



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

# AccessAbility

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## PEARLS OF WISDOM

by Maria Dibble

Pearls and diamonds are precious, beautiful and quite valuable, each a marvel of nature and a pleasure to behold. The pearl is a symbol of the thirtieth anniversary, while the diamond is used to celebrate six decades of a successful endeavor.

STIC is pleased to be commemorating 30 years of service to our community, with all of the achievements and obstacles that the passage of time usually entails. For the last three issues I have looked back on our inception, growth and dreams. Now I want to look ahead to what I hope our Diamond Anniversary will be celebrating.

The very best scenario of all would be if STIC didn't need to exist, that our mission was accomplished and all people with disabilities were living integrated, fulfilling and independent lives in their neighborhoods. The pragmatist has to rear its ugly head at this time and say, we won't be there yet. So where will we be?

Not being gifted with clairvoyance, my imagination will have to suffice.

As long as there are people with disabilities, at least in the foreseeable decades, there will be needs to address.

I envision a world where:

✧ The incidence of permanent disability through accidents will be reduced due to

improved surgical techniques and new medicines.

✧ The prevalence of disability from aging will go down because of the availability of new medicines and therapies.

✧ Care for veterans will be significantly better due to improvements in triage techniques, development of new prosthetic devices, and increased understanding of traumatic brain injuries, post-traumatic stress disorder and other wounds of war.

✧ Community integration won't be a buzz word but rather largely a reality.

✧ Every corner will have a curb cut and overall access will be stellar compared to today.

✧ There will be a much greater acceptance of "disability" as just another part of life's circumstances.

So what about STIC?

Well, while it will be our Diamond Anniversary, I'm sure we still won't be a perfect gem. We will remain a "diamond in the rough", reshaping our identity and still responding to people's dreams and aspirations.

For STIC I envision a place where:

✧ People are overwhelmingly in control of their own services, with STIC assisting

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in navigating obstacles that they may encounter.

✧ Ordinary people with disabilities from all walks of life, not just those who are service providers, control the advocacy agenda, taking leadership roles in Albany, Washington and perhaps in the world, while STIC serves in more of an advisory capacity.

✧ STIC will engage in much more policy research and analysis and will advise the disability leadership of our findings and recommendations.

✧ STIC will be at the cutting edge of a completely seamless service system, where Centers for Independent Living will be the single point of access for all services.

And we will continue with our mission to: shape a world in which people with disabilities are empowered to live fully integrated lives in their communities.

# AccessAbility

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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.

# Fanmail for Some Flowers

by Ken Dibble

*Back when we did 50s Sock Hop fundraisers, we used to print a program for the event. This essay first appeared in our Sock Hop program from April 1993. (For those too young to remember, the title is a pun that refers to the now-ancient "Rocky & Bullwinkle" cartoon TV series.) It was reprinted in this newsletter during an unusually cold month of June four years later, when we said that it was not only still seasonally appropriate, but relevant in other ways as well. Now, nearly 20 years after it was written, we're running it again as part of our 30th. Anniversary commemorations. Clearly, many things have changed in that time. We'll leave it to you to decide whether it still speaks to you.*

Every year, as spring approached, my mom used to say:

"Spring is sprung!  
The grass is riz!  
I wonder where  
Them flowers is?"

She would recite this with arched brows and a grin to show she knew it was bad English. Yet the raw exuberance of that little rhyme outdistances a thousand formally arty "Odes to Spring". It is not great art. It is not intended to be. It is a simple, stripped down, highly accurate communication of the excitement and anticipation most people feel as the days begin to lengthen and the snow melts away. As my mother knew, nobody could dispute the meaning of the rhyme, but they could ridicule and discount the rhymers, and thereby miss or ignore the message.

Providing services to people with disabilities should be a matter of simple, direct communication. Instead, it has become an esoteric Art that communicates only with and about itself.

The professionalization of disability services was not originally conceived to meet the needs



of service providers. It is the offspring of a marriage of compassion and ignorance. As with many "scientific" endeavors of the 19th. century, intellectuals seeking the truth got side-tracked onto an obvious, but superficial and ultimately false path. The path became a trail, then a road, then a superhighway leading nowhere. Today, because it serves their needs, its custodians will not admit its uselessness and let it crumble away.

Dorothea Dix, the great 19th. century disability service reformer, toured the nation's institutions in the 1830s and '40s and was appalled by what she found: people chained, naked, lying in filthy straw on cold floors in buildings that were little more than stables. Food was thrown at them. Once in a while the straw was changed. That was the extent of the "services" they got. When she questioned the professionals running these charnel houses, they said, "We just don't understand these strange ailments and deformities; we don't know what to do for them."

Dix said, "Your lack of understanding is no reason to treat them like animals." She began a campaign to embarrass the professionals and the governments that paid them into cleaning up the cells, getting the people off the floor and giving them something to do.

150 years have passed since Dix began her campaign, but that's as far as we've come today. We have (mostly) clean institutions and (most of) the people in them have something to do. Even that basic reform took too long and it still isn't universal. As recently as the early 1970s some people spent their days lying naked on the floor in their own excrement in New York State institutions. Some of the people who worked in or ran those hellholes are still "disability service professionals" in the state system today. That system now keeps its own facilities clean, but still funds some private group home and rehabilitation facility operators who neglect or abuse the people in their charge. And while material conditions



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

for most people with disabilities have improved, understanding of their “deformities and ailments” remains, essentially, at 19th. century levels.

19th. century intellectuals loved to categorize and systemize human behavior in the name of “scientific” theories which usually derived from their personal prejudices. That’s how Sigmund Freud, the “father of modern psychology”, invented his (now repudiated) theory that childhood sexual fantasies cause mental illness. He just could not bring himself to believe that all the stories of sexual abuse told to him by prim middle-class ladies were true. As a result, thousands of psychoanalysts deepened the emotional disturbances of uncounted hundreds of thousands of people. Karl Marx, another 19th. century theorist who worked off the top of his head, made invalid assumptions about human society that eventually led half the world’s people to enslave themselves in the vain hope of a brighter future.

Few strict Freudian analysts are working today, and still fewer Marxists are in power. But most of the disability establishment still embraces

an invalid theory—that people with disabilities are fundamentally different from other human beings. Using superficial 19th. century logic—“They look different, they talk different, so they must *be* different”—most of them still cling to the beliefs that people with disabilities must be separated from other people, must be expected to do less, and must be “protected” in ways which ensure that people won’t accept them as equal. In 150 years, most disability professionals have learned nothing new about the relationship of disability to the human being as a person. So what have they been doing all this time? Creating and refining the Art of Disability Service. Weaving a complex web of procedures, terminology, paperwork, medical mystique and bureaucratic intrigue around the simple act of *treating people with disabilities differently*.

This Art is now so complex that, like the Abstract Expressionists in painting or the Deconstructionists in literature, the artists can only communicate with each other, and then only after years of intensive education. That explains their response when the average person with a disability makes a reasonable request in plain English, such as, “I wonder where them

flowers is?” First they say, “We’ll study it and get back to you.” Then they meet privately and smirk and fret over the unsophisticated style of the request: “Don’t they know this is Great Art?” Then they conclude that the person can’t benefit from flowers, or that the pollen might make them sneeze and is therefore a health risk, or they analyze the word “wonder” and conclude that the person doesn’t really want flowers at all. Finally, months later, they offer a picture of a flower encased in Lucite plastic, and they just can’t understand the “negative” response they get.

Southern Tier Independence Center is controlled and operated by people with disabilities. We treat people with disabilities as people who know what they want, we take their requests at face value, and we expect them to succeed. We are the only disability service agency in the Southern Tier dedicated *exclusively* to treating people with disabilities, and ensuring that others treat them, the same as everybody else. No discrimination, no paternalism, no “shelters”, no “special programs”, for *anybody*. Just people learning, growing: slowly coming into flower after a long winter hidden from the sun.

## WHAT’S THE TRUTH?

As he sought to prevent the closures of Broome Developmental Center (BDC, including the Broome Local Intensive Treatment Unit) and the Greater Binghamton Health Center (GBHC), NYS Senator Tom Libous apparently resorted to misleading claims and irresponsible innuendo, as reported by the *Ithaca Journal* on November 18, 2013.

Here is what Libous was reported as saying, followed by the facts:

Libous: “There are people here who could be extremely dangerous,” Libous said. “Not could be, they are. We do not need these folks in the community. This is a very serious point that has to be addressed.”

Fact: The point has been addressed. When all of OPWDD’s projected closures are completed in March 2017, OPWDD will still have 150 “beds” in two secure settings for people who are objectively determined to require them.

Libous: The *Journal* article reported that Libous said there are “60 forensic inpatients,

including 15 registered sex offenders” in the Broome Intensive Treatment facility.

Fact: “Forensic” includes people who are merely accused—not convicted—of petty offenses and been remanded by judges because they were deemed incompetent to stand trial. When nondisabled people are convicted of like offenses, they are not locked up. They are fined, placed on probation, or required to perform community service. “Registered sex offenders” includes people guilty of misdemeanor “sexual misconduct,” which can mean things like being 16 years old and doing anything sexual with a person who is also 16 and willingly participates, or being an adult with a significant intellectual disability and doing anything sexual with a willing adult who also has that disability. (See page 5 for more information on who really lives in the Broome LIT Unit.)

Libous: The *Journal* article reported this quote from a letter Libous sent to Governor Cuomo regarding the closures of both BDC and GBHC: “The lost capacity from this 235-

bed reduction will push our emergency rooms and county jails past the breaking point, and force hundreds of state employees to leave my district to carry on their careers.”

Fact: This statement confuses results from closing BDC and GBHC and presents a worst-case scenario.

Historically, closures of institutional facilities operated by OPWDD show the agency has consistently ensured that the people who lived in them were enveloped in a system of residential and day activity services that met or surpassed their needs. Admittedly, OPWDD sometimes mismanages an individual’s transition from institution to community, especially when the person wants personalized integrated services instead of cookie-cutter group homes and day programs. However, it is very rare for a person to go from an OPWDD institution to a truly unsafe situation.

Thus, it’s unlikely many OPWDD employees will lose their jobs or have to move away from the Greater Binghamton area to keep them. Instead, their jobs will be transferred to new or expanded residential or day service programs right here in this community.

By contrast, it is common for people with mental illness who are eligible for services funded by OMH or county mental health programs to be underserved. These people often end up in emergency rooms, homeless, or in the county jail. This is because the families of people with developmental disabilities have put together a very wealthy and powerful lobby that has convinced New York's politicians to lavishly fund the OPWDD system. People with mental illness don't seem to tug at the heartstrings as much as cute kids with Down syndrome or cerebral palsy; and they don't benefit from faddish media attention the way that, for example, people with autism do. People with mental illness don't have much money of their own, and they don't seem to have many wealthy backers (except for drug companies, which tend to lobby for more drugs, not more community support services). So the same NY politicians who, over the decades, proudly claimed credit for beefing up OPWDD services, simultaneously supported the dismantlement of the state's mental health services and the transfer of most of the money to pay for things like sports stadiums, failed industrial development schemes, and tax cuts for the wealthy.



The looming danger is that our community, which already lacks adequate mental health services, will lose essential temporary intensive inpatient crisis management services.

Libous: The *Journal* reported that Libous told Cuomo in his letter, "Contrary to advice you may have received, I don't believe these closures are required by federal court decisions or agency directives."

Fact: There are three important issues here: The US Supreme Court's *Olmstead* decision, the OPWDD rate-setting and abuse scandals, and the negotiations with the federal Centers for Medicare and Medicaid Services (CMS) over expansion of Medicaid managed long-term care. We've covered this in detail over the years, but here's a recap:

- *Olmstead* Decision: The Americans with Disabilities Act (ADA), back in 1990, made it illegal for state governments to discriminate on the basis of disability in any programs or services they operate or fund. In 1999, the *Olmstead* decision established that unnecessary segregation of people with disabilities by state governments violates the ADA. It requires that if a state provides support services to people with disabilities at all, it must do so in the most integrated setting appropriate to the person's needs, taking into consideration all of the state's

resources as well as what is necessary to meet the varying needs of all of the people affected. It also provides that people don't have to be placed in a "community setting" if they don't want to. Some people are using this to argue that we don't have to close institutions in New York State. But the fine print in the *Olmstead* ruling also says: "most integrated setting appropriate to the person's needs" is to be determined by qualified disability service professionals who, federal regulations state, must be impartial—not frightened family members, angry state workers, or grandstanding politicians. It also says that states can only protect themselves from justifiable lawsuits on this issue if they have a reasonable, "effectively working plan" to ensure that everyone who can benefit from more integrated services receives them in a timely manner. Later federal court decisions have required states to transfer

existing funds from segregated to integrated settings to meet these requirements. At least one conservative federal judge has agreed that people who don't want to move to a "community setting" are not entitled to stay in any specific institution; the state can instead downsize and consolidate those facilities and group the hold-outs in a single location—and it is the official position of the federal Department of Justice that no one has a "right to remain" in any specific institution; see page 10. None of these decisions entitle anyone not already in a segregated setting to be placed in one.

- Scandals: Beginning in 2010, the Poughkeepsie *Journal* began reporting questionable rate-setting practices at OPWDD, and later that paper and the *New York Times* reported on widespread abuse and neglect at institutions as well as group homes operated or funded by OPWDD. OPWDD was charging Medicaid over \$5000 per person in a developmental center per day, but the actual cost to the agency was closer to \$1200 per day. Further, the federal Medicaid Inspector General found that services in a DC were not substantially different from those provided in community-based ICFs, where the daily cost was closer to \$700.

And it was found that whereas only a small number of people working in segregated facilities were abusers, a much larger number aided and abetted abuse by looking the other way. (An example from a report on the Valley Ridge Center for Intensive Treatment in Norwich, issued by the NYS Commission on Quality of Care and the NYS Medicaid Inspector General, was considered by those authorities, as well as by then-OPWDD Commissioner Burke, to be fairly typical: Across 48 months, 754 instances of abuse or neglect were reported to the facility's investigators. Nearly 20% of those reports were found to be true. Only 2% of those reports were made by the staff though. The rest of the truthful reports were made by the residents or their families.)

- CMS Requirements: Following these events, the Cuomo Administration attempted to negotiate terms for new Medicaid managed

long-term care waivers with CMS. None of these waivers, at press time, had been fully approved; CMS was still requiring more details and assurances from the state. Sources close to the process have reported that CMS officials were outraged by both the abuse and financial shenanigans, and that those officials made it crystal clear that *nothing* would be approved unless OPWDD reversed its reliance on segregated programs. Publicly available evidence of this is plentiful. For example, over the years of the People First Waiver development process, OPWDD downsized its projections of people who would remain in institutional settings from “around 1000” to “about 300” to the current goal of 150, with changes coming after each new round of discussions with CMS. OPWDD officials have also publicly stated that CMS officials have pointed out that 13 states have no institutions for people with developmental disabilities at all, so “it’s hard to justify even one.” The Transformation Agreement between NY and CMS compels the state to carry out its stated closure plans for institutional settings for people with developmental disabilities, not only developmental centers and “special units,” but also so-called “community ICFs.” There have also been well-publicized demands from both Congress and CMS that NY dramatically cut its Medicaid spending and that OPWDD cut its rates.

The evidence is thus overwhelming that the federal courts in general, and the federal bureaucracy in particular, have imposed very clear requirements on NY State to downsize and close as many segregated settings for people with developmental disabilities as possible. It is false, ludicrous, and irresponsible to claim otherwise.

However, this is not the case for temporary intensive inpatient crisis management services. These are not institutions; they are community services, just like hospitals for people with acute physical issues who need surgery or other medical treatment. Federal lawsuits have required the state to stop permanently housing people with mental illness in segregated facilities like adult “homes” or nursing “homes.” But the GBHC is not a permanent residence for anyone. Rather, it’s a location where temporary intensive mental health treatment services are provided—services which are critically needed to enable the people who

receive them to spend most of their lives in integrated settings.

Libous: Allegedly, in speaking of the proposed closures, Libous told Cuomo, “Nor are they likely to save the state much money over time.”

Fact: Again, this confuses the issue. First, there are tens of thousands of New Yorkers with developmental and/or mental disabilities who receive few or no services at all—and that number constantly grows. If we are really going to provide adequate amounts of services to everyone who needs them, we aren’t going to “save” anything. We are going to spend a lot more than we do now. So in one sense, Libous is correct.

The question really is, how much more? If we don’t stop spending money on services we don’t need, we will never be able to serve everyone. We have to reduce *unit costs*—that is, the one-time cost of providing a specific service to a specific person. We can definitely do that. The money facts are beyond dispute and can be looked at in a lot of ways. For example, the federal Medicaid Inspector General recently found that “community ICFs” operated by not-for-profit agencies in NY provide essentially the same services as state-run developmental centers for less than half the cost. A couple years ago, the average cost to keep someone in a state-operated Individual Residential Alternative (IRA) group “home” was over \$150,000 a year; in a not-for-profit IRA that same cost was \$90,000. Various datasets show that savings for serving similar people with similar needs in integrated settings range from 1/3 to 1/5 the cost of serving them in segregated settings. There are always exceptions, but they are rare, and across all of the people served, integrated settings cost considerably less. Nearly all of the people served prefer them too, once they’ve actually experienced them.

OPWDD’s plan is designed to improve our ability to objectively understand what people really need, and make sure they don’t get segregated services they don’t need just because they (or more likely, other people) are afraid they won’t be safe.

Understandably, this threatens unionized state employees and the politicians those unions support. Most (but not all) not-for-

profit service providers are not unionized. But there is no objective evidence that state agencies provide better quality than not-for-profit agencies; among both, quality varies widely from program to program, building to building. We agree that wages for direct care workers in the not-for-profit sector are too low. But since a state-operated service costs at least 40% more than the same not-for-profit service, the state could afford to increase not-for-profit wage scales by a big chunk and still cut those unit costs deeply.

On the other hand, based on what we’ve learned about GBHC over the last few months (see page 7), we don’t think there is realistically much money to be saved by closing that facility. And as we’ve said, doing so would not be closing an institution. It would just be moving critically needed community services out of our community.

Senator Libous has proposed legislation to attempt to delay some of these closures. We don’t want you to think that he is the only locally elected official beating this drum; Assemblywoman Donna Lupardo says she plans to introduce a similar bill.

The bill doesn’t actually change much. It stops any OPWDD closure from happening before April 1, 2015. The Monroe and Wassaic closures are already scheduled for completion in December 2013; it’s unlikely this bill would pass before then. O.D. Heck (Albany) is the next to close, but not until the day before Libous’s deadline. BDC is not scheduled to close until March 2016. The bill actually authorizes potential state psych center closures after April 1, 2015. Although the OMH “Centers of Excellence” plan is supposed to “begin” in July 2014, there is no official closing date for GBHC and nobody believes that it could be closed before 2015. The rest of the bill simply requires both OPWDD and OMH to publish more details on how these transitions will be handled—a good idea, but something they were going to do anyway.

So we know that this is just political posturing for the sake of state employee unions and wealthy lobbyists. Still, the temperature of the rhetoric needs to come way down. Nobody likes to be smeared in the media, do they? That includes people with disabilities. So let’s cut it out and work together to do the right thing.

## Who Really Lives in Intensive Treatment Units?

Since OPWDD announced that the Broome Developmental “campus” will close by March 31, 2016, various people and groups have been campaigning to reverse that decision. The campus includes both Broome Developmental Center (BDC) and the Broome Local Intensive Treatment Unit (LIT). About 140 people live in those places, which employ over 680 workers.

This is an emotional issue for many people. It involves potential changes to people’s livelihoods and obvious changes to living situations. Some family members and state employees, uncertain about the future, and in some cases feeling threatened, can be expected to say almost anything if it might help stop this plan. We understand that.

Less defensible have been statements made by local officials, union leaders, and some of our elected representatives.

These people have claimed that it would be dangerous to close the LIT because allowing its residents to live anywhere else means releasing dangerous criminals and predators into society. The media have uncritically reported these statements and predictably frightened the public.

But these statements are extremely misleading. They are offensive to people with disabilities as well as irresponsible. Here are the facts:

When the Poughkeepsie *Journal* ran its series of articles on the OPWDD rate-setting scandal in 2010, the reporter was told by OPWDD officials that the IT Unit at Wassaic Developmental Center only housed dangerous criminals. However, after filing a Freedom of Information request to learn about the people living in that facility and others around the state, the *Journal* learned:

- About 10% of IT residents had been found guilty of crimes.
- Another 10% had appeared in court on criminal charges and been found incompetent to stand trial.
- Another 12% were in the IT Unit for “elopement” only; that is, they were in some facility or program that they did not like and they tried to leave without permission.
- The remaining 68% were indistinguishable from the people in developmental centers,

and some of them had such severe multiple lifelong physical disabilities that they were completely incapable of any criminal acts, violent or otherwise.

Knowledgeable former high-level OPWDD employees also told the *Journal* that contrary to OPWDD’s claims, the types of services IT residents received to address their “special needs” were no different from standard programs ordinary DC residents attend. STIC staff frequently visited both BDC and the LIT over several years and have confirmed this.

Since 2010, many of these people have been discharged, and so the percentage of IT unit residents who have some involvement with the criminal courts has risen. However, it is not widely understood what sorts of crimes we are talking about.

First, many people are remanded to IT units because they have been charged with a minor misdemeanor and found incompetent to stand trial. Nondisabled people convicted of the same offenses typically get probation, are ordered to do community service, pay a fine, or at worst, spend a small period of time (sometimes weekends only) in the county jail. They are not considered a “danger to the community” by anyone—not even the police.

Second, some people are in an IT Unit because they were provoked to anger by someone who was paid to serve them. We aren’t relying on residents’ claims for this; STIC staff have personally witnessed these exchanges. Some employees deliberately taunt, threaten, or even physically prod the people in their care, who understandably react with anger. Then the victims are blamed for being “violent” and packed off to an IT unit.

Third, some people don’t like segregated settings or the people they are forced to associate with in them. These are adults with no legal restrictions against going where they wish when they wish. Unable to get any reasonable response to their requests for more personalized services in settings that they can control, they will sometimes simply leave. When someone is admitted to a certified OPWDD program, although they are unrestricted “voluntary admissions,” regulations require the staff to track down and forcibly return the person if s/he is absent without leave. Then they may be placed in an IT unit to keep them from doing it again. They are punished for the “crime” of leaving a place they don’t like by being locked up in a place they like even less.

Some people in the IT Units are alleged to be “sex offenders.” Although this is an uncomfortable subject for many, it’s important to understand that the term “sex offender” is very broad. It includes people accused but not convicted of anything. It also includes teenagers “guilty” of statutory rape, and adults with the intellect of a 3-year-old child who were found masturbating in a public place, as well as intentionally violent offenders and pedophiles. Some of the “sex offenses” allegedly committed by the small number of people in IT units are of an innocent nature and do not pose a serious danger to anyone.

There are currently about 300 people in IT Units in NY. If we subtract the people described above from that number and provide adequate personalized integrated supports to them, OPWDD’s plan to keep 150 “beds” open will be plenty. Closing the Broome LIT will not result in people who genuinely need such a placement going without it.

NY State has a serious problem handling petty crimes committed by people who lack both intention and awareness that they are committing a crime. Current judicial practices often result in a completely inadequate and inappropriate response to these situations.

Intellectual disability can’t be cured, and the extent of impairment can’t be reduced in an adult brain. If an adult with an intellectual disability is deemed “unable to assist in his own defense” and is remanded to a facility until they are able to participate in a trial, that’s a life sentence. And so we have people locked up indefinitely merely because they are accused (NOT convicted) of behavior that, if exhibited by a nondisabled person, would result in probation, community service, a fine, or perhaps a brief stay in a county jail. This is clearly wildly unjust.

Solving this problem requires legislation limiting the ability of judges to remand people with intellectual disabilities. It may require creation of “developmental disability courts,” similar in purpose to “mental health courts.” Whichever route, the results must be:

1. No person **accused** of a petty crime and found incompetent to stand trial will be locked up for a period longer than s/he would have been if tried and convicted of that crime.
2. If a person is remanded to an OPWDD facility without meeting the formal eligibility qualifications for admission, then when that person is released, s/he must be deemed eligible for OPWDD community services solely on the basis of the remand.

## **Before You Can be Excellent, You Must at Least be Good**

As we went to press, the Central NY Regional Center of Excellence Team was expected to hold its final meeting and prepare recommendations for the Steering Committee. The formal planning process doesn't allow much more time for input. However, we suspect that process is about to be derailed because the proverbial fertilizer has encountered the wind machine since it was announced.

Politicians and union leaders all over the state hate what little they've seen of the plan and are determined to stop it. Sadly, they are mostly doing it for the wrong reasons, but they may buy us some time to push the Cuomo Administration to think hard, and in detail, about this issue, and maybe they will actually, eventually, get it right.

Since August (see *AccessAbility*, Fall 2013) we've boned up on the issue and learned a lot of new things. We also attended two public hearings, sponsored by state legislators, and presented oral and written testimony. Our application for a slot on the regional team was rejected. STIC provides services to lots of people with mental health disabilities, including psychotherapy and a full range of peer counseling, skills training, and advocacy services, but none of it is funded with state or county mental health money. Apparently only agencies that receive those funds had a shot at getting on the team. There are some good people on it though, and we wrote a brief paper explaining our local issues and sent it to every single member of that team and to the Steering Committee. We've also had some personal conversations with some of those people.

Here is what we said:

The adequacy of community mental health services varies across regions of the state. Assumptions made about the availability or quality of a particular program model based on experience in one region of NY may not hold true for other regions. Central NY RCE Team planning needs to consider actual conditions in the Greater Binghamton Region.

Community mental health services in this region are completely inadequate to meet the need. The community mental health system in Broome and Tioga Counties:

- discriminates against people with dual mental health and developmental disability diagnoses

- is highly dependent on law enforcement and jail facilities for crisis response

- has long waiting lists for essential ongoing support services

- does not respond flexibly to individual needs

Temporary intensive inpatient crisis stabilization IS a community service. Even in a much richer community service environment than we presently have, it will still be necessary for some people. The ability to have frequent contact with family and friends while hospitalized is essential for recovery. These services must be available in every local community of significant size. It is completely inappropriate to move them 90 or 100 miles away.

The Greater Binghamton Health Center (GBHC) campus consists of several buildings, owned and operated by OMH. Closing it may not bring the results that OMH expects.

This campus houses essential temporary inpatient crisis stabilization beds for adults and children. It's not an "institutional setting." The person remains there for a few days or weeks; the longest stay we are aware of is 3 months. The GBHC has no long-term or permanent residents. Our community hospitals offer similar services, but with insufficient capacity to meet current needs. The GBHC also includes two transitional housing programs that effectively assist people with mental health disabilities to return to the community. The OMH facilities at GBHC are vital training environments for local medical, nursing, and social work students.

The GBHC campus also houses a Veterans Administration medical clinic, and a not-for-profit crime victims program. An effort is underway to establish a medical school on the GBHC campus. Finally, the campus includes the original NY State Inebriate Asylum, a building on the National Historic Register that cannot be torn down and must be maintained, occupied or not. OMH provides maintenance services for all of the programs and facilities on the campus, and receives rent or fees from the non-OMH programs. We are not sure if there is currently any significant amount of empty space not designated for future use by the proposed medical school on the GBHC campus.

We understand that OMH expects to get funds to expand community services by closing state psychiatric centers, and that it believes expanded community services will prevent many hospitalizations.

The prevention scenario may work, but only if the expanded services are put in place FIRST, BEFORE any inpatient beds are closed. A plan to close facilities first and THEN beef up community services will fail. We don't object to moving the temporary inpatient crisis stabilization services to local hospitals if it would save money and preserve capacity until sufficient community supports are fully available to effectively address the needs of those at risk. But those services must not be moved out of the local community.

We agree that there is excess institutional capacity in the OMH system statewide, but the GBHC's capacity is less clear. It seems unlikely that very much, or any, of the campus could be closed, or that much money would be saved by such a closure. Potential savings would be only a fraction of what is needed to expand local community mental health services to effectively address real needs.

Although the community mental health services environment seems richer in Syracuse, the OMH "data book" ([www.omh.ny.gov/omhweb/excellence/rce/docs/cny\\_databook.pdf](http://www.omh.ny.gov/omhweb/excellence/rce/docs/cny_databook.pdf)) indicates that it is very sparse in the north country. The closures projected for the Central Region, taken together, would not likely produce enough savings to adequately expand community mental health services in the Central Region, even if 100% of those funds were reinvested in such services, a target to which the state, so far, has refused to commit.

Other funding sources must be found besides those projected from closures and consolidations. OMH will seek a new 1115 Medicaid waiver from the Centers for Medicare and Medicaid Services (CMS) to fund expanded services. This is a good idea, but planners should be cautious about its success. Currently NY has two other new Medicaid waiver proposals pending at CMS, but that agency has been highly critical of and resistant to approving those proposals. It is uncertain that a new OMH waiver would be approved quickly enough to meet the RCE plan timetable. No reduction of temporary intensive inpatient crisis stabilization services should be made until such a waiver is approved and service providers are online.

Below is a brief discussion of the inadequacies of the current system of community mental health services in Broome County.

### **CPEP (Comprehensive Psychiatric Emergency Program)**

The CPEP at Binghamton General Hospital has only 7 beds (according to testimony provided by CPEP officials at the September

13, 2013 Assembly Standing Committee on Developmental and Mental Health Disabilities hearing in Binghamton) and in 2012 served over 5200 people (Broome County Mental Health Department 2012 Annual Report), or over 14 people per day. Wait periods before initial evaluation at the facility average about 4 hours. If the individual is not sent home, several more hours pass before any further assistance is rendered.

If the individual receives any crisis stabilization services at all at CPEP, s/he is typically released quickly and without an adequate discharge plan. Typically the person is given contact information for service providers. The person can contact those providers and get on waiting lists for their services, but rarely obtains immediate ongoing support services.

Sometimes CPEP sends the person to a local hospital inpatient program or to the GBHC inpatient program. Those programs are effective at what they do in-house, but their discharge planning functions are inadequate. Similar to release from CPEP, a release from a hospital lacks an adequate, in-place set of community support services.

This is one reason why local police and county sheriffs are frequently the first responders to a mental health crisis, and why so many individuals in crisis in this community end up in the county jail instead of receiving community mental health support services. The Broome County Jail has one of the best mental health discharge planning programs in the region; it is pretty effective at avoiding release of a person until some supports are in place, and as a result it has a lower recidivism rate than other emergency response providers. But this is absurd. County jails should not be the first line of defense in a truly adequate community mental health system.

Many families of people who have co-occurring mental health and developmental disabilities report that when they seek emergency services at CPEP, they are turned away with the explanation that the person's issues are "behavioral" and not "psychiatric," or that CPEP simply doesn't serve people with developmental disabilities. These reports do not seem entirely consistent, indicating that the pressure of constant high demand for emergency mental health services at this undersized and understaffed facility, along with apparently inadequate or inconsistent training for staff, are combining to cause these rejections. Such rejections are clearly not a statewide policy, since they do not occur at the Syracuse CPEP facility (and in fact some Greater Binghamton Region families have taken to traveling to the Syracuse CPEP

to get emergency services for their dually-diagnosed relatives because it is not provided reliably here). Nevertheless, we have complained about this issue repeatedly to the CPEP director and to the Broome County Commissioner of Mental Health without any improvement in the situation.

### **ACT (Assertive Community Treatment)**

ACT services are available locally. But like every other community mental health service, it is not always immediately available to people in crisis. One must get on a waiting list to receive it. Our region has only one provider of this service for adults, and apparently, only one ACT team. In 2012 it served 78 people (Broome County Mental Health Dept. 2012 Annual Report).

Also, the local ACT service does not comply with the model published on OMH's website (<http://bi.omh.ny.gov/act/index>). It doesn't provide 24-7 response services to individuals in crisis even after they are registered with the program. The amount of contact the ACT team provides is strictly time-limited, and sometimes ACT team members deem individuals "manipulative" or "too demanding" and refuse to attend to them. The result is decompensation, followed by homelessness, involvement with law enforcement, or suicide.

An ACT team is designed to provide as much assistance as is necessary to keep the person functioning in the community as well as possible. Making value judgments about a person's motives for seeking assistance is inappropriate and counterproductive; it could result in failure to provide assistance and deterioration in the person's condition. In addition, the ACT team is poorly equipped to deal with co-occurring developmental and mental health disabilities.

This situation is another result of failure to adequately fund community mental health services. If ACT services were adequately supported, there would be more ACT teams, their members could spend more time with each person, they would experience less stress and be less likely to respond inappropriately to people's expressed needs.

### **Residential Supports**

These also are inadequate in our region, which is a reason why the Broome County Jail functions as a transitional living facility and is seeking funds to increase its service capacity, according to testimony at the 9/13/13 hearing. As with other mental health services, residential supports are available only after

time on a waiting list, during which people face serious risk of homelessness, hospitalization, or jail. There is only one supported housing provider in Broome County, and it served only 35 people in 2012 (Broome County Mental Health Dept. 2012 Annual Report).

Further, the available services are rigidly defined, allocating a maximum number of hours of a specifically limited list of services to residents. A person needing as little as an hour more per day of support than a residence offers can't get it and may be ejected from the residence if s/he is unable to cope. A person who functions well if her access to prescribed medications can be controlled and she can be regularly assisted to take scheduled doses, may be forced to move to a different residence to get that help. A person needing less assistance than the residence provides may be forced to move out of his/her accustomed home. This leads to more stress and a greater likelihood of decompensation.

Underlying the problem is a shortage of low- and very-low income housing. Much of this housing was destroyed by the 2006 and 2011 floods and has not been replaced. We cannot emphasize enough that NY State needs to provide more low- and very-low income housing. Not "supported housing" but simply places for people to live. Having a stable home is a stress-reliever and a major contributor to recovery for people with mental health disabilities.

As indicated by the law establishing the Money Follows the Person program ([www.ssa.gov/OP\\_Home/comp2/F109-171.html](http://www.ssa.gov/OP_Home/comp2/F109-171.html)), and by CMS's proposed new definition of "community-based setting" (see page 6, and: [www.federalregister.gov/articles/2012/05/03/2012-10385/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#h-122](http://www.federalregister.gov/articles/2012/05/03/2012-10385/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#h-122)), which according to the NYS Olmstead Plan, OPWDD will adopt for its Medicaid-waiver-funded residential services, people with disabilities have a right to fully control their residential settings. This means that the model of bundling housing with services owned and operated by a single provider is no longer necessary, and depending on execution, may no longer be legal. NY must stop emphasizing this model. It must support an array of community services from which residents of ordinary housing units can choose instead. These services must be designed flexibly to meet the needs of individuals, with as many or as few hours of service provided as needed to ensure the person can remain stable in their home, on a schedule that meets the needs of the person, not of an agency.

# THE OLMSTEAD PLAN: WHAT IS REALITY?

Finally, after a delay of several months, the Cuomo Administration's Olmstead Cabinet published its promised "real Olmstead Plan" this fall.

An "Olmstead plan" describes how a state government will comply with the US Supreme Court's 1999 *Olmstead v L.C.* decision, which requires states to provide any disability support services in the most integrated settings appropriate to individuals' needs. Although not required to have such a plan, the Supremes advised states that having an "effectively working" one might help avoid losing lawsuits under the Americans with Disabilities Act. New York has already lost a couple big ones, so a plan is a must here.

Sadly, though, the document that Cuomo published is only a little more "real" than past efforts from the state's Most Integrated Settings Coordinating Council.

We prepared detailed comments on the Olmstead Cabinet's publication, *Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting*. You can read the publication yourself at:

[www.governor.ny.gov/assets/documents/olmstead-cabinet-report101013.pdf](http://www.governor.ny.gov/assets/documents/olmstead-cabinet-report101013.pdf)

Below is a very brief summary of what we said about it:

## **1. There are many good new ideas in the Report, especially:**

- The proposal for OPWDD to apply the proposed new CMS definition of "community-based setting" to all of its HCBS waiver-funded residential services.

Taken at face value, this will mean that all existing, as well as new, Individual Residential Alternatives (IRAs), whether "supervised" or "supported," will have to: give residents occupancy rights and protections similar to a lease; let residents have single rooms with locks to which they have keys (roommates cannot be required); choose specific roommates if any; have fully personalized activity schedules in and outside of the residence, with adequate staff support to make them practical; have access to food at any time; have any visitors they choose for any purpose at any time. Exceptions to these rules could be made only for objectively demonstrated, specifically documented safety needs for individuals, and never for the

convenience, or to satisfy the personal beliefs or preferences, of the facility operator or staff, or of the resident's relatives.

- Work to create a more uniform needs assessment system.
- The proposal to introduce "community first" assessment and service planning for people with various types of disabilities into the Medicaid managed care system.
- The proposal to reform the Article 17A guardianship provisions to require procedures similar to those under Article 81.

This would mean no "special" guardianship provisions for people with developmental or intellectual disabilities. Today under Article 17A, all a relative needs to do to obtain legal guardianship of an adult with intellectual or developmental disabilities is submit a request along with documentation of the diagnosis, and the request will be granted. With this reform, a person requesting guardianship will have to submit legally-admissible evidence of incompetence in specific decision-making areas (such as health care, finances, or residential choices) to a judge, who may or may not grant limited guardianship in one or more of those specific areas. This process is already required for people with all other types of disabilities in NY.

- The proposal to modify the Nurse Practices Act to ensure that people with disabilities can get assistance with semi-medical tasks, such as taking medication, without having to be attended by a nurse or be inside a medical facility.

## **2. The Report is neither "comprehensive" nor a "plan":**

- It does not adequately address employment services for blind people.

There is no mention of the NYS Commission for the Blind (CFB) except a vague promise that it will "coordinate" activities with the Department of Labor. Unlike all other disability employment programs in NY, there is no commitment from CFB to end reliance on sheltered or segregated employment.

- It does not address local public special education services.
- It does not address local county and municipal government failure to comply with relevant federal and state laws and regulations.

- It does not, for the most part, include measurable needs data, goals, timetables, or designated responsible administrators.

**3. The state's approach to housing for people with disabilities continues to over-rely on bundled housing-with-supports programs, and does not focus on increasing accessible low- and very-low income housing with freedom of choice regarding support services.**

**4. The OPWDD employment plan is inadequate because it relies on unspecified, un-committed changes to procedures and rates by ACCES-VR.**

**5. The general section on employment is devoid of meaningful action, especially any action to increase availability and effectiveness of supported employment.**

**6. The section on transportation contains no meaningful solutions to the extensive problem of inadequate public transportation outside of major urban centers.**

**7. The sections on mental health and correctional services are inaccurate and vague.**

- The Report grossly misrepresents NY's historically shameful behavior in failing to ensure the money that supported institutional settings followed individuals out of those settings and into community services. This history has resulted in mass homelessness and/or incarceration of people with mental illness for decades, and the prison system continues to mistreat thousands of prisoners with mental health disabilities.

- The vague OMH Centers of Excellence Plan does not guarantee adequate future funding for woefully deficient community mental health services, including "pre-arrest diversion" programs, and proposes to move vital temporary intensive inpatient crisis intervention services out of local communities to distant locations.

**8. The Olmstead Cabinet's role in developing an Olmstead plan, unlike that of the MISCC, is not authorized in statute and stands on shaky legal ground.**

- The Cabinet limited the role of people with disabilities and their advocates to a one-time provision of comment, and superseded their ongoing central role in plan development, resulting in a process that lacks legitimacy.

- The NYS Most Integrated Settings Coordinating Council (MISCC) needs to resume a controlling role in this process, led by a representative of the Executive Branch with authority to command state agencies.

Southern Tier  
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## COURTS WATCH

### No Right to Remain? *Sciarrillo v Christie*

This case was brought by several elderly guardians of people with developmental and other disabilities who live in two New Jersey developmental centers. NJ, under Republican Governor Chris Christie, is trying to close the centers and provide more integrated community services to the residents. The plaintiffs don't want that to happen.

These guardians' lawyers are certainly making some very creative—though completely bogus—arguments. The case is important to us because some of the people who have spoken out against OPWDD's planned closure of Broome Developmental Center have made similar arguments. We don't know if they are familiar with the case, but we suspect some of the state legislators are. If they're thinking about using it as a model, they should probably think again.

This is a class action suit, naming over 30 individual plaintiffs (ages ranging from 37 to 68), and claiming all of the residents of the two facilities as class members. The complaint was filed in federal district court in June 2013. There hasn't been any action by the judge yet, as far as we can tell. That includes certifying the class. In order to get past that hurdle, plaintiffs will have to prove that there are no conflicts of interest between them and any members of the class. That might not be so easy, because it's unlikely that everybody who lives in those DCs wants to stay there or wants them kept open.

Here are some of the arguments the plaintiffs are making:

- If a professional evaluator finds that someone qualifies for an "ICF/ID level of care," then any evaluation indicating that s/he doesn't *need* to be in an ICF must be wrong.

Yes, you read that right. The plaintiffs, or their lawyers, don't know, or are pretending not to know, the difference between a level of care determination and a needs assessment. Yeah, we know, highfalutin technical terms. So let's explain them.

An ICF/ID is an "Intermediate Care Facility" for people with intellectual disabilities. All developmental centers are ICFs/ID. These facilities were invented in 1971, long before

anybody ever heard of organized community services for people with disabilities. Medicaid makes the rules about them. In order to be qualified to have Medicaid funds spent on a person in an ICF, s/he must have certain types of needs. Later, when the disability rights movement began calling for community integration, Medicaid said, "Okay, if you have those types of needs then we'll offer an alternative way to use our money, and we'll call it a Medicaid Waiver." To qualify for the waiver, you must have the same types of needs that qualify for an ICF level of care, but you can use the money for services in the community instead. Most states now use Medicaid waivers to pay for most services for people with developmental disabilities.

See? Meeting the qualifications to live in an ICF *doesn't have anything to do with* whether you actually need to be in, or would be best served by, an ICF. Congregate, segregated settings are not, by themselves, an element of "medically necessary treatment." The entire federal Medicaid establishment is solidly behind the idea that people who could be allowed to live in an ICF can be just as effectively served in more integrated settings. Trust us. No sane judge is going to buy this argument.

- The US Supreme Court's *Olmstead* decision says people don't have to be moved to community settings unless qualified professionals evaluate them and determine that's the best thing for them.

Okay, that's true. And all of the named plaintiffs claim they have evaluations showing that it's not the best thing for them. The question is, who did these evaluations? Though not stated explicitly, the context of the complaint suggests they were done by employees of the facilities slated for closure.

Do the guardians of ICF residents have a right to limit "evaluation and assessment by treating professionals" to those conducted by professionals who might, or believe they might, lose their cushy union-protected jobs in the ICF if they recommend more integrated settings? Isn't there at least a common-law protection against conflicts of interest in such situations?

There probably is. More to the point, the complaint itself cites federal regulations stating that such evaluations must be "impartial." We

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don't think the State of New Jersey would have a hard time convincing the judge that, at the very least, these people should be re-evaluated by professionals who have no personal stake in the outcome.

- Poor care rendered in the ICF is a reason why ICF residents are entitled to remain in the ICF and get better care.

As New Jersey began moving people out of the developmental centers, it did what everyone wants state governments to do when they close these places: preserve the jobs of the facility employees by having them follow the residents into the community.

That meant that the facilities not only had fewer residents, they had fewer staff. The plaintiffs claimed that the remaining residents were neglected as a result. They ignored the fact that this happened because they insisted on keeping their wards in the facilities instead of letting them go where the staff now worked.

ICFs are required to maintain specific minimum staff ratios and service availability. If they don't, they won't get that Medicaid money. As the judge in *DOJ v Arkansas* unfortunately said a few years ago, ICFs aren't required to provide "Cadillac" services, they only have to meet the minimum standards. The plaintiffs don't offer specific evidence that these facilities aren't doing that, so legal precedent suggests that they're out of luck on this point. Residents aren't any more entitled to insist that high-quality services be maintained in a specific developmental center than they are to sue their top-rated chiropractor for moving out of town because now they have to see some quack instead.

- ICFs are more integrated than group homes because ICFs hold events that include lots of nondisabled people right on the premises! But if you live in a group home you may have to go somewhere else to hang out with nondisabled people.

We just *knew* that by defining "integration" as merely "maximum opportunity to have contact with nondisabled people," the feds were throwing a wrench into the machinery! The definition needs to have "who are not paid to serve them" tacked onto the end of it.

Let's try this: when was the last time you attended an "integrated" event at a developmental center that didn't consist of the same crowd of staff and family members you see every time you go? Compare that to the

"opportunities to interact with nondisabled people" that you can have in a real job, restaurant, public sporting event, concert, or nightclub. This argument is just trivial and ridiculous.

- Integrated settings violate the ADA because they are "more restrictive" of individual "rights" than segregated settings.

What rights are those? Why, the right to be segregated, of course! And to be segregated in the institution of your choice!

The US Department of Justice (DOJ) filed a statement of interest in this case in September. It begins by quoting from the ADA itself: "Congress recognized that 'historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.'" Get that? Segregation is not a "right," it's a social problem. DOJ goes on to cite federal court rulings that say that it's not illegal under the ADA for states to close institutions, and points out that the famous *Olmstead* quote that there is no "federal requirement that community-based services be imposed upon those who do not desire them," only means that states are not required by the ADA to move people who don't want to be moved. It does not mean that such a move would violate the ADA.

DOJ is the agency designated by Congress to issue regulations and guidance to carry out the ADA. Federal courts, including the Supreme Court, have a rule: When an agency is designated by Congress to interpret a law, you listen to them. But if you think that the DOJ is just a bunch of liberals who don't understand mainstream America, then you should read the settlement in *DOJ v Virginia* (see *AccessAbility* Spring 2012 & Fall 2012). After the parties reached a preliminary settlement on closures of developmental centers, a bunch of parents much like those in NJ complained loudly. The conservative judge was very sympathetic, and he modified the agreement to ensure that they would have ample opportunities to keep their children institutionalized. But even he said they don't get to pick the institution they end up in.

We realize that these elderly guardians have experienced only one way of providing services to people with developmental disabilities for 20, 30, 40, or even up to 50 years. The complaint indicates that they and their lawyers don't really understand the needs and abilities of their own children the way that modern disability service professionals do. They don't believe that people with developmental disabilities can ever really communicate their own wants and needs, and therefore they must always speak for them. The complaint cites, as a cause for action, written evidence in residents' service plans that professionals accepted input directly from the residents and used it to design those plans.

Nor do the guardians understand what integrated community support services really are. And the defendants' counter-arguments, frankly, will not be well-served by the state's system of cookie-cutter group homes and day programs, which do not truly individualize services to meet specific people's needs any better than New York's do.

But this little story gives the flavor of how these people think:

"In some cases, such as that of Plaintiff Andrew Sekela, [New Jersey Developmental Center] personnel discussed his transfer to a group home with Andrew without the consent or participation of his guardian. NJDC allowed group home providers to interview Andrew without the notification, participation or consent of Andrew's guardian or members of his NJDC staff. Talk of the move upset him. He understood the move as imminent release and has acted out by eloping."

You see, people with developmental disabilities just aren't like us at all. They are very, very different, so it's just crazy to imagine treating them like other people. Isn't it obvious? How are you ever going to integrate people who, when they really love a place and want to stay there, they run away from it?

Or maybe Andrew communicates better than anybody involved in this case understands.

With his feet.





## Haunted Halls Resurrected

by Bill Bartlow

STIC's 4th annual Haunted Halls of Horror fundraiser was, pardon the pun, a "screaming success." Seven evening and two afternoon matinee performances thrilled, surprised, and generally entertained Halloween celebrants who purchased over 3100 admission tickets. Set, prop, animatronic, make-up, scare-actor development, and the outdoor show far surpassed the previous year's levels of customer approval. Some of our troupe of dedicated volunteers took the stage, transforming from their daily identities into creatures populating a first class haunt, while others coordinated a myriad of new sophisticated laser-activated

computer, pneumatic, sound, and video equipment. Support personnel lent their talents and time to ensure that our event remains the region's premier Halloween attraction. A huge "Thank You" to them!

Yes, Lucy, there is a Great Pumpkin and "someone" has to plant the pumpkin patch. Well, the "someones" who nurture this growing fall holiday celebration are our amazingly generous sponsors. Regional and statewide businesses, organizations, foundations, and individuals, aware of STIC's mission to assist the people with disabilities in our community to realize their goals of independent living, were the benefactors whose generosity make the event possible.

Among 2013's outstanding supporters are:

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On behalf of Executive Director Maria Dibble, Southern Tier Independence Center staff, and those whom we serve, we offer our sincere gratitude to all involved in contributing to the success of this increasingly popular event. We also invite your feedback, suggestions, and participation to make our 5th. annual event in 2014 an even greater triumph. Follow us online at [www.hhh-stic.com](http://www.hhh-stic.com) or on Facebook through our website.

## Swinging through the Trees

by Bill Bartlow

Home for the Holidays at Roberson Museum and Science Center features showcase trees, an International Forest, and the historic Roberson Museum. It's a must-see event November 20 through January 5. Included in the array of yuletide decorations you will find the Southern Tier Independence Center's celebratory offering.

In commemoration of STIC's 30th. Anniversary Year: behold a traditionally warm and radiantly festive tannenbaum of faithful constancy with holiday expectation. Topped by a sparkling silver star, the branches are adorned with white doves, teal and ivory bulbs, and wrapped by garlands



HH Christmas Tree 2013



30th Anniversary Christmas Tree 2013

and pearl accents. STIC's new 30th. year logo stands framed at the base to tie the theme together.

Ah, but we're not done. This elegant beauty of the holiday-tree runway has a sister who demands the visitor's attention and poses for the cameras with a stunning self-assurance of her own. Just when you thought she was gone, feast your eyes upon the Halloween Tree. This eerie surprise of the forest nearly steals the show and bears the Haunted Halls of Horror logo to remind the viewer of her darker side. Recently on display during our most successful 4th. Annual Halloween fundraiser, she has reappeared not as the crone, but in her guise as the alluring maiden. The pointed hat, broom, companion crows, pumpkins, and protruding bones reveal an unmistakable character, but now the light of a mesmerizing, bewitching, almost seductive attractiveness captivates the eye.

The transformative magic of STIC employees Sue Lozinak and Brooke Akam brought our holiday twins to life. Our thanks and appreciation for a remarkable presentation.

These festive visions again remind us of STIC's community involvement and extend our best wishes to all for the holiday season.

## Up Against the Wall!

by Maria Dibble

STIC is very pleased to announce our celebration of 30 years by introducing our "Wall of Fame", containing articles, pictures and remembrances from the last three decades. It will be available for viewing between 9:00 am and 5:00 pm, Monday through Friday. Drop by and spend a while reminiscing, laughing, smiling and maybe even shedding a tear. It is a work of love and passion for the people we serve, the mission we embrace and the values and philosophy we live. May we never stray from our roots, forget who we are, or where we dream to go.

## Give Us Grief!

*This is an abridged version of STIC's Consumer Rights and Responsibilities brochure. You have a right to know!*

Southern Tier Independence Center (STIC) is a Center for Independent Living (CIL). Not only does STIC comply with the laws of both New York State and the United States of America, but also with its own commitment to human rights that are protected by law.

CILs foster independence, help people with disabilities to develop networks and supports, and promote self-reliance. CILs advocate for the inclusion and integration of people with disabilities in all aspects of community life. It is the responsibility of STIC's staff to ensure that every person we work with knows his or her rights and responsibilities as a consumer. These rights and responsibilities reflect STIC's belief in the Independent Living Philosophy.

### Policy and Practice

As a CIL, STIC firmly believes that people with disabilities should be empowered to control the direction of their own lives. This means choosing their goals, plotting their course, and taking responsibility for their actions and the results. It is STIC's policy and practice that every consumer:

- Is fully informed of his/her rights and responsibilities as a consumer.
- Is not deprived of any civil or legal right guaranteed to all citizens and/or legal aliens, solely because s/he has any type of disability.
- Is treated with respect and dignity regardless of race, religion, national origin, creed, age, gender, sexual orientation, ethnic background, veteran status, cultural identity, disability, marital status, genetic disposition, or carrier status.

- Is free from physical, sexual, or psychological abuse.

- Is protected from commercial or other exploitation by STIC staff or others affiliated with the organization.

- Will receive services, including assistance and guidance from staff trained to administer them competently, skillfully, safely, and humanely.

### Consumer Rights

Every consumer has the right to:

- Live, work, and participate in all other activities in the most integrated setting possible and desired.

- Be treated with consideration, respect, and full recognition of his/her dignity and individuality.

- Make his/her own choices and decisions, including the right to make mistakes and learn/benefit from those mistakes.

- Be involved in all aspects of his/her services, including an in-depth person-centered approach to planning and service delivery.

- Make her/his own choices about services and have control over the direction of those services to the fullest extent possible.

- A process for resolving objections, problems, or grievances relative to his/her rights and responsibilities, access to the Executive Director, Board President, and government agency overseeing the services s/he is receiving.

### Consumer Responsibilities

Consumers of STIC are expected to:

- Choose, fully participate in, and direct their own services to the fullest extent of their abilities. STIC will not do anything for consumers that they are capable of doing themselves. STIC will, however, assist consumers to learn the skills needed to pursue their goals and dreams.

- Be responsible for the results and consequences of their actions and choices.

- Report any changes that affect their services, including but not limited to changes in address, phone number or insurance information.

- Respect the rights and dignity of other consumers, STIC staff, and volunteers/interns.

### Confidentiality of Consumer Information

STIC respects the confidentiality of all consumer information. We will only use or share information about a consumer as: allowed by law, is necessary for billing services, and/or as required by funding

sources, subpoenas, and program audits. STIC complies with the confidentiality requirements of HIPAA, as well as those specific to people with AIDS or who are HIV positive, have substance abuse issues, or receive psychotherapy services.

## Grievance Procedures

It is STIC's policy to provide quality services to everyone in a courteous and respectful manner. If you believe you have been mistreated or abused, or that your choices are not being respected, you have the right to file a complaint. During the period a complaint is being reviewed or appealed, STIC will continue to offer and provide all mutually agreed-upon services in accordance with your wishes or that of your legal guardian.

Informal and formal grievance procedures are available to resolve complaints or concerns.

### Informal Complaint Procedure

Before filing a formal complaint with the Executive Director, please communicate with the staff member you are concerned about and give them a chance to resolve your complaint. You may also contact a staff member's supervisor to discuss performance issues. If a staff member is abusing you in any way, please report your concerns to any supervisor, the HR Coordinator, Assistant Director or Executive Director immediately.

### Formal Complaint Procedure

If you are unsatisfied with the staff's response to an informal complaint, or the situation is serious enough to bypass the informal procedures, you may file a formal written or electronic grievance with the Executive Director. Within seven (7) business days of receiving a formal written or electronic complaint, the Executive Director will contact you to discuss the complaint and collect information. The Executive Director may also conduct a further investigation into the complaint, as s/he deems necessary to render a fair and informed decision. A written or electronic response to your complaint will be sent to you within fifteen (15) business days of receiving your original complaint. If the Executive Director is not available, the Assistant Director will address the complaint.

If you are unsatisfied with the Assistant or Executive Director's decision, a formal written or electronic objection may be made to the President of STIC's Board of Directors, requesting a hearing before the Board or appropriate Board committee. Within seven (7) business days of receipt of a formal written or electronic objection, a hearing will be scheduled before the Board President or designated committee, with no less than ten (10) business days' notice. You will receive a written or taped response within ten (10) business days of the hearing. Be aware that ordinarily complaints will be heard on the date of the next regularly scheduled Board meeting (unless the complaint is serious enough to warrant more immediate action).

If you are still unsatisfied, you may contact the governmental agency that funds the services you receive from STIC to file an additional complaint.

## **My Family's Journey through My Brother Dave's Deafness**

By Evan Dietrich

*(This article was written by a young middle-school student with impressive writing skills. Several names—including the author's—as well as dates and locations, have been changed to protect confidentiality.)*

Have you ever felt so hungry, but your mind is on something totally different, and you just can't eat? Have you ever been doing something you love, but so distracted that you have no fun? Well, that is exactly how I felt this past summer.

My mom, my grandmother (who is deaf), and my brothers Dave and Eddie were at a children's hospital in Massachusetts, to see if Dave was deaf. He had had many other tests at local and regional hospitals here, and local audiologist offices, but the results weren't clear. We wanted a diagnosis as soon as possible, and we were sure that this hospital could help.

Almost two years earlier, our family—my parents, my sisters Susan, Emily, and Ruth, my brother Eddie, and I; all two years apart—welcomed a smiling, happy, redheaded, six pound, ten ounces, bouncy baby boy named Dave at one of our local hospitals. He was the favorite sibling of each of us from the start, but we never suspected that he couldn't hear.

At the local hospital, he had his newborn hearing screening and failed it. The administrator of the test, determined to get Dave to pass, tested him many more times, one right after the other. In the end, David Richard Dietrich had a total of thirteen newborn hearing screenings. He failed them all.

We were all concerned about little, week-old Dave's hearing. I don't want to say me only, because my siblings and parents definitely would argue that they also were concerned. We started slamming doors, dropping loud, heavy things, and shouting to see if he responded. It was an anxious time for all of us, but we convinced ourselves he could hear.

When Dave was six weeks old, my mom and dad took him to a regional hospital for an Auditory Brainstem Response test, or ABR. Basically, during an ABR, the baby is asleep; naturally or sedated with medicine. Dave was hooked up to sensors and ear pieces and sounds are sent in, while they measure the brainwaves. Dave passed! We were overjoyed and the next 10 months we weren't concerned about his ears. We focused on teaching him to walk, to talk, to feed himself. He was very bright and very tough; living with five older siblings, he

had to fall and hit his head at least once. He might cry for ten seconds, but then would get up and start playing again. However, he was never very good at talking. We weren't concerned. He was still little, and he didn't really need to talk. Everyone always seemed to know what he wanted.

Then Dave, my parents, and I went to Berlin, Germany for a week. After we got back, we began to get suspicious again about his ability to hear. He wasn't talking at all, and he was not responding when we talked to him.

At his 18-month checkup, his pediatrician said that there might have been thick fluid in his ears that was preventing him from hearing. He was put on an antibiotic for the next two weeks. At the end of the two weeks, the doctor was not sure if there was still fluid in his ears or not.

Two months later, at a school event, my mom noticed that a friend's baby, who was about the same age as Dave, had a pretty large vocabulary. Dave had no words. Nothing. No "milk," no "mama," no "dada," nothing!

My mom, being the concerned, loving mother she is, called an Ears-Nose-Throat doctor, an ENT, who said that there was most likely more fluid in his ears, so he went back on the antibiotic for two more weeks. Again, after the two weeks, the doctor said there may or may not have been fluid in his ears. We were then sent to a local audiologist. He said there definitely was something wrong with Dave's hearing, but he didn't know quite what it was.

My mom was determined to get an answer, and wanting the very best for her child, called the children's hospital. This is one of the best children's hospitals in the world, and she made an appointment for Dave at the hospital in Massachusetts, with the chief ENT there, Dr. Torelli, late this past summer. I really wanted to go, but I couldn't, but both my brothers, my mom, and my deaf grandmother went. I spent the entire day wondering what Dr. Torelli would say. When my mom got back, I questioned her until I felt that I was there too, and found out that Dr. Torelli said he definitely was deaf, just not sure how deaf. He guessed about 90 decibels, which is as loud as the sound a motorcycle makes.

We were upset, but glad that we had the first year and a half of his life when we thought he could hear, and treated him like any other kid. He had regular doctor visits and, to us, he was hearing.

Another appointment was scheduled at the same place as before, the following month, but we weren't just going to sit there until then. He was going to learn sign language. My grandmother works with a Deaf Services Coordinator who knew of another family who had experienced almost exactly what we were experiencing. The mother of that family created and published American Sign Language (ASL) videos to help her daughter learn to communicate. Thus, *Signing Time* became a part of our family.

We loved *Signing Time* from the start. Dave was learning signs, we were learning the signs, and we all fully opened the door to the world of communication with our two-year-old.

This door was already opened a little, as our grandmother was deaf and fluent in ASL, my mom was fluent, and we were signed to from birth. We knew the basics: love, more, milk, mom, dad, and we all had name signs, but we all learned a lot more in about a month by watching the videos with Dave.

I went to Dave's next appointment, even missing one of my first days of school for it. When we got to the office in Massachusetts, I was amazed how nice everyone was. First, we had a quick hearing test with an audiologist named Amy. She was very nice, and let me blow bubbles for Dave so that he would be quiet for the test. Next, we saw Dr. Torelli for a few minutes to check if there was wax in his ears. There was a little, and Dr. Torelli got it out. Dave didn't like that one bit. Then we went and got ready for the ABR and MRI, a brain scan. This was another ABR, but unlike the first one, he was put to sleep with medicine instead of falling asleep naturally.

He got a little, purple, hospital gown and got ready to be sedated, or put to sleep with anesthesia. The doctor of anesthesia, Dr. Hays, explained to us that redheads were the hardest to give anesthesia, and put up a good fight, but the doctor always won. *[Editor's Note: Being a redhead myself, I emphatically agree.]* We laughed, but when it was time for the IV, we found that he was right. Dave hated that IV so much that he pulled it out of his arm...twice! When he finally went in for the tests, we were free to explore the local mall. It was the biggest mall I had ever seen, and I'd been to the Syracuse mall. Three floors, probably three *hundred* stores, but we only had an hour and a half. After the test, we found out that his ears and brain were fine, he just couldn't hear until 90 decibels, like Dr. Torelli had predicted. (Vestibular auditory nerve damage was the diagnosis.)

A month after that, he went back to the children's hospital with just my mom and grandma this time, to get his hearing aids. Now we have to see if they make a difference or not.

We don't know what his future will be like, but we do know that it will be great. My grandmother knows just about everyone at a summer camp for deaf children in the Adirondacks, called Camp Mark Seven. In the Bible, read Chapter Seven in Mark's Gospel.

Dave is loved by all who meet him. He has a team of wonderful people including all the doctors, audiologists, our priest, and the people at Camp Mark Seven, and, of course, our family loves him dearly!

Have you ever felt so hungry, but your mind is on something totally different, and you just can't eat? Have you ever been doing something you love, but so distracted that you have no fun? Well I have, but I know now that no matter what, you'll always want to eat again, and you'll always have more fun because my brother, little David Richard Dietrich, couldn't have been born into a better family.



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