Broome, Cayuga, Chemung, Chenango, Cortland, Delaware, Otsego, Schuyler, Steuben, Tioga, and Tompkins Counties. This federal demonstration project provides supports for individuals who are leaving long-term institutional settings and helps them transition into integrated, community settings.

Participation in this project is voluntary and the first phase focused on those in nursing homes, rehabilitation facilities, and hospitals. We have worked closely with social workers, discharge planners, ombudsmen, and other agencies that serve this population and we are excited to further our outreach and networking opportunities. The expanded program now includes individuals leaving developmental centers and ICFs.

### Who is eligible?

Individuals who:

- have Medicaid or are eligible for Medicaid/managed long-term care, and

- have lived for 90 or more consecutive days in a hospital, nursing facility, developmental center or ICF, and

- would like to move back into their home or apartment that is owned or leased by them or a family member, or

- would like to live in a community residence that DOES NOT have more than 4 unrelated individuals residing there

Another addition to this program is a peer outreach component. Each region is looking for peers who have transitioned from institutional settings into integrated, community settings. STIC is looking to compile a list of peers with varying characteristics (age, gender, disability type, and history/experience of living in an institutionalized setting) to work with those using the MFP project. Selected peers will receive paid training and fees for providing services. The peer training will be tailored to each peer’s specific ability, and we are looking for those in OPWDD settings and former residents of nursing facilities or rehabilitation settings.

### How can I learn more about MFP and/or Peer Outreach and Referral?

Contact:

Peg Schadt: (607) 724-2111 ext. 386 (voice/TTY)

Dacia Legge: (607) 724-2111 ext. 314 (voice/TTY)

Email: [MFP@stic-cil.org](mailto:MFP@stic-cil.org)

# Accessibility Advocacy Committee (ASAC)

by Sue Hoyt

The ASAC committee is an advocacy group at STIC that works with local business to help make our community more accessible. We focus on issues such as parking, building access, accessible bathrooms, and much more. We have been a committee for a little over two years and have been working on several local issues to improve accessibility.

ASAC would like to recognize and thank a few of the businesses that have made efforts to become more accessible.

- **Lourdes Primary Care** – Upper Front St., Binghamton – for correcting signage in their handicapped parking spaces
- **Port Crane Post Office** – for re-stripping

their lot with correct handicapped spaces

- **Lourdes Breast Care Center** – for their fully accessible mammography rooms and machines for people of all abilities

We applaud your efforts and would like to point you out as an example to other businesses in the area. Thank you on behalf of people of all abilities.



## Haunted Halls Spring Preview

by Bill Bartlow

2015 will mark our 6th. Annual Halloween celebration and fundraiser.

Construction of new attractions is well underway, including remodeling of the Mad Scientist's morgue/autopsy area, relocation of the Psycho Circus, and replacement of the Creepy Children's Toy Box. We are also introducing a new feature: the Black Out Zone. If you weren't afraid of the dark before, you will be now.

We have also renovated our reception area, affording a larger indoor pre-ticketing space. As the weather can be unpredictable in late October, this will help eliminate the outdoor waiting line. Your goose-bumps will be from the haunt, not the wait.

The demented butcher has gotten completely out of control. He has spread his carnage to engulf the majority of the beginning of the haunt. Even the walking-dead zombies scatter when they hear his chainsaw. The catacombs and cemetery will be updated with additional ossuaries and crypts for the restless departed. After

passage through a long dark tunnel we'll encounter horrific visions of Tolkien's Mordor and Dante's Inferno. Then you can try to return to the "real world": take the bridge and the stairs back to the surface. There you can try to escape through a maze of pallets, fencing, and fog, past the spotlights and guard towers to freedom.

We will again feature live fire-spinning performances. Refreshments and souvenir Haunted Halls of Horror merchandise will be available.

Our redesign guarantees new frights for 2015.

**We're Excited:** This March HHH's staff will attend the international haunt exposition, "Trans World," in St. Louis. This three-day experience will keep us on the leading edge of new developments and industry techniques. We'll bring it all back to ensure that we remain Binghamton's premier Halloween attraction and provide our visitors with a memorable time.

**Help raise funds** for the Haunted Halls by attending a **Binghamton Senators hockey** match vs. the Rochester Americans on Saturday April, 18, at 7:00 p.m. at the Floyd L. Maines Veterans Memorial Arena. By purchasing your ticket through STIC, a portion of the cost will be donated to HHH.

**Watch our Website:** [www.hhh-stic.com](http://www.hhh-stic.com) for build schedules, volunteer orientations, workshops, and fundraising events.

We couldn't present this Halloween adventure without the support of our many dedicated volunteers and the generous support of our sponsors, advertisers, and patrons. Southern Tier Independence Center extends huge thanks to all those involved in our first five years of operation, during which we raised \$140,000 to help those with disabilities in our community.

**You can participate.** Bring your enthusiasm, ideas, and talents to the show.

Contact Todd & Bill at:

[media@stic-cil.org](mailto:media@stic-cil.org)

[development@stic-cil.org](mailto:development@stic-cil.org)

(607) 724-2111 (voice/TTY)

## NOW HIRING!

### Habilitation Support Staff

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

Applicants must have:

Flexible hours

Valid driver's license.

Starting Wage: \$12.00/hr

Please email your resume to:

[hr@stic-cil.org](mailto:hr@stic-cil.org)

# SELF HELP

FREE TRAINING FOR PROFESSIONALS!

## **Hands Across the Service Systems: Learning, Sharing, and Understanding Developmental Disabilities and Mental Health**

May 20, 2015

8:00 am – 4:00 pm

STIC is working to establish a permanent source of free cross-training and continuing education for professionals in our community who are involved with people who have both mental health and developmental disabilities.

The target audience is medical, education, social service, public safety, social work, and other professionals who work with people with mental health disabilities, developmental disabilities, or both. Up to 300 people may attend.

Our goal is to present a complete overview of the services available in Broome County to people with co-occurring mental health and developmental disability diagnoses. This approach will help professionals understand:

- what is available to whom,
- how to access service resources, and
- how we can work together to support people with these disabilities in our community.

Keynote speakers for this event will include:

Alan Wilmarth, United Health Services  
Ann Marie Peterson, Deputy Director, Broome DDRO2  
Maria Dibble, Executive Director, STIC

The event will feature four one-hour panels, each with four or five presenters, focusing on:

- Children's services
- Treatment services
- Residential services
- Crisis services

Registration begins at 8:00 am. Keynote presentations start at 8:30. Light refreshments will be served.

We're still working out the details. Watch for our invitation later this spring!

## **SAVE THE DATES**



### **Children & Youth Services Information Fair**

Broome County Coordinated  
Children's Services Initiative (CCSI)

The Children's Services Fair is designed to give you an overview of the many different programs that are offered in our community for children who have involvement in the following areas: Department of Social Services, Purchase of Services Programs (for children with an open DSS case), Family Court, Child Protective Services, Sexual Abuse, Family Court, Mental Health Services, Substance Abuse, Juvenile Delinquency, PINS, Developmental Disabilities, Special Education, and other community services.

**The Children's Services Fair is free and will be offered on three different days, with each day dedicated to a specific area of services.**

A panel of speakers representing agencies that work in the service area will provide up to date information on program services & eligibility requirements for children & youth in Broome County.

#### **Please Save These 2015 Dates**

**Wednesday April 15**

**Purchase of Services Programs: 9 am to 12 pm**  
(for children with an open DSS case)

**Wednesday May 6**

**Mental Health Services: 9 am to 12 pm**

**Monday June 1**

**Other Community Services: 9am to 12 pm**

#### **Location:**

Southern Tier Independence Center  
135 E. Fredeick St Binghamton NY

Questions? Please Call Deb Faulks at (607) 723-8313 x 821

To Register: please email Jennifer Roy at [Jennifer.Roy@dfa.state.ny.us](mailto:Jennifer.Roy@dfa.state.ny.us)



## Are You Ready?

by Sue Ruff

Are you and your family prepared for emergencies? Have you put together a “go-kit” to take with you if you have to leave home due to emergencies such as floods?

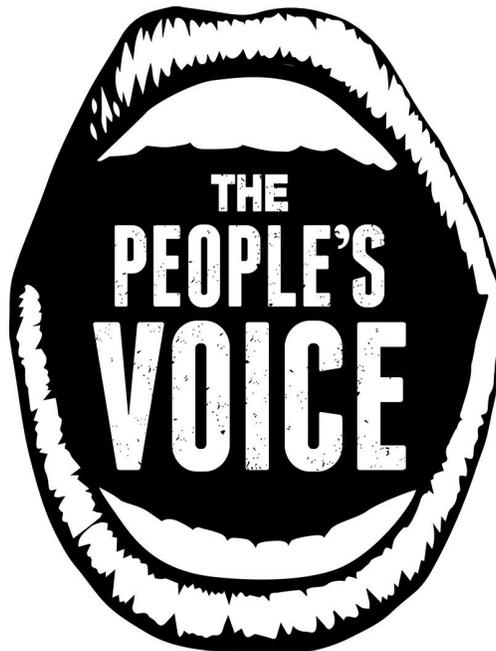
Join us at STIC on Saturday, April 18, 2015. Jill Deskins from the Red Cross is working with STIC’s Emergency Preparedness Committee on presentations and materials to assist people with disabilities and their families in preparing for emergencies. The doors will be open from 9-3 and trainings will run throughout the day; people do not have to stay for the entire time.

Jill will offer information about the Home Fire Preparedness Campaign (which includes family disaster planning) and “The Pillowcase Project” (for children 8-11). The Home Fire Preparedness Campaign can assist people with fixing or getting smoke alarms in their homes. Watch for more information on STIC’s website as April approaches.

## The People’s Voice

by Mary-Lou Ayers

Amazing! Educational! Enlightening! Those are the words that flash into my head when I remember my trip to the NYAIL Legislative day in Albany on February 11, 2015. As I complete my bachelor’s degree in Social Work, I also intern at STIC. This



experience was an excellent opportunity to expand my educational experiences.

As I walked the marble halls, I was awe-struck, marveling at the architecture and vision of our forefathers walking these same halls a century ago. It was a humbling experience.

In the conference room of Senator Libous’ office, with its dark mahogany table and deep red leather chairs, I realized that my voice makes a difference. As our group spoke about various NYAIL issues, it dawned on me the monumental task we were accomplishing. We were entrusted with conveying the people’s voice to the government. On this trip, I got to know the other advocates from STIC and to appreciate first-hand their dedication and enthusiasm. I never envisioned myself being active in policy and advocating at the state capital, however after this trip to Albany, I cannot wait until I participate again.

## Living in the Community Independently through Self Direction Services

by Anonymous

I’ve been living in the community independently through self direction services for a year as of March 3, 2015.

I have supports living in the community. I enjoy being responsible, paying taxes, bills. I enjoy making choices for myself. I enjoy going shopping for food. I enjoy taking good care of my apartment.

I really enjoyed looking for a job. I found myself a job at a fast food restaurant and I like it very much.

I go to Self Advocacy meetings every week. I also do horseback riding, bowling, Special Olympics. Sometimes I go to the gym, bike riding, fishing. Freedom to make choices on my own. I even enjoyed going to parades. I’ve gone to baseball games and basketball games. I am also making friends in the community on Facebook/Internet.

# COMMUNITY PROGRAMS

## **Aspire Dance Company - Inspiring Change through Dance**

by Tina Christina-Price

Aspire Dance Company is an entertainment group dedicated to changing the perception of dance and disability. This group is comprised of mixed-ability dancers who are committed to challenging their physical limitations and transcending preconceived notions about dance. It uses dance not only as a medium for expression, but also as a tool for inclusion and healing. Mixed-ability dance creates a new vision of integration with exhilarating, poignant, and thought-provoking performances.

This began with one woman who was entranced by the idea of ability. With a background in dance, she knew all the right moves. She loved performing, but something was missing. She searched and she searched, never quite finding her *pas de deux*. Though the years passed, she never gave up; that's when Tina met Rik. A man and his machine, Rik was always up for a challenge. With a strong will and steady grip he knew in a moment it was going to be bliss. They plotted and planned, choreographing just the right steps to balance her nimble toes and his lightweight wheels. After practices and performances they founded a troupe. Together they are Aspire Dance Company.

Check them out:

<http://youtu.be/BckmB9qOQXk>

<http://youtu.be/w25iGDZF05U>

The company is looking to expand. We need dancers willing to explore the endless possibilities when people of mixed abilities perform together. Experience is a plus but not necessary. We are inspired to find the best in everyone.

Please contact Tina Christina-Price at: [tcp@stny.rr.com](mailto:tcp@stny.rr.com)

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## Free Access Is Not Free

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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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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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