

AccessAbility

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Dream Catchers

by Maria Dibble

So often we are subjected to comments about how people “can’t” leave an institution, that they “aren’t ready”, “aren’t capable”, “lack the skills”, and the like. Let me take a moment to tell you about a few people who stood up to those statements and said, in so many words, “I want to live on my own.” “I can do it!” “I *will* do it!”—and they have.

All identifying information has been stripped from these stories, but they are true, and they are reminders that determination and perseverance can do far more than some useless assessment conducted on paper, often by people who never even spoke to the individual.

Consumer A wanted to leave Broome Developmental Center. One obstacle after another was thrown in the path of this person. The more barriers that the “professionals” tried to build, the more determined the person became, and a supportive, assertive, and tenacious Medicaid Service Coordinator assisted the person to develop a practical plan, find an apartment, and face down every new obstacle until the day the person moved out. More barriers were to follow, but this determined individual found a job, and is now working two jobs, studying

for a driver learning permit, and living a fully independent life. So much for those “assessments”. STIC believes in *people*, and we work with them to attain their goals. Sometimes a little belief goes a very long way.

Our second person was living in a group home, was deemed a “behavior problem”, and often ran away. I’m not sure if anyone but the service coordinator ever thought to wonder, “Why? Why is this person running away? Could he be unhappy with where he lives and with whom he lives?” He was told he couldn’t manage his own money. The people at his “home” would give him \$20, and until he submitted receipts documenting how he spent it, he couldn’t get more, more of his own money! His dream, like so many, was to be on his own in his own apartment. Well, it took a few trial and error experiences, but this person now has his own apartment, manages his own finances and takes care of his daily needs. “They” said he’d never succeed, but he proved them wrong, as many will if given the opportunity to try.

Our third example has worked for years to be on his own and no one believed it could ever happen, except of course the members of the

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support system he had at STIC. He moved from Broome Developmental Center to a group home where he faced many artificial barriers invented by “the professionals”. Now, after several years, he has his own place, with support staff who help with any day-to-day issues that may come up but do not interfere with his freedom.

His service coordinator said, “He went from a person who depended on others to tell him what his life was worth, to a person who is able to advocate for himself while remaining confident in his decisions. Most importantly, he is proud of everything he has done and has made the decision to become a fully independent adult. Words cannot express how grateful I am to work with him, and see him so excited for his future.”

Some people say that dreams never come true, but I’m here to tell you that they do. I’ve seen it over and over again. It may take time and a lot of work, and a support system that believes

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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.

in the dreamer, but it can happen. Yes there are sometimes setbacks, but don't we all have those? Isn't that a part of being human? And trust me, these are all vibrant, successful human beings who deserve our support, our applause, and then for us to move on to the next dreamer so she can finally have her dream come true as well.

We need to stop judging people based on a piece of paper written by someone who doesn't have the time to get to know the person she is evaluating. We need to stop and take the time to listen to the people we serve, to listen to their dreams and help them come true. We have to stop placing a value judgement on someone else's dreams, based on what we think, feel and believe. The barrier builders always pounce on any mistake a person makes in the community, as if this is proof that the person will never succeed. I think just the opposite. Those mistakes, or "failures" as some like to call them, are simply building blocks to a stronger and more independent person.

I'll end with one final example. There was a blind woman who was told, in 1983, that she could never run an Independent Living Center. After all, how could she do a budget if she couldn't see? Of course a talking calculator removed that particular "barrier". She was told that she didn't really have leadership skills, she didn't have enough experience, etc. That was a

long time ago. We had one grant of \$100,000, and under her guidance, STIC grew to what it is today, an agency employing over 500 people, with an \$11.1 million budget.

Have I made mistakes along the way? Yes, I've made some big ones! But I've striven to learn from each one and grow stronger for it. Have I done it alone? Of course not! I have wonderful, talented people working with me, and together we've made my dream come true, and that dream is STIC.

Is my story different because I don't have an intellectual disability? In some ways, yes. But we must never assume that people with intellectual disabilities don't dream and can't achieve their goals. They can, with help, just like me, and each and every one of you.

Want to see more? OPWDD has produced a video that tells more stories like these. You can check it out at: www.opwdd.ny.gov/opwdd_services_supports/stories_transition

Want to learn more? OPWDD's new brochure is for you:

www.opwdd.ny.gov/news_and_publications/brochures/general_information/get_into_it



Riding the Waives

Last time we reported that the state Department of Health (DOH) had been prodded to involve "stakeholders" in its plans to transition the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Medicaid waivers to managed care. Since then there have been several meetings between DOH and stakeholders. DOH has provided a detailed transition plan that has evolved in response to criticism.

At this point there is still debate on the details.

DOH wants to move as many of these services as possible into the Community First Choice (CFC) program, which is a Medicaid State Plan service option that will gain the state a higher amount of federal Medicaid matching dollars. DOH is promoting a model in which managed care organizations (MCOs) would purchase State Plan services such as CFC as necessary for individuals. DOH says that the Regional Resource Development Centers (RRDCs) would carry out "service needs assessments" and recommend purchase of

various services to the MCOs, which would make the final decision. DOH also insists that people already in the waivers will not be subjected to "capitation" in managed care. This seems to mean that they will be able to continue to draw down funds from the state on an as-needed basis without the MCOs acting as fiscal gatekeepers. However, DOH makes no such promise for new enrollees.

The service definitions in the CFC program broadly encompass most of what's available from the two waivers today. However, because they are not precisely the same, there is argument about what is actually covered. Those arguments can probably only be resolved by the actual regulations that DOH must issue to implement the program.

However, DOH has no credibility with most advocates or consumers of waiver services. The disrespectful and unresponsive behavior of various officials charged with administering these programs over several years has come back to haunt the agency. Even if new

people with new attitudes are now in charge, no one trusts DOH to back them up.

So as this process has been going on, advocates have been working with state legislators to delay or block the movement of these waiver services to managed care. In early February Assembly Committee on Health Chairman Richard Gottfried introduced a bill that mandates DOH to meet several specific requirements in order to proceed. Included is provision of service coordinators who aren't employed by the MCO and have caseload

limits of 17 people, and a requirement to provide services that are “substantially comparable to those services offered to ... waiver participants.” The bill requires provision of housing subsidies, subject to legislative appropriation. It restores the statewide Neurobehavioral Resource Project, which provided individual consulting to people whose traumatic brain injuries cause challenging behaviors. And it requires DOH to offer a “high needs” rate so MCOs will be able to serve everyone eligible for these services “in the most integrated setting appropriate” and,

presumably, stop rejecting them as “too high-need” as they are doing today. On February 18, Senator Hannon, Chairman of the Senate Health Committee, introduced an identical bill in his house.

We believe these bills are a very good start. And we remind everyone that the text of the final regulations implementing the program, including quality assurance measures to make sure that MCO needs assessments are fair and that MCOs follow genuine person-centered planning procedures, will be crucial.



TRANSFORMERS 237: REVENGE OF THE BUREAUCRATS

The state Office of People with Developmental Disabilities (OPWDD) has been busy this winter. The agency released a draft application to renew its Medicaid Home and Community Based Services (HCBS) waiver, and “instructions” to sheltered workshops on how they can “transform” themselves. The agency’s hand-picked “Transformation Panel” also released a draft set of recommendations. Just before we went to press, they published a batch of “reports to the Legislature,” one of which was the final Transformation Panel report. Meanwhile, the semi-official “Housing Task Force” hosted by the NYS Association for Community Residential Agencies (NY-SACRA) released a report on “Housing for People with Developmental Disabilities in New York State.”

As you read this, the public comment periods for the waiver renewal, OPWDD’s workshop transition plans, and the Transformation Panel recommendations have passed. STIC submitted comments and encouraged others to do so. We did not have time to fully analyze the reports to the Legislature but can include a few interesting points here.

The waiver renewal application still does not allow for a separate, discrete safety supervision service like the Home and Community Support Services option available from the TBI and NHTD waivers.

Those two waivers have that option because they never had an infrastructure of segregated congregate programs that they could rely on to include supervision as part of doing other things. OPWDD’s planners still do not seem to understand that they can no longer rely on such an infrastructure continuing to exist.

Not everybody with a developmental disability needs safety supervision. But a lot of them do, and they have a legal right to live outside of segregated programs. It is indefensible to insist that they be involved in “meaningful activity” in order to get it.

This issue is an example of the problems that bundling services with buildings and programs cause. We urged OPWDD not only to create a discrete waiver safety supervision service, but also to stop bundling services,

especially “residential habilitation” services, into group-rate packages. Group-rate “res hab” is a major reason why people living in group homes go on “van rides” or group trips to the zoo instead of being supported to go separately to different places at different times. The rates don’t pay enough to provide individual support. Group rates are also why, if you don’t have a home of your own, and you don’t need 24/7 support at home but you need more than 3 hours a day, you must accept a restrictive 24/7 “supervised” residential setting. The CMS regulations require OPWDD to offer every waiver participant the option of receiving whatever amount of services they need in an ordinary home, or in a single-person apartment if they choose. Bundling is a big reason why the agency can’t comply with that requirement today.

We don’t have room to cover our other objections to the waiver renewal application here.

The Transformation Panel’s recommendations were mostly good—but vague, with no details on how they will be implemented.

We supported most of the recommendations but we strongly opposed one: a plan to “advocate” for an amendment to the NY State Department of Health (DOH)’s Medicaid Section 1115 “Partnership” experimental waiver to bring managed care to OPWDD services. Managed long-term care is being rolled out to other groups under this waiver with not-so-

good results. People are being denied necessary services and in some cases, managed care organizations (MCOs) are refusing to accept them as being too “high need.” The Panel claims it needs the 1115 waiver to maximize “flexibility.” We think they want to avoid complying with the rigorous requirements for conflict-free case management, community integration, and real person centered planning that come with the HCBS waiver regulations.

The report did contain slightly more detail on increasing flexibility of housing supports; the Panel at least appeared to understand the need to enable people to get no more and no less than the specific amount of residential support they need, even in group homes.

As we reported last time, OPWDD’s second-draft version of its “options” for converting sheltered workshops into “integrated employment settings” was barely changed from its first draft. It still allowed sheltered workshops to operate as segregated congregate places of employment with only cosmetic changes. The options would let workshops have workforces consisting of 99% people with some type of disability, and only 1% nondisabled co-workers. Despite our comments and those of others, in December OPWDD went ahead and issued “instructions” to workshops on how to apply for approval for “conversion” plans that included those options largely unchanged. All we can say is, OPWDD entered into a legally binding agreement with CMS that none of its money will be used to support sheltered workshops beginning in 2020, and if any of that money is used for that purpose after that date, OPWDD can expect to be sued.

OPWDD’s report to the Legislature on its Residential Request program (formerly “NY-CARES”) contained some very interesting data from the agency’s survey of people on the waiting list for housing supports:

“60.7% of caregivers said that they would like their family member to remain living at home if they had more services.

Over 90% of respondents are interested in learning about residential options other than those that provide 24/7 staffing support.

62.0% reported preferring a residential setting where services and supports are provided by an agency.

32.8% of caregivers reported that owning or renting a home where needed supports and

services would be available was desired for their family members.”

These numbers bear out what we have been telling OPWDD for years: A growing number of people want fully integrated individualized options, preferably in ordinary homes. And the younger the individual and/or their family member, the more likely they are to prefer integration.

The report also noted: “Higher behavioral health support needs are often a more important factor in determining the urgency of placement needs than the intensity level of direct support needs. Providing enhanced assistance for families with loved ones with behavioral support needs is critical.” We have said for years that if OPWDD would increase the availability of behavioral support services to families, the number of families seeking outside placement of their loved ones would drop. This supports our request that the agency stop viewing its Intensive Behavioral Services option as a crisis-intervention program only for people who are in imminent danger of sending a family member away.

As we have also said, the agency needs to expand availability of respite services, something requested by over 50% of respondents. The agency is still “studying” that issue, which has been ongoing for 20 years. Why are they so reluctant to do anything about this?

The Housing Task Force report was surprisingly good. It conveyed clear recognition that segregated group housing is not desirable and its use should be curtailed over time. It called for a number of positive measures to ensure that organi-

zations wanting to provide fully integrated housing supports in ordinary homes will have adequate funding and regulatory support to do so. The Task Force is funded by a federal Balancing Incentives Program (BIP) grant, which at least should provide its organizers a seat at the table as the Cuomo Administration makes decisions about housing.

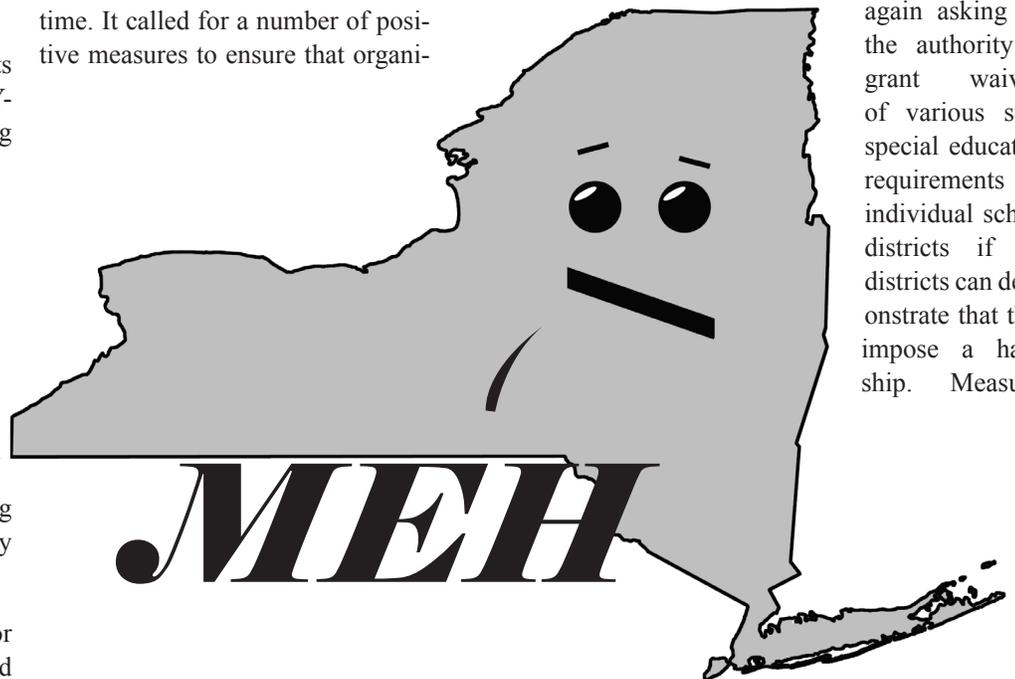
NY State Budget: Meh...

It’s budget time again. Owing to STIC’s closure due to a plumbing problem, it’s unlikely that you will be reading this in time to be able to affect the outcome, so we’ll keep it brief, and let you know what happened in June.

Cuomo included his two perennial nasties: ending “prescriber prevails” in Medicaid prescription drug coverage, both for managed care and fee-for-service, and ending “spousal refusal” for recipients of community long-term care Medicaid. We’ve explained why these things are bad so many times that we’ll just suggest you check our back issues online if you need a refresher.

Cuomo proposed level funding in the state’s general-operating contracts for Centers for Independent Living like STIC. Last year’s \$1 million increase, the first in 11 years, got mostly snatched out of our hands because the State Education Department decided to use some of it to fund two new contracts. This year we are asking for a \$5 million increase, and at press time there was some support for this in the Assembly.

Cuomo is once again asking for the authority to grant waivers of various state special education requirements to individual school districts if the districts can demonstrate that they impose a hardship. Measures



for evaluating the legitimacy of such requests and ensuring they are not used to violate the federal Individuals with Disabilities Education Act are lacking.

There are some good things in Cuomo's proposals also.

As usual, there is a lot of money allocated for housing, and it's hard to figure out how much of it will fund new housing for people with the lowest incomes, as opposed to renovating existing units or building "affordable" housing for people with middle-class incomes. We are in favor of anything that will reduce the state's community housing shortage for people with disabilities, as long as people with disabilities are not required to accept bundled in-house services in order to get a place to live. As usual, there's too much of that sort of thing in the budget too.

OPWDD would get an additional \$15 million to expand its START mental health crisis program around the state, something we've been requesting for years.

Behavioral Reform for People with Social Bigotry Disorder

A new bipartisan federal bill contains some of the ideas in Congressman Tim Murphy's (R-PA) "Helping Families in Mental Health Crisis Act," but leaves out that bill's most obnoxious points. It's called the Comprehensive Behavioral Health Reform and Recovery Act.

The bill provides a lot of new money for grants and demonstration programs to expand mental health services. It also requires better enforcement of federal mental health parity legislation, clarifies that HIPAA does not forbid mental health practitioners to disclose information to family members or law-enforcement agencies when it is appropriate to do so, and expands Medicaid and Medicare coverage for people with mental health disabilities.

HIPAA Clarification

The bill requires the Department of Health and Human Services (HHS) Office of Civil Rights (OCR) to issue new regulations to clarify the "guidance" it published on Health Insurance Portability and Accountability Act (HIPAA) information disclosures in February 2014. That guidance makes it clear that

practitioners can disclose information about people with mental illness who have not authorized disclosure, if it will reduce a serious likelihood that the person will harm him or herself or others. The information can be given to family members, friends, and law enforcement, if the practitioner believes that the information recipient can actually help.

Some medical providers prefer to avoid making hard decisions about this and they blame HIPAA for it, but HIPAA has never prevented them from releasing information to prevent a tragedy. In fact many states have laws requiring them to do so, and HIPAA does not override them. However, the law always has prevented providers from giving information to people about adults with mental illness merely because family members falsely believe they could help, or that they have a "right to know". The new bill will turn the "guidance" into regulations, which may be easier for people to understand and follow.

Medicaid and Medicare Expansions

Federal law has, for decades, explicitly excluded most people with mental illness from receiving Medicaid-funded long-term care or specialty services for reasons that that we don't understand. This bill will remove a few of those limitations.

It will add a new type of institutional "level of care" to the list of those that qualify people for Medicaid Home and Community Based Services waivers: psychiatric residential treatment facilities for children. A "level of care" is just a minimum qualification for admission.

The bill will allow children in an "institution for mental disease" (IMD) who are eligible for Medicaid to receive the full array of Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services that other Medicaid recipients under the age of 21, including those in an ordinary hospital, are entitled to.

The bill codifies into law recent regulatory changes allowing Medicaid managed care programs to pay for short stays (15 or fewer days) in an IMD for crisis stabilization. It also

removes the statutory requirement that the Medicaid Emergency Psychiatric Demonstration Project, which has successfully allowed 11 states to let people in crisis use fee-for-service Medicaid to cover stays in IMDs, be renewed by act of Congress.

If a child on Medicaid is incarcerated in a juvenile detention facility, states would no longer be allowed to terminate her Medicaid; they could only suspend it for the duration of the detention, theoretically enabling faster resumption of coverage when the child is released.

And finally, the bill would eliminate the 190-day lifetime limit on inpatient psychiatric services under Medicare.

Increased Requirements for States to Provide Services

States would have to use at least 5% of their Community Mental Health Services block grants "to support evidence-based programs

that address the needs of early serious mental illness, including psychotic disorders."

States would be required to have "assertive outreach and engagement programs that seek to engage individuals with serious mental illness in comprehensive services to avert relapse, repeated hospitalizations, arrest, incarceration, suicide,

and to provide these services in the least restrictive setting." This includes peer support, Assertive Community Treatment, "Housing First" supportive housing for homeless people, and other good things, all of which are completely voluntary on the part of people with mental health disabilities.

State Medicaid programs would have to "allow payment for mental health or primary care services provided at a community mental health center or a federally qualified health center when the mental health service was received on the same day as the primary care service, if those services are not already provided as part of a bundle or other payment arrangement."

Enforce Federal Parity Rules

"Mental health parity" means that health insurance plans must not limit the types or amounts

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contains some of the ideas in Congressman Tim Murphy's (R-PA) "Helping Families in Mental Health Crisis Act,"
but leaves out that bill's most obnoxious points.

of services that they cover for mental illnesses or substance abuse that they do not limit in the same way for people with physical illnesses or injuries. The federal law requiring this is full of loopholes, however, and has not been enforced.

The bill would require HHS to study the extent to which insurance companies exploit loopholes and issue a report to Congress. It would also require “greater disclosure by insurers and increase audits and enforcement by the federal agencies responsible for implementing parity. It requires [HHS] to conduct randomized audits of ... health plans ... to determine compliance with parity.”

New Grant Programs

The bill contains a lot of these, and they are all worthwhile, though most don’t come with a big checkbook. Here are a couple of especially nice ones:

There would be new grants for state mental health agencies to establish an internet-based, real-time “bed registry,” including available beds in inpatient psychiatric facilities, residential crisis stabilization units, and residential community mental health and substance abuse treatment facilities, to make things easier for just about anyone trying to help someone in an emergency. It authorizes \$15 million per year for five years beginning September 2017.

HHS would get \$20 million a year for the same five years for “grants, contracts, or cooperative agreements ... to assist local communities and schools in applying a public health approach to mental health services both in schools and in the community, [which must] provide comprehensive

age-appropriate services and supports, ... be trauma-informed, and incorporate age appropriate strategies of positive behavioral interventions and supports.”

Murphy’s Law

The “Murphy Bill” is still out there, under consideration by the House Energy and Commerce Health Subcommittee, the same committee in which the new bill was introduced.

Murphy’s bill has two really bad provisions:

It would forbid Protection & Advocacy for Individuals with Mental Illness (PAIMI) programs to advocate to protect the civil rights of people with mental health disabilities, especially their right to refuse inappropriate treatment or to have their information inappropriately released. PAIMI programs could only advocate to protect people from “abuse or neglect,” narrowly defined.

It would make receipt of additional federal funds for mental health services contingent on beefing up so-called “Assisted Outpatient Treatment” programs (known in NY as “Kendra’s Law”). These programs allow people with mental health disabilities to be court-ordered into treatment upon the complaint of people who may or may not be qualified to determine whether they need it. As we’ve said before, Kendra’s Law provides a benefit not often understood: Most people with serious and persistent mental illness that threatens their safety or that of others voluntarily ask for help but are turned away. Kendra’s Law forces *the state* to provide treatment when it otherwise would not, more often than it forces treatment on people who genuinely do not want it. However, because people who

are in serious danger are either already seeking treatment, or can be persuaded to accept it voluntarily, and because Kendra’s Law is more often invoked against people of color than against white New Yorkers, the forced treatment approach is a bad idea and should be scrapped.

Advocates hope that the new comprehensive bill will put Murphy’s repressive measure in the shade, and that, because the new bill has bipartisan support, it can be passed by both houses. However, since it contains a lot of new spending, it’s got a difficult road ahead. Stay tuned.

Nothing Succeeds Like Success

The “Every Student Succeeds Act,” a bipartisan bill, was passed and President Obama signed it in December 2015. It has stronger expectations for students with disabilities than its predecessor, the Elementary and Secondary Education Act aka “No Child Left Behind.” This is a win for disability education advocates, who were facing the prospect of losing ground they’d gained in the previous law.

Like its predecessor, the new law requires schools to achieve minimum test scores to demonstrate that they are functioning effectively. The old law let schools administer less-difficult tests (“alternate assessments”) to an unlimited number of students with disabilities, but they could only report 1% of those scores as part of the total required for compliance.

The new law forbids schools to use alternate assessments for more than the 1% of their stu-



dents—those with the most significant cognitive or intellectual disabilities. And schools cannot prevent even those students from working toward the same levels of achievement as other students.

The law also requires school districts to reduce the use of restraint and seclusion, devise measures to prevent bullying and harassment, and use disciplinary techniques that don't rely on removing children from classrooms.

While the new law has higher expectations, it has weaker enforcement than No Child Left Behind. State education departments, not the federal government, have primary enforcement responsibility. That's a potential problem in New York, whose State Education Department has failed to aggressively enforce the special education provisions of the federal Individuals with Disabilities Education Act (IDEA), and whose Governor wants to grant waivers for compliance with special education requirements to school districts.

Feds Stand up to States on Homecare

In February, the federal Centers for Medicare and Medicaid Services (CMS) announced new regulations to remove the "homebound" limitation on Medicaid Home Health Services.

CMS stated some years ago that this service cannot be limited to a person's home and must be provided as needed in community settings. The new regulations codify the change.

It's important to remember that Medicaid Home Health Services are a required element of any State Medicaid Plan, and they are not the same as State Plan Personal Care services, which are optional for states. Home Health services are medically-oriented services provided through Certified Home Health Agen-

cies (CHHAs). They include things such as assistance with taking medication, catheterization, and ventilator maintenance.

New York's CDPA program allows attendants to perform these tasks without being licensed or supervised by a CHHA. However, CDPA is not available to people who cannot self-direct their services and do not have someone to serve as their Designated Representative.

CMS is also prohibiting states from imposing arbitrary limits on medical supplies, equipment or appliances under Medicaid, such as orthotics, prosthetics, pressure stockings, nutritional supplements, and other things that New York has tried to limit in the past.

Unfortunately, these changes do not affect Medicare regulations. The new Medicaid regulations will take effect on July 1, 2016.

Flawed-ism Action NY

NYS Assemblyman Angelo Santabarbara has presented a set of legislative proposals called the "Autism Action NY" plan. The proposals contain some good ideas but are oriented toward family members of autistic children, and do not provide autistic people with a strong voice in determining what services will be available to them. The package includes:

State Autism Spectrum Disorder Advisory Board (A.8635)

The board appears to be the initial step in creating a separate administration for autism-related services. The bill's language calls for the board to receive and direct the expenditure of funds to "implement" those services. That sounds like an infant state agency to us.

We don't think a new disability service "silo" is a good idea. It will support a divide-and-conquer approach by those who oppose disability rights, as well as interfere with efficient and fair distribution of funds and create eligibility barriers for people with multiple disabilities like those we see for people who have both developmental and mental health disabilities.

We agree with advocates that any advisory board on disability services should consist of a majority of people with disabilities, and not state agency administrators or nondisabled people.

Autism ID Card (A. 8389)

The idea here is to provide an official government-issued card identifying the bearer as

autistic and providing information to "first responders" (such as police or firefighters) about the person's condition so as to avoid unpleasant events. The bill language states, "The card shall contain a statement explaining autism spectrum disorders, and how they may give rise to physical agitation and impair an individual's ability to communicate or respond to directions."

This is similar to the proposal by some Deaf advocates that they have a state-issued card for use with police during traffic stops. However, a card explaining that you don't understand spoken English is quite a bit different from a card explaining that you might be difficult to deal with.

People should think about whether it's really a good idea to have a state-issued ID card officially identifying a person as likely to become "physically agitated." Moreover, expecting a police officer to take time to read a long printed statement about a person who is behaving in a threatening manner before responding is unrealistic.

A better approach is to support advocates calling for universal training of first responders concerning behavioral issues related to various disabilities.

Home Loan Program (A.8696)

This bill would make available no-interest loans for families to construct semi-separate apartments in their homes for adult family members who have developmental disabilities or who are over the age of 62. The loans can be for whichever is lower, up to 50% of the total development cost or \$50,000. Repayment can be deferred, presumably, until the owner sells the home or it is disposed of by the owner's estate. The program would be available to families whose incomes are less than 80% of the median income in the area where they live.

This is probably a good idea for some people. We support advocates who believe that a similar program should be available directly to people with disabilities who wish to have a home of their own, not under the control of family members.

We would also point out that 80% of the median income in some areas is a lot of money, and the state shouldn't subsidize people who can afford to do this. We agree with advocates who urge that such programs be available to people with the lower incomes more typical of people with disabilities.



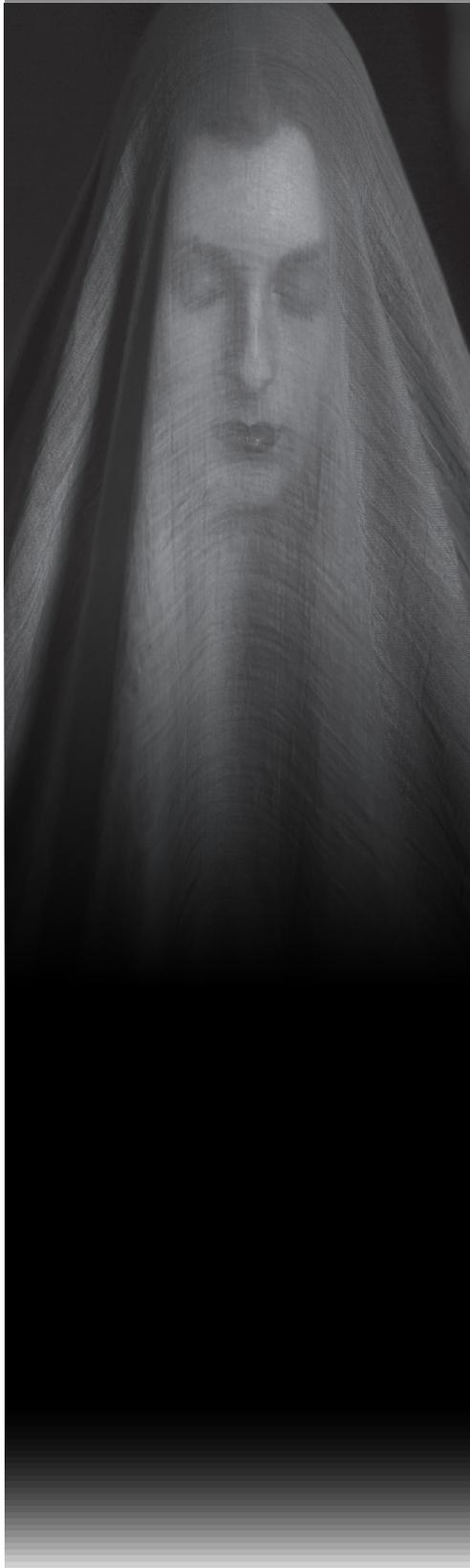
This bill would require the state vocational rehabilitation agency, ACCES-VR, to pay for communication support services. These services would be available to people with “pragmatic language impairment,” among other diagnoses. That impairment is linked with autism

spectrum disabilities and recognizes issues with communication as a neurological processing problem, not a “social development” issue. Examples include not understanding jokes, or subtleties distinguishing truth from falsehood, or not grasping the impact of non-verbal signals. Services include training and coaching to help people better interpret what’s

going on, as well as to defuse tense situations that result from misunderstandings.

The bill would make the services available as part of a vocational rehabilitation plan, which would limit use of the service to the context of getting and keeping a job.

We support the provision of this service.



ASSISTED SUICIDE: LIFTING THE VEIL

There are two bills to legalize assisted suicide before the NY State Legislature this year: Assemblywoman Paulin’s “Patient Self-Determination Act” and Assemblywoman Rosenthal’s “New York End of Life Options Act.” The bills are somewhat different. Neither is “better” than the other, though each has “better” provisions on some points. Both of them drape a veil of privacy over some very dangerous beliefs and actions.

Rosenthal’s bill allows persons aged 18 or over to ask a doctor to write a prescription for lethal medication. Paulin’s bill is restricted to persons 21 and older.

Both bills allow assisted suicide only for people who have a disease that is considered likely to result in death within six months. However, Rosenthal’s bill requires that the disease be both incurable and irreversible, and that the determination requires reasonable “medical” judgment. Paulin’s bill doesn’t contain those requirements; it can be read to mean that anybody’s “reasonable” belief that the disease is terminal is sufficient. You might think this last is a minor quibble, but it opens the door for people who believe they have a terminal disease to sue doctors who won’t help them die because they don’t agree with them.

Rosenthal’s bill requires that anyone requesting assisted suicide be provided with information about options, such as the availability of palliative/hospice care and pain relief. Paulin’s bill does not require this specific information be provided to patients.

Rosenthal’s bill requires that anyone seeking assisted suicide from a physician must be referred by that physician to another physician for a second opinion on whether the person’s

condition is indeed terminal, and on whether the person has capacity to consent. Paulin’s bill does not require a second opinion, but leaves it up to the doctor’s discretion.

Rosenthal would require the doctor to specifically offer the person an opportunity to change their mind before they write the prescription. Paulin would not.

Rosenthal’s bill specifically allows someone other than the person requesting death to pick up the medication from the pharmacy; Paulin’s bill is silent on this.

Rosenthal’s bill imposes Class A felony penalties on anyone who forges a request for a lethal prescription or coerces someone to make such a request. Paulin’s bill has no penalties.

Rosenthal offers a loophole for doctors whose employers forbid them to write lethal prescriptions; they can “contract” directly with the patient. Paulin’s bill doesn’t have this clause.

Both bills require that a death by lethal prescription cannot be considered “suicide” or “assisted suicide” for any legal purposes.

Several disability rights advocates, including STIC, have spoken out publicly against physician-assisted suicide. Consistently around 70% of the general public disagrees. Their responses to advocates are usually very dismissive, and fall into three categories:

“You’re a religious extremist.”

Religion plays no part in our opposition and never has.

We oppose these types of assisted suicide bills for two reasons:

courts watch

First, “six months to live” is not a scientifically valid prediction. Every year hundreds of thousands of Americans who were told they have less than six months, live well beyond that time. Doctors make mistakes: Many people are told they have a fatal illness when in fact they have a different, treatable issue.

Second, these bills don’t protect people with disabilities from being pressured or coerced by caregivers to kill themselves; in fact, they don’t protect people with disabilities from being murdered by those caregivers if they change their minds about taking the medication once they’ve picked it up from the drugstore.

“You’re an expensive burden on the taxpayers and your families and you should off yourself.”

This callous and shockingly common attitude fully explains why we oppose these bills: They won’t protect a person with a disability from being killed by someone who feels this way.

“I don’t want to suffer and you have no right to tell me I have to.”

This one arises, in many cases, from people’s lack of knowledge about what their options really are. Any New Yorker who is near death from a terminal illness already, today, has the right to:

- refuse treatment
- refuse food and water
- request enough pain medication to make them comfortable, up to and including being rendered unconscious until they die

New York law provides these options through hospice services, either in a hospital or at home, which means that impartial witnesses are involved and ensure that the person actually made their own choices and was not manipulated by others.

As the New York Association on Independent Living (NYAIL) says, both bills are “simple immunity statutes, protecting everyone involved in the death except for the patient, no questions asked.”

NYS Senate Majority Leader John Flanagan has announced that he is opposed to assisted suicide, making adoption of these measures unlikely, at least this year. Stay tuned.

Peoples v Fischer: Final Settlement

This was a class-action lawsuit in federal District court alleging that the NY Department of Corrections and Community Supervision (DOCCS, the state prison system) routinely relies on solitary confinement as a first-resort punishment for minor infractions, resulting in significant mental illness and frequency of suicide attempts among inmates (see *AccessAbility* summer 2013 and spring 2014).

In February the NY Civil Liberties Union announced a final settlement agreement with DOCCS. The highly detailed 78-page agreement was awaiting approval by the federal judge at press time.

In brief, the settlement will remove about 1100 people, including those who have served the longest sentences in solitary confinement, people with developmental or substance abuse disabilities, and children, from solitary con-

finement to more “rehabilitative” settings with treatment programs, day activity rooms and more recreation opportunities.

Twenty thousand guards will be re-trained to focus on “de-escalation” techniques designed to defuse tense situations with prisoners. And the state would commit to spend some \$62 million to implement the settlement, including re-designing prison spaces to make more rehabilitative programs and environments available.

Just about all authorities, including prison administrators, agree that long-term solitary confinement is harmful and tends to cause mental illness. Most experts say that more than 15 days in solitary is dangerous, so it is difficult to see how this settlement will fully address the problem. However, it does represent progress in a battle that goes back to the days of the Pataki Administration (see *AccessAbility* Fall 2006).



NYAIL Agenda

(abridged)

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs are controlled and primarily staffed by people with disabilities. ILCs 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’s 2016 legislative priorities support implementation of the state’s Olmstead Plan by addressing barriers to community living and ensuring individual rights. We urge the Legislature to support the following priorities:

PUBLIC POLICY PRIORITIES

HEALTH

- Authorize an exemption to the Nurse Practice Act to allow for advanced home health aides to perform certain tasks under the supervision of a registered nurse. A.7188 (Glick) and S.5855 (Parker).

The establishment of Advanced Home Health Aides (AHHAs) is crucial to fully implement the Community First Choice Option (CFCO), a long-term services and supports system for all people to access as an alternative to nursing facility/institutional placement, regardless of age or diagnosis. This amendment to the



Nurse Practice Act (NPA) would allow non-licensed professionals, who will be trained and certified, to perform assistance with health-related tasks.

HOUSING

- Make discrimination by landlords based on a tenant's source of income, such as Section 8 and subsidies tied to the Nursing Facility Transition and Diversion and Traumatic Brain Injury Medicaid Waivers, illegal under State Human Rights Law. A.3059 (Weprin).
- Incorporate inclusive home design/visitability features in new residential housing that receives financial assistance for construction from federal, state, county or local governments. A.6402 (Simon) and S.4597 (Krueger).
- Enact a tax credit for purchase, construction or retrofitting of a principal residence to achieve universal visitability.

Housing built with basic accessibility features—known as “inclusive design” or “visitability”—would meet the needs of people throughout the lifespan and allow homes to be visitable by friends and family members with disabilities. A tax incentive to include visitable features when constructing or retro-fitting homes will increase the stock of housing with basic accessibility features. The tax credit will also ease the financial burden of retro-fitting a person's home after they acquire a disability, which helps keep people out of unwanted and costly institutions.

In the 2015 legislative session, the legislature passed a bill to do this. Governor Cuomo vetoed it but agreed it should be addressed in the “upcoming State Budget.” Yet he failed to include a visitability tax credit in his proposed budget. A tax credit would help keep people in their homes and out of institutions. NYAIL calls on Governor Cuomo to include a visitability tax credit in the State Budget.

CIVIL RIGHTS

- Waive the State's sovereign immunity to claims under the ADA and Section 504. A.5388 (Lifton)

The Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973 each provide comprehensive protection for the civil rights of people

with disabilities under federal law. However, people with disabilities cannot sue the State for violations. This bill would allow the State to be sued in State or Federal court for any violation of the rights of state employees under the ADA. In addition, it will ensure the right of people with disabilities to bring a civil action against the state for failure to provide access to services, programs and activities provided by New York State to people with disabilities.

- Establish basic civil protections for people with intellectual and developmental disabilities in the guardianship process. S.4983 (Ortt).

Currently a family member can obtain “full” guardianship over an adult with a developmental disability without demonstrating that the individual has any actual incapacities that affect their ability to make sound decisions. This bill provides legal protections for the person with the disability and imposes limitations on the guardian's powers.

EMPLOYMENT

- Establish a small business tax credit for the employment of people with disabilities. A.5513 (Cusick) and S.4093 (Addabbo).

Working-age people with disabilities in the State have a 31.6% employment rate, resulting in an employment gap between people with and without disabilities of 41.1% (*Disability Status ADA 25*, CIDNY, 2015). The poverty rate for people with disabilities in NY State is 17% higher than for nondisabled New Yorkers. This tax credit would provide an incentive for small businesses to hire individuals with disabilities, increasing the opportunities for New Yorkers with disabilities to achieve gainful employment and self-sufficiency.

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

The State needs to encourage self-employment business opportunities by including New Yorkers with disabilities in the State procurement program. Peers could have businesses certified in the Minority and Women Business Enterprise process under a “disability” minority classification.

- Direct ACCES-VR to include communication support among the suite of vocational rehabilitation services currently offered. A.5141 (Santabarbara) and S.4256 (Carlucci)

Many individuals with disabilities may have difficulty with interpersonal communication that can hinder their ability to find and maintain employment, even when they possess job skills, higher education, and access to existing vocational rehabilitation services. Communication support is defined as a range of services focusing on improving communication-related skills.

TRANSPORTATION

- Require transportation service providers, such as taxis and limousines, to buy accessible vehicles.
- Cap fares for paratransit at levels no higher than the base fares for transportation of non-disabled adults using the public transit system. S.3720 (Espaillat).

Charging higher transit fares for people with disabilities than for non-disabled citizens is discriminatory. Period.

BUDGET PRIORITIES

INDEPENDENT LIVING CENTERS

NYAIL urges the Governor to increase base funding for ILCs to \$18 million. This much needed increase of only \$5 million is long overdue and essential to sustaining IL services statewide.

ILCs have been woefully underfunded for the past twelve years and have been losing ground. After receiving level funding for eleven years, ILCs finally received a much needed \$1 million increase in the 2015-16 fiscal year. This was intended to provide each of the existing 39 state funded ILCs with a \$25,641 increase. While this amount doesn't come close to making up for eleven years with no cost of living adjustment, given the rising cost of doing business—including the costs associated with general operating expenses, health insurance, workers compensation insurance, disability insurance, etc.—it was a start. However, SED used a significant portion of the increase to create two new centers. As a result, existing centers did not receive the fiscal relief this modest increase was intended to provide.

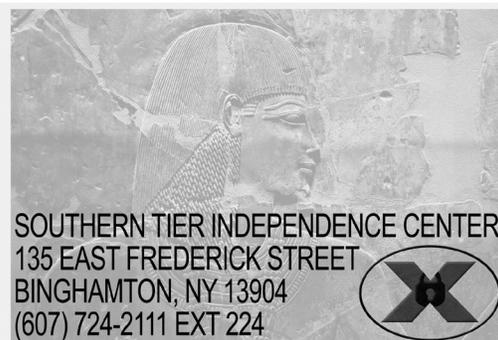
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In 2013/14, the state's network of ILCs served 91,769 people with disabilities, family members and others. This demonstrates the pressing need for IL services in communities. ILCs provide critical services to people with disabilities, all designed to assist them in navigating the ever-changing service system in order to live independent, fully integrated lives in the community. As the state continues to redesign health care, ILCs play a crucial role. ILCs provide services to address the social determinants of health: education, employment, housing, social skills.

Furthermore, adequate funding of ILCs is essential to ensure successful *Olmstead* implementation in NY and would result in additional Medicaid savings to the State. Data from ACCES-VR show that the work of ILCs to transition and divert people with disabilities from costly institutional placements **saved the State more than \$1.8 billion since 2001 as a result of avoided institutional care. ILC transition and diversion activities save the State more than \$9 in institutionalization costs for every state dollar invested in ILCs.** The State has an unprecedented oppor-

tunity to use ILCs to assist in implementing *Olmstead* and the Medicaid Redesign Team's reforms affecting people with disabilities. The State should invest savings from implementation of CFCO into ILCs over several years, ultimately bringing the State appropriation to \$25 million. **NYAIL urges the State to increase IL funding to \$18 million in 2016-17.**

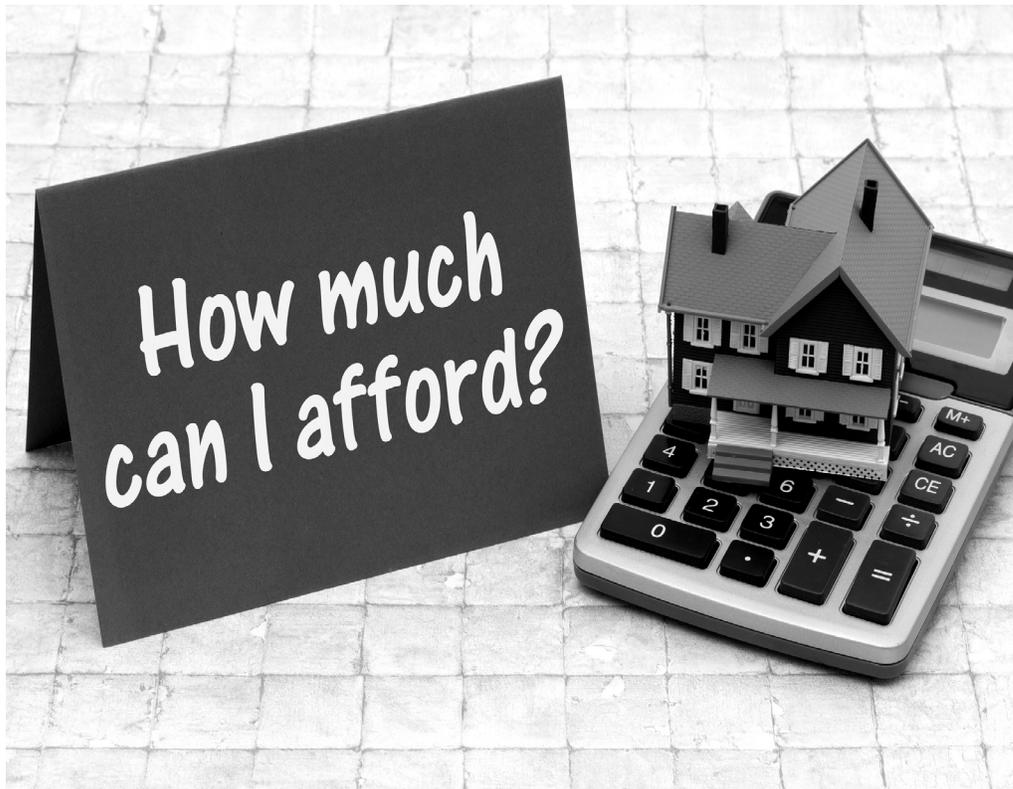
HEALTH/MEDICAID

NYAIL strongly opposes prohibiting a spouse or parent from refusing to financially support their child or spouse in order for that individual 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 in the budget, the refusal will only be honored and Medicaid be granted if a parent lives apart from their child or if a spouse lives apart or divorces the potential Medicaid recipient. This proposal will force low-income individuals to institutionalize their loved ones purely for financial reasons, creating a discriminatory institutional bias.

New York must maintain the current Community Spouse Resource Allowance. NYAIL strongly opposes Governor Cuomo's proposal to lower the Community Spouse Resource Allowance to \$23,844, the minimum allowed by federal law. Currently, NY allows a community spouse to keep the maximum allowed by federal law. As New Yorkers face some of the highest costs of living in the country, this makes sense. Reducing the resource limit to the lowest allowed by Federal law will have dire consequences for the community spouse, who is not on Medicaid and who may require assets in order to pay his or her own medical expenses.

NYAIL strongly opposes eliminating Provider Prevals. This proposal would repeal an important patient protection in the Medicaid program that restored "prescriber prevails" for several classes of drugs in the fee-for-service and managed care programs. We believe that prescribers are in the best position to decide what drug therapies are best for their patients, not Medicaid administrators. NYAIL urges the State to protect Provider Prevals.

NYS must ensure funding for overtime and travel to prevent a crisis in continuity of



care. The new Federal Labor Standards Act (FLSA) regulations requires attendants be paid for travel time and time-and-a-half for any hours worked over 40 per week. However, this rule did not come with additional federal funding to ensure that attendants would actually be paid more for overtime, meaning agencies would be forced to cap attendant hours at 40 and put consumers at risk of unnecessary institutionalization. The State must ensure these vital services are not interrupted by changes to the labor law and develop a rate for overtime and travel within CDPA.

Fully fund the Community Health Advocates (CHA) program at \$4 million. The CHA program helps with navigating the complex health care system. Since 2010, CHA has assisted 240,000 New Yorkers to obtain coverage, saving the State \$15 million. Governor Cuomo proposed funding the CHA at \$2.5 million, however the program requires \$4 million to maintain current services. We urge the legislature to ensure full funding for CHA.

Expand funding to the Independent Consumer Advocacy Network (ICAN). ICAN provides individual, independent consumer assistance services for people in Medicaid managed care who receive long-term care services. NYAIL calls on the legislature to increase funding to ensure the ICAN program can expand as more people join Medicaid managed care.

ACCESS TO HOUSING

Broaden eligibility to the JP Morgan Access to Home funds. The JP Morgan allocation plan in the 2015-16 budget earmarked \$19.6 million for Access to Home, a successful program administered by NYS Homes and Community Renewal (HCR) that provides funding for home modifications to allow people with disabilities and older New Yorkers to stay in their homes and out of costly institutions. This is significant as the program has been severely underfunded at only \$1 million for many years. Unfortunately, the eligibility for this new funding was limited to veterans with disabilities. This was not the original intent and HCR recommended an amendment to the appropriation language in the 2016-17 budget to broaden eligibility. This change is further supported by the fact that HCR only received \$3 million in applications during the 2015 Access to Home for Veterans funding round, despite there being \$6 million available.

As NY continues to implement *Olmstead* and more people continue to transition back into the community, the need for accessible housing will only increase. NY should use JP Morgan Chase settlement funds to adequately fund Access to Home for all people with disabilities.

Ensure access to shelter for people with disabilities who are homeless. NYAIL com-

mends Governor Cuomo for proposing to spend \$10 billion to address homelessness and the inadequacies of the shelter system by adding 27,000 new beds and services. Part of this proposal includes inspection of shelters to address health and safety violations, but it also needs to include inspecting shelters for accessibility. Too often people with disabilities are rejected for shelter placement due to inaccessibility and instead sent to nursing homes. The State must ensure that supportive housing is accessible. We urge the legislature to support this proposal and to include an audit of whether emergency homeless shelters meet the physical, communications and program requirements of the Americans with Disabilities Act Title II.

ADDITIONAL BUDGET PROPOSALS

Establish an Office of Community Living. NY must better align state services in a way that breaks down silos and makes services more responsive to people's needs. The 2015-16 budget called for a stakeholder process to examine the feasibility of creating an Office of Community Living (OCL) in NY. This process resulted in a report that identified several gaps in existing services and areas for improvement in coordination of service delivery. Unfortunately, this year's Executive Budget does nothing to advance the proposal further. The state must move forward with the creation of an OCL. Such an office would be strongest if it focused on the needs of individuals—regardless of age or disability—to live independently. We think NY could effectively combine aging and disability services under one state agency to create this new office. At a minimum, the State should create an OCL with disability and *Olmstead* as the focus. NY must not stall creation of an OCL any longer.

New York State must fund the proposed minimum wage increase. Increasing the minimum wage to \$15 an hour without commensurate funding to human services and Medicaid-funded programs will gravely hurt people with disabilities and the organizations that serve them. ILCs rely on a State appropriation for operating expenses—including core staff—and are already severely underfunded. Without a commensurate increase, ILCs will have to cut back on programs that enable people with disabilities to live and receive services in the community.



STIC NEWS

Disabled Veterans Welcome

by Michael Tamm and Maria Dibble

The Veterans Outreach office here at STIC is not the government and does not work for the government per se. No matter what the state of a veteran with a disability's military discharge is, STIC can and will still help them!

While we intend to assist and welcome all veterans with disabilities, our priority is those who are most vulnerable: those with less than honorable discharges due to any number of things that render them ineligible for federal benefits from the Veterans Administration, sweeping them under the carpet and furthermore shaming them needlessly, placing them all too often on a course ending in poverty and/or homelessness. These are the people we want to reach before that happens.

Hundreds if not thousands of men and women who served our country have been dishonored



and stripped of earned entitlements and left twisting in the wind. These are the disabled veterans made to believe that there is no support available to them because of some so-called "dishonor."

Military service labeled "other than honorable", or worse, cannot negate or completely discount the service given by the veteran. Leaving the disabled and shamed veteran to fend for him or herself is not how this office will conduct business. It is our intention to aim this office's ability at the most vulnerable and forgotten veterans of solid military service, who have had their honors stripped due to any number of possibly spurious and minor offenses, such as behavioral issues related to head injuries or post-traumatic stress syndrome, and including "offenses" that may not even bear on the quality of their military service, such as sexual orientation.

Other veterans with disabilities, who have honorable discharges, retirement benefits or pensions may not think they need the help of this office as desperately, but we have much to offer even those veterans in a better financial position. We can help with housing, information about a wide variety of supports in the community, peer counseling (a friendly ear to hear about your life and your needs) and much more. See our website for details: www.stic-cil.org/services.html

We will work with all disabled veterans no matter what their disability or discharge status.

Contact: Michael Tamm

Email: veteran@stic-cil.org

Phone: (607) 724-2111 ext. 391

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9:00 am to 2:00 pm

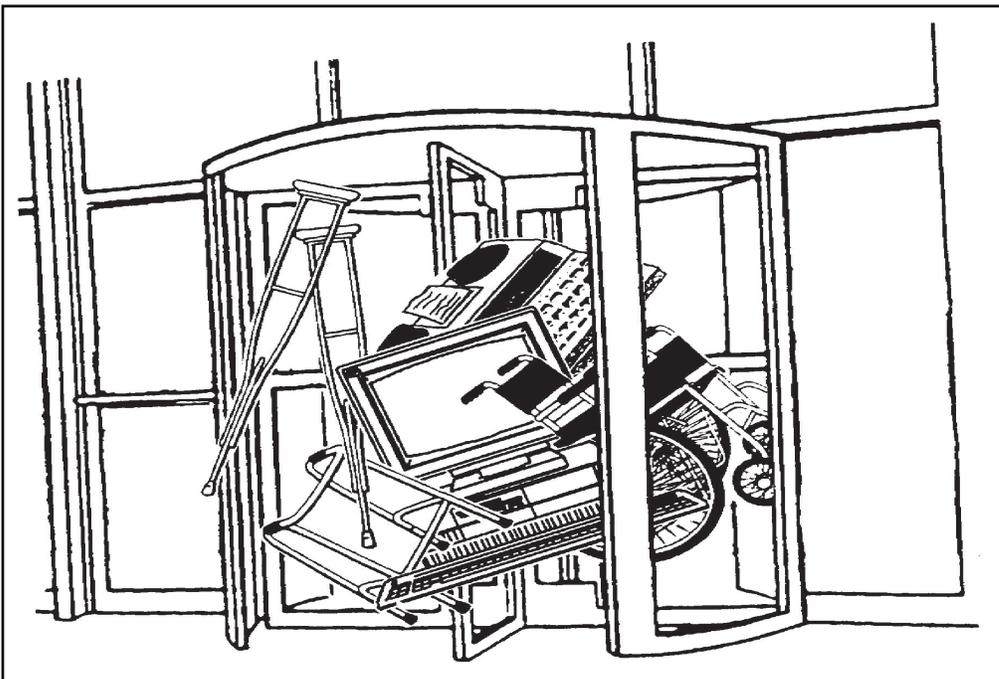
5 more years! 5 more years!

by Kevin Jackowski

The votes are in and Albany has spoken. STIC has been awarded the TRAIT (Technology Related Assistance for Individuals with Disabilities) grant once again. This means funding is in place to keep the TRAIT loan closet open for 5 more years.

From walkers, canes, crutches, and wheelchairs to shower chairs, tub benches and more, we have equipment that can be loaned out for 60 days free of charge. These loans can be used to try out a piece of equipment before you go through the process of getting one for yourself. Let's be honest, sometimes an insurance company will push back on buying equipment you need. Being able to tell them you know a piece of equipment will work because you borrowed one and it met your needs can be a useful justification. And even when the insurance company approves a piece of equipment, it always takes time to get it. These loans can be used to fill that gap as well.

This TRAIT program is available to individuals of all ages with any disabilities, their family members, service providers, employers, educators, and any others who are interested in assistive technology (AT) and disability issues. The TRAIT Center at STIC serves Broome, Chenango, Delaware, Otsego, and Tioga counties. If you or someone you know lives outside of these counties contact us and we'll find the TRAIT center nearest you.



Fair Housing for People with Disabilities

by Joanne Carlyle

Save the Date: May 17, 2016!

Don't miss the opportunity to attend a workshop where you will learn about Fair Housing Laws, protection for persons with disabilities and reasonable accommodations. There will be discussion on the definition of a service animal and public accommodations for them. We will have local property managers available to discuss what they offer, with rental properties, waiting lists etc.

This will be open to tenants, landlords, property managers, service providers, and real estate professionals. Other persons interested are welcomed to attend.

More detailed information will be sent out at a later time.

SELF HELP

Resources for Supported Decision Making

(from ASAN, the Autistic Self Advocacy Network)

Are you a person with a disability? Do you have a right to make choices in your life?

Are you under guardianship? Does your guardian make choices for you that you don't want?

Do you have the supports that you need to make decisions about where to live, what to do, how to spend money, or when to see a doctor?

Have you been advised to seek guardianship of your child? Are you looking for alternatives to guardianship? Do you wish that there were better alternatives than the ones you've seen?

If you're wondering about any of these questions, our new guide will help. This guide helps people with disabilities understand decision-making laws. You will learn about different kinds of support you can use to make choices. You will also learn about how people in different countries have changed their laws to help people with disabilities make our own choices. Freedom to make our own choices is a human right.

The toolkit comes in two forms, with each form tailored to a different audience:

A Plain-Text or Families Version for either those with vision-related disabilities or those who would prefer a version without accompanying graphics:

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf>



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Our Easy Read Edition. The Easy Read version is divided into five parts, each containing one subject discussed in the toolkit: Supported decision-making, guardianship, the Convention on the Rights of People with Disabilities, the state of the law on guardianship and supported decision-making in multiple countries, and the glossary explaining the terms we use in the toolkit.

Chapter 1: Introduction

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-1-Intro-v3.pdf>

Chapter 2: Supported Decision-Making

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-2-Supported-Decision-Making-v3.pdf>

Chapter 3: Guardianship

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-3-Guardianship-v3.pdf>

Chapter 4: Convention on the Rights of People with Disabilities

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-4-CRPD-v3.pdf>

Chapter 5: Guardianship and Supported Decision-Making Laws

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-5-Guardianship-and-SDM-Laws-v3.pdf>

Chapter 6: Glossary

<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-6-Glossary-v3.pdf>

We hope that this toolkit will help people understand the laws on the right to make choices, and on how that right can legally be taken away. Understanding these laws will help people with and without disabilities to advocate for the rights of people at risk for being put under a guardianship. It may also help advocates and policymakers identify legal frameworks that enable supported decision-making as an alternative to guardianships. ASAN created this toolkit in support of a future in which all people with disabilities in all countries can get the support they need without having their decision-making rights taken away from them.

We hope that you find our toolkit useful and distribute it widely.

Please send any concerns, feedback, or comments on how you plan to use the toolkit to ASAN's Director of Public Policy, Samantha Crane, at: srane@autisticadvocacy.org.

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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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Dacia Legge Peg Schadt Pat Myers

NHTD RESOURCE CENTER:

Daena Scharfenstein Danette Matte

Laura O'Hara Ellen Rury Lori Willmot

PTAC: Sue Lozinak Beth Kurkoski

Shannon Smith

PEER COUNSELING:

Jane Long Danny Cullen Robert Deemie

Richard Farruggio Susan Link

PERSONAL ASSISTANCE SERVICES:

Susan Hoyt Pierre Barosy

Katina Ruffo

PSYCHOTHERAPY:

Charlie Kramer Jane Long

RVR-CES:

Tara Ayres Kim Luther Karen Lawrence

SERVICE COORDINATION:

Jo Anne Novicky Marci Germond

Erin Gabriel Jessica Arnold Stacey Engel

Cynthia Meredith Jaime Latimer

Sann Dee Walter Emily Neville

Tammy Virgil Kathy Sas Craig Lucas

Laura DiRenzo Jaye Neiss

Marcy Donahue Angela VanDeWeert

Leslie Hadden Cynthia Lord

Jessica Hinton

SUPPORTED EMPLOYMENT:

Kandi Stevens Amanda Rutty

SYSTEMS ADVOCACY: Susan Ruff

TBI RESOURCE CENTER: Belinda Turck

Janese McElwain Stacey Bischoff

Betsy Giannicchi Jamie Haywood Ellen Rury

TECHNOLOGY SERVICES:

Keesha Agron Kevin Jackowski

VETERANS SERVICES:

Michael Tamm