



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

AccessAbility

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A Last Look Back

by Maria Dibble

After a year of celebratory events, hard work, much planning, and a good deal of fun, STIC's 30th. anniversary culminated in the unveiling of our "Wall of Fame," hosting an open house, and holding ceremonies to highlight three decades of advocacy and service to our community.

Excitement seemed to vibrate through the halls of STIC, as for the first time staff were able to view the "wall" in its entirety. Each year has a panel featuring achievements, issues, and events important at that time, and every decade has two panels to enhance the impact. Newspaper articles, photos, drawings, and much more, are used to illustrate our history and philosophy, describe our growth and development, and craft a panoramic view of our agency over time.

Staff carefully selected pictures from thousands of photos, read countless articles, sifted through library archives for newspaper gems, uncovered long-forgotten moments of import buried in newsletter editorials and features, plowed determinedly through old reports, and much more, to create this 30-year review and celebration of who we were and where we've been, as well as the impact we've had on our community, important issues,

and hopefully most of all, the people for whom we work.

On December 10, 2013, we brought together people we haven't seen or spoken to in years, to remember our past—like former County Executive Carl Young, longtime consumer Joan Gibson and many others—as well as to look to the future. Visitors toured the Wall of Fame and were quite impressed. Many shed a tear as we honored and bid farewell to one of our founding board members, Milrene Smith, who passed away last summer. We also laughed as old friends brought up stories that were buried in our memories but apparently not forgotten. We reminisced about "the good old days" as we bade farewell to them, and then we set our sights on the future.

We closed the afternoon by listening to some excellent music by the band Flame!, eating a piece of our anniversary cake, and enjoying the warm feeling that always comes when you're with old friends.

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STIC Executive Director Maria Dibble with old friends Bob Gumson (ACCES-VR), Rural Health Network of South Central NY Executive Director Jack Salo, and former Broome County Executive Carl Young (from left)

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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.

www.stic-cil.org



Flame! performs at STIC

Still Loud and Proud

by Ken Dibble

The cover of this issue is the last place you'll see our special 30th Anniversary logo. Although STIC was founded in 1983, the first issue of this newsletter appeared in the spring of 1984. So we're having our own little 30th anniversary here at *AccessAbility*.

One of the first things the publication did was ask for ideas to name the newsletter. "STIC Newsletter" just didn't cut it. Neither did "STIC It" or various other snarky suggestions. It turns out lots of people have had the same punny idea we eventually settled on, but we may have been the first.

Because STIC was always dedicated to advocacy, the newsletter began early on to be used

to recognize that the people they're dealing with have minds of their own.

As journalists, we don't believe in "balance." We have never been afraid to criticize, not just the wealthy and powerful in the disability "biz," but advocates who we think are getting it wrong. And we get it wrong sometimes too. We're happy to revamp our position when we get better information. But the truth isn't always balanced. Not everything is a matter of opinion, or subject to debate. Our job is to report the truth, as best we can, not to play "he said/she said" with important issues.

We're proud of our voice. We plan to continue to comfort the afflicted and afflict the comfortable in the disability universe. We thank you for reading and contributing. Keep it up. Here's to 30 more years!



30th Anniversary Party

as a tool to educate and inform people who were trying to get attitudes and service systems about disability changed. And it seemed people were listening. Long before the 80s ended, several of our editorials had already raised hackles in the disability establishment. People got mad, but it made them think. Over the years *AccessAbility* has been a major factor in getting the people who make disability policy

We Found Our Way Home!

After several years of public discussion, the federal Centers for Medicare and Medicaid Services (CMS) have released final new regulations that define “home and community based settings.”

We’ve been following this odyssey (see *AccessAbility* Fall 2009, Summer 2012 for a detailed history of its evolution) and its ups and downs. The results could revolutionize residential services for people with developmental disabilities—or they could not.

“Home and Community Based Settings” (HCBS) is a concept that applies to certain Medicaid-funded long-term care services described under Section 1915 of the federal Social Security Act. This dates back to 1981, Ronald Reagan, and Katie Beckett, a 3-year-old child with disabilities who was forced to live in a hospital because her parents couldn’t get services for her at home.

These programs were created specifically to channel Medicaid long-term care funds to services not provided in institutional settings—that is, not in developmental centers, psychiatric centers, nursing “homes,” intermediate care facilities (ICFs), sheltered workshops, or congregate “day programs.” There was already Medicaid, and other sources of money, available to pay for those places. There wasn’t money for community services until HCBS came along.

The progress toward HCBS regulations defining “home and community based settings” has been a treacherous minefield for CMS. Billions of dollars were involved, a lot of it invested in the bricks and mortar of segregated mini-institutions called group “homes.” CMS received hundreds of comments on its various proposals, some of which were veiled threats of lawsuits if certain provider agencies’ oxen were gored. There were also a surprising number of comments from people, including those presumed knowledgeable and informed, like state agency administrators, who didn’t understand that if you want to run an ICF or hospital or developmental center, you can get plenty of Medicaid money to do that without involving HCBS.

As expected, the final regulations do not please everybody, including us. However, they are not all bad. The biggest problem may be how our state officials interpret them. More on that later.

The regulations are published in the Federal Register. The full document is huge because it includes response to comments and explanation of the regulations. So we will summarize:

What is a Home and Community Based Setting?

CMS says that HCBS rules *do* apply to non-residential services funded under Section 1915 programs, but they did not issue specific regulations for them. They plan to put out “guidance” on employment, training, and activity programs later on. Right now we’re primarily talking about residential settings.

The setting must be chosen by you from a range of options that includes non-disability-specific settings, and individual living spaces (no roommates) in a provider-operated setting.

These settings must maximize your ability to: interact with nondisabled people; make your own decisions and control your own activities; have competitive employment; and play a meaningful role in the larger community. “Community” means what it means to most nondisabled people: the generic public arena in which all people come and go. It does not mean the “community of interests” or “community of peers” that segregationists tried to slide in under the door. A clear victory for real integration.

It’s important to understand that CMS clearly says that these requirements cover every person who receives any kind of Section 1915(c),(i), or (k) HCBS services, whether or not the place they live in is funded by those programs, or the person gets services funded by those programs in that place. In other words, if the *place where you live* doesn’t meet the requirements, it is illegal to use HCBS funds to provide *any* services to you whatsoever, *anywhere*. This is an unexpected and very important victory. Properly understood, it will

potentially require a lot of people to be moved to more integrated settings. For example, if you live in a group “home” that doesn’t meet the requirements, even if something other than HCBS pays for that group “home”, any HCBS funding for your day habilitation or supported employment services should be cut off.

If you live in a place owned or operated by a disability service provider, there are several more specific requirements.

You must have tenant rights equivalent to those any nondisabled renter would have in your state, including a written lease or other agreement. The room(s) where you live must be lockable and you must have a key. Appropriate staff may also have keys. You must have your preferred individual activity schedule so you can go where you want when you want, and adequate support to follow that schedule. You must be able to have visitors of your choice at any time in that place. You must have access to food at any time. You must be able to choose to have individual living space, without a roommate, if that is consistent with available “resources” (see below). If you choose to live with someone else, you must be able to choose who that person is.

These rules represent rights and freedoms and can never be modified on a generic basis. They can only be modified for individuals, for specific documented reasons. If your rights and freedoms are to be restricted, your person-centered plan must describe the specific, limited restriction, document the reasons for it, describe how less-restrictive options have been tried and failed to meet your needs, and explain how these restrictions will regularly be reviewed to see if they can be lifted.

What is Person-Centered Planning?

All HCBS programs require an individual service plan that is developed through a person-centered planning process. The process must have these elements:

You must direct the process to the maximum extent of your ability. If you have a legal guardian or other representative, you must still direct the process as much as you can.

You have control over who participates in the planning.

The process must be free from coercion.

Planning must take place in locations and at times that are convenient for you.

You must be offered a range of available choices for living situations, including the most integrated setting appropriate to your needs. We emphasize, the most integrated setting must be an available choice: if you choose it, you will get it. No waiting list. Period.

Your services must be responsive to your assessed functional needs and address your preferences. The plan must describe both paid and any natural supports, but you cannot be required to use any particular natural support (that is, your family cannot be required to do anything for you if they are unable, or do not wish, to be involved).

You must be offered the option to direct your own services, either by controlling your individual budget, or by hiring and supervising service providers, or both.

Your choices must be informed. You must be provided complete information about all available services and service providers, and be given an objective presentation of the pros and cons of each option.

Your plan must be reviewed and reconsidered on a regular basis by members of your planning group, and you can request such a review at any time.

No plan can be implemented without your consent (and your signature if you are able to sign), even if you have a legal guardian or representative.

You must have conflict-free service coordination. Specifically, a person who provides direct services to you cannot also be your service coordinator, and vice-versa. More importantly, an organization that employs your service coordinator cannot also employ the people who provide direct services to you, and vice-versa. The only exception is if your geographic region lacks two organizations that can provide the needed services.

What Could Possibly Go Wrong?

CMS says all HCBS programs must comply with these regulations, and states that have existing programs will have to negotiate a transition plan with CMS to get their programs into compliance, to be completed over a maximum of 5 years.

We think OPWDD, the biggest current beneficiary of HCBS, has a lot of work to do. We are very concerned because top OPWDD officials have said they think they're already pretty much in compliance. This is clearly not true.

OPWDD recently said that 60% of people served under its auspices get both service

coordination and direct services from the same organization. That clearly violates the new regulations in most cases. To be clear, this is the actual regulation: "Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person centered service plans in a geographic area also provides HCBS." Now, "geographic area" is not defined in the regulations, but there is no common-sense understanding of that term that would allow any person with a developmental disability in Broome County to continue to receive both service coordination and direct services from the same OPWDD waiver provider. We can't imagine how any OPWDD official could believe otherwise.

Other points to watch out for:

You are supposed to have the choice to live on your own with supports and without roommates if you don't want them. But provider agencies pointed out that it will be much more expensive to offer group "homes" with individual bedrooms than to continue putting two people in a room. So CMS included a clause implying that you may only be able to get an individual setting if you have some additional source of funds to pay for it—but if you have those kinds of funds, you may not be eligible for Medicaid at all. What we think the new rule really does is require OPWDD to make support available for individual settings—"supported apartments," if you will. OPWDD already claims to do so. The important point is that you are supposed to be offered the choice of such a setting, and the choice must actually be available, so that if you choose it, you move in quickly and are not placed on a waiting list. That's potentially revolutionary—and another point on which OPWDD is not already in compliance, no matter what they claim.

If you live in a provider-operated setting, you are supposed to have your own schedule: to go where you want, and to do what you want, when you want. That includes staying home during the day, or doing something different than participating in group bowling or the notorious "van rides" so common in group "homes". The regulations specifically say you are entitled to an individual schedule and the support to follow it. Most group "homes" today don't have adequate staffing to make this work. OPWDD is kidding itself if it believes that it and its sub-contractors currently comply with this requirement.

Your right to have visitors you choose at any time also needs protecting. How many group homes will, say, let your girlfriend come and stay overnight in your bedroom? How many will allow gay couples to be alone together? This is going to become a big problem, especially for facilities operated by religious organizations. We don't think OPWDD has even realized this yet.

We have the rules that protect your rights on paper, but they're still a long way off from ensuring you really can live the way you want with the supports you need. Educate yourself on your rights, be informed consumers, and insist on the letter of the law. When you do that, we'll be there with you.

Centers of Excellence: Following the Money

As predicted, the Cuomo Administration's plan to close the Greater Binghamton Health Center (GBHC) got stopped dead in its tracks. We opposed the plan (and explained why in *AccessAbility* Winter 13-14). But would it be too cynical to say that we had nothing to do with the decision, that it was stopped by the public employee unions, and the state legislators whose campaign expenses they pay?

Yes, as it turns out, that is a bit too cynical. It *was* primarily the unions that got legislators riled up. But action, or rather inaction, by the federal government also played a role.

The unions and politicians who opposed closing GBHC also oppose closure of Broome Developmental Center (BDC) and its Intensive Treatment (IT) unit. However, those plans are going forward. A bill supported by Senator Tom Libous, and Assemblymembers Donna Lupardo and Clifford Crouch, among others, that would allegedly delay closures, appears to be going nowhere (and doesn't delay anything either). The difference is that the federal Centers for Medicare and Medicaid Services (CMS) have explicitly required the state to reduce its institutional capacity for people with developmental disabilities—to zero for developmental centers, and around 150 for IT units. Federal courts, with the support of the federal Department of Justice (DOJ), have ordered the state to stop permanently segregating people with mental health disabilities in institutional settings such as adult "homes" and nursing "homes," but GBHC is not a permanent residence. It's a temporary intensive inpatient treatment program. Keeping it open doesn't require the state to violate federal orders; keeping BDC open does.

And federal policy on closure of institutional settings is definitely influenced by disability advocates, more than ever before. STIC has been very vocal on this issue for many years, expressing our views to both CMS and DOJ. So we'll take a bit of credit for this.

But problems persist on the mental health front.

The Cuomo Administration initially said that about \$72 million would be "reinvested" from psych center closures to expand community mental health services over 3 years, with \$25 million being available in fiscal year 2014-15 as an "advance payment" to beef up services before facilities are closed. This was promoted as "\$110,000 per closed bed," and various mental health advocates got on board to praise the plan. But they didn't look at the fine print. The proposal was actually to close 665 beds at \$108,270 per bed, and reinvest about \$36,000 per bed per year.

That sounds like a lot. Analysis of 2012 Broome County Mental Health Department data shows that overall, the county spends about \$1000 per person served per year. So for each bed closed the county could theoretically serve 36 more people. But that figure is an average; it covers very simple, limited informational or counseling services as well as intensive ongoing service coordination, treatment, and emergency services. In reality one closed bed might equate to one or two new people getting useful services in the community.

One-for-one doesn't sound so bad. But based on 2011 figures, OMH actually spends \$292,730 annually per state psychiatric center bed for adults, and \$522,680 per bed annually for children. So Cuomo was offering to reinvest, on average, about 12% of savings from closed adult beds, and about 7% of savings from closed child/youth beds, in non-residential community services. Where is the rest of that money going? Or where was it supposed to go?

The Central NY Regional Center of Excellence planning team's final recommendations were a laundry list of possible community service models, and some of them are very good ideas, such as expanded mobile crisis-response services, supported housing, and peer support programs. These important lynchpins of a community mental health system keep people with mental health disabilities productive in the community and out of jail or hospitals. However, the buck was passed on what specific services to expand, and by how much, to individual counties. We don't know anything about how Broome

County will use whatever reinvestment money it gets, but we do know that current county mental health administrators are hostile to peer support programs.

Then in late December, Cuomo, responding to pressure from legislators, announced that GBHC (as well as Elmira Psychiatric Center) won't be closed, just downsized. GBHC will retain its 16 beds for children, and only 34 adult beds at the two hospitals (instead of 162) will be closed.

Cuomo promised to create 60 new "community" residential beds in our region (and more in Elmira), and a "Children's Behavioral Health Center of Excellence for the Southern Tier" at GBHC. This includes "expanded clinic capacity and access" and a new "Mobile Integration Team to respond to calls from schools, families, and pediatric services to provide assessment, consultation, first line treatment, and linkages to services."

We don't know if the new residential beds will be integrated (scattered-site, perhaps "supported" housing) or group homes. Or if the funding for those services will have to come out of the \$72 million or from some other pot of money. Or even if it's still \$72 million because the total number of beds to be closed has dropped from 665 to about 400.

Meanwhile Cuomo announced plans to strengthen various other mental-health-related activities, some of which appear primarily administrative in nature. But some possibly good ideas are included. One involves boosting rates for some people served by "health homes": programs that are expected to do much more than the rates the state offers can pay for. Also mentioned, Medicaid Redesign Team "supportive housing" projects, but it's not clear how much, if any, OMH reinvestment money is aimed at those projects.

Then there are the OMH "Health and Recovery Plans" (HARPs). As we've reported, the idea is to offer a range of community support services, similar to those available to people with developmental or physical disabilities, to people with mental illness, following the Medicaid Home and Community Based Services (HCBS) model. HARPs would offer things people with mental health disabilities have never been able to get before, including habilitation services, peer support, and real coordination with law enforcement agencies to keep people in crisis out of jail, with person-centered planning required and self-directed options available. It's a great idea.

HARPs would be a form of managed long-term care, offered through "Behavioral Health

Organizations." OMH originally proposed this with a Medicaid 1115 demonstration waiver, but recently HARPs have been described as Medicaid "1915(i)-like" services, delivered via the Medicaid State Plan instead of a waiver. It's complicated, but the gist is: State Plan services can't be managed care. The state has a complex rationale for delivering State Plan services under managed care. It says it's going to do it for the Obamacare "Community First Choice" program also, but we don't understand it no matter how many times they explain it. And it all has to be approved by the feds, who haven't been in a very approving mood lately. Still, Cuomo proposes spending some money on HARPs in FY 14-15, and it's not clear if that's conditional on getting federal consent or if he's going to start rolling these services out using state-only dollars.

We don't know how much of any of this will be paid for with OMH "reinvestment" funds. OMH says it will redeploy state workers from psych centers to new or expanded community locations, but we don't know if a dollar value has been attached to those workers and calculated into the mix. We also don't know if counties will have control over how those workers are deployed, or only over cash granted to provider agencies. All we can say is that the figures we're seeing don't appear to come close to 100% reinvestment. Cuomo still refuses to commit to 100%, and he is pushing tax cuts harder than service expansion in this election year.

Introduction to Budgeting

Normally we do a big "state budget" article this time every year. The topic is a bit misleading, because the state does about 90% of its legislative business during budget negotiations, and a lot of that business is not strictly about money. This year it's worse—murkier—than usual. It has become difficult to determine precisely how much money is even being proposed for certain things. Everything appears tied to various ongoing "planning" activities—the Medicaid Redesign plan, the OMH Regional Centers of Excellence Plan, the Olmstead Plan—whose details have not been finalized, or at least not made public. So we're doing it differently this time.

Most of the disability-related items in the Cuomo Administration's proposed 2014-15 budget, and related "Governor's program bills," involve ongoing issues we've been covering for a long time. And the policy decisions that hang in the balance are more

important for the long term than the money. So look for separate articles on those issues.

There are a couple of strictly budget-related things to mention though.

Cuomo wants to end the so-called “across the board” 2% Medicaid spending cut that he imposed with his first budget. He’s projecting a surplus instead of a deficit this year, and while he appears focused on getting votes this fall by enacting tax cuts or caps, he apparently knows that he can’t justify his tight squeeze on disability services when he’s got more money than he’s spending.

This cut was never really “across-the-board”; it was focused more heavily on Medicaid-funded homecare programs than on things like OPWDD’s specialized services or nursing homes. The cut has made it hard for homecare providers, including STIC’s Consumer Directed Personal Assistance (CDPA) program, to keep up with inflation and offer competitive wages and benefits to attendants. This means it’s getting harder for people with disabilities to find, and keep, good attendants. In some cases people can’t get all of the services they have been assessed to need. So restoring the cut should help with that. But other Medicaid cuts remain in place.

In particular, the “efficiencies” imposed on OPWDD-funded programs after the rate-setting scandal and federal cutback, are still there. You probably heard that Cuomo’s cut to OPWDD services was “restored” in a deal with legislators last year. That’s not really accurate. The deal was that OPWDD would eyeball every provider agency’s budget and cut out anything deemed “unnecessary” or “excessive,” and if that didn’t save enough money, the difference would be made up with state non-Medicaid dollars. Neither OPWDD nor Cuomo yet believe they have hit rock bottom on possible cuts that would trigger this “make-up” funding. The big media story was about super-high salaries for not-for-profit executives being cut back. That’s also not strictly true. What happened was that the amount of OPWDD money that could be used for such salaries was capped; those agencies can still pay the rest of those high salaries with other funds. Meanwhile, OPWDD and the Department of Health keep demanding more controls on spending, and more paperwork to document it. This increases administrative costs, but OPWDD is slowly tightening the noose on administrative budgets. Again, this affects agencies’ ability to offer attractive wages and benefits for people like habilitation

workers, increasing the already significant shortage of those workers.

Cuomo once again seeks to eliminate “spousal/parental refusal” for people who get Medicaid under some circumstances.

Spousal/parental refusal is a provision in Medicaid law that lets families whose total income is too high to qualify for Medicaid “refuse” to support a family member who needs medical or long-term care services, so that the family doesn’t have to impoverish itself by paying medical bills. It’s important to remember that the income eligibility threshold for Medicaid is very low. These aren’t rich families trying to rip off the government; they are families barely north of the poverty zone, who would be wiped out financially by big medical bills.

Because the Cuomo Administration includes a refusal provision in its Medicaid managed long-term care (MLTC) roll-out, and because Obamacare requires states to include refusal provisions in all HCBS waiver programs (such as OPWDD, TBI, and NHTD waivers), the problem affects a slowly shrinking number of people. Most notably, MLTC is not available in most upstate counties yet, and there are people in those counties who will qualify for it when it arrives, but under Cuomo’s proposal would lose their State Plan long-term care services in the meantime. Also, in order to get on a waiver that provides a refusal option, a person must first be approved for ordinary Medicaid, then apply, and wait a very long time, for a waiver. During the waiting period there is no refusal option, so the person might not get the initial Medicaid approval. Advocates need to be especially vigilant about this now.

When a Plan Comes Together...

We are keeping track of how the various proposals promised to New Yorkers with disabilities in the state’s “Olmstead Plan,” released in October 2013, are being carried out. One item, expanded community mental health services, is a big enough issue to justify its own article; see page 4. Here are some other developments:

Managed Care for Nursing Facilities

We learned recently that the plan’s claim that managed care will create an incentive to stop segregating people in nursing “homes” is misleading. What the plan actually does is require managed long-term care companies

to cover nursing “home” placement for *new* participants. Since integrated long-term care services are much less expensive than nursing “homes,” it’s in the companies’ interest to serve people in their own homes. But people already in nursing homes were “carved out” of Medicaid long-term managed care, so there’s no incentive to get them out.

Nurse Practice Act Reform

Most states have “nurse practice” acts that restrict performance of certain medical-related tasks to licensed nurses. This is presented as a protection for healthcare consumers to ensure that they are treated properly and safely. However, overly rigid laws of this type can prevent some people with disabilities from getting services at home, because nurses are scarce and expensive.

The plan promised to amend NY’s Nurse Practices Act (NPA) to expand availability of community-based and self-directed services. Cuomo’s budget-season package of bills includes language to do this.

It’s been proven that people other than nurses can safely and effectively do many things that nurses traditionally handle. For example, in NY’s developmental centers, psychiatric centers, and group “homes”, minimally-qualified, lightly-trained aides have given oral and topical medications, and first aid, under an NPA “exemption” for well over 30 years. Attendants working under the Consumer Directed Personal Assistance (CDPA) program, supervised and trained only by the people they work for, or by designated representatives (DRs) chosen by those people, have been doing those things, plus giving injections, inserting catheters, suctioning tracheas, tube-feeding, and other “advanced” medical tasks, under another exemption since the early 1990s. In CDPA, once a nurse finds that the person or his/her DR can train and supervise the attendants, there is no more nurse involvement. There are virtually no incidents of health or safety problems with the CDPA program.

We need to expand the ability of people other than nurses to do these tasks to programs besides CDPA. Many people with developmental disabilities get homecare-like services, and training and assistance outside their homes, from “habilitation” workers funded by OPWDD. Those workers aren’t allowed to give medication or perform other tasks that CDPA attendants can do. This means,

for example, that some people have to return home from work or community activities at regular intervals to get medication from family members or even CDPA aides. And we need a way for attendants working under the new Community First Choice (CFC) program, which offers home-based services to people with disabilities who aren't eligible for them under other programs, to perform these tasks.

CDPA itself has arbitrary limits on services that should be removed. For example, CDPA attendants can't shovel snow, mow lawns, clean the kitty litter box or diaper a baby for people who can't do those things themselves. CFC allows those tasks.

Cuomo's original proposal was severely limited. However, he listened to advocates' objections and sent a much better, though still not perfect, final version to the legislature. Here's what we ended up with:

The NPA exemption for OPWDD residential facility employees will be extended to any "direct support staff" employed, funded, or authorized by OPWDD, but it requires these staff to be trained and closely supervised by a registered nurse, including periodic visits to observe their work, whether the person is self-directing or has a DR, or not. This covers people who can't qualify as self-directing, and that's good. But it's unnecessary for those who can self-direct or have a DR to do so. Agencies like STIC that offer habilitation or similar services under OPWDD will need at least one nurse on staff to train and supervise workers to take advantage of this. But not excluding self-directing/DR people from the supervision requirement will require more nurses than necessary. The severe shortage of nurses, and the expense to employ them, will limit availability of this service.

CFC participants will be able to use the CDPA program, and CDPA-allowed services will be expanded to include outdoor maintenance, pet care and child care as needed (at least for CFC; we aren't sure if it covers all CDPA consumers). But CDPA is limited to people who are self-directing or have a DR. Some who don't meet those requirements, such as people with brain injuries or dementia who have no close friends or family, could live in the community if they could get the same kinds of services. So a new NPA exemption will be added for new kinds of highly-trained, experienced, nurse-supervised certified home health aides who can do those things for people who are not self-directing.

What's Really at the Core?

by Laurie Wightman

The implementation of new learning standards and accountability reforms surrounding NY State's Common Core Learning Standards Initiative has created a complex set of challenges for early childhood educators. Educational standards are not a new concept to the educational process. Standards help teachers ensure their students have the ability and knowledge they need to be successful learners by providing clear goals and objectives for student learning. Carol Copple and Sue Bredekamp, authors of *Developmentally Appropriate Practice in Early Childhood Programs Serving Children from Birth through Age 8*, explain that a challenge now confronting many early childhood educators is how to establish a balance between instructional approaches that align with new learning standards and accountability reforms, and still be considered developmentally appropriate for diverse learners. Many parents of children with and without disabilities have expressed concerns regarding the Common Core standards, as well as the expectations and demands placed upon the children. Numerous educators throughout the state have reported higher levels of anxiety in children. As a result of reports from parents and professionals, the Board of Regents formed a work group committee in December 2013.

The Work Group of the Board of Regents P-12 Committee was charged with reviewing the feedback the Regents and the State Education Department (SED) have received from various constituencies throughout the state. The Work Group was instructed to present ideas to improve the implementation of the Common Core standards to the Regents. Specifically, the Work Group was asked to identify assessment policy adjustments to be considered as part of the Elementary and Secondary Education Act (ESEA) Waiver renewal application. Also, the Group has been asked to review the development process, including the role of educators when using the optional Common Core standards curriculum materials created as part of the Race to the Top Initiative.

NY does not prepare large percentages of its students for success in college and career readiness. Whereas 74% of students graduate from high school within four years, it is estimated that only 35% graduate with English and mathematics skills necessary to enroll and succeed in college. According to SED, "Every year, despite our state's many excellent districts and schools, 140,000 students leave high school without the skills they need for college and career success." The Regents joined 45 other states in adopting the Common Core, the new college and career readiness standards. The Work Group has been tasked with analyzing the practices of districts experiencing the greatest success with Common Core standards implementation and replicating the "model programs" throughout the state.

A summary of 19 adjustment options has been identified. The Common Core standards will periodically be reviewed and updated. The review should gather feedback from stakeholders including teachers, higher education, faculty, business leaders, parents, special education advocates, and bilingual education experts. The Work Group has advocated for Governor Cuomo and the state legislature to adopt the Regents State Aid Proposal recommendation seeking funding for a Core Instructional Development Fund to support Common Core implementation and parent engagement activities. This amounts to \$125 million in 2014-15, \$200 million in 2015-16, and \$200 million in 2016-17.

The Regents have agreed to extend the phase-in for Common Core aligned Regents examinations required for graduation. The future class of 2022—current 4th graders—will be the first class required to pass English and mathematics Regents exams at college and career-ready levels. The Work Group has proposed that "smarter testing options" be offered for students with severe disabilities. This allows for students with disabilities, who are not eligible for the alternate tests, to be assessed based on instructional level rather than chronological age.

Parents throughout NY have voiced concerns that Common Core “teaching modules” are “scripted and timed” and educators may not “deviate” from the script. However, the www.engageny.org website, where the modules are listed, says the modules are optional and “suggested,” not “scripted,” and teachers are encouraged to modify them. Hence, the Work Group has suggested the creation of a new “Teacher Portal” to share resources and eliminate confusion surrounding adaptations of the modules.

Many teachers and principals cite concerns regarding their yearly evaluations based on student performance on the state assessments. The Work Group suggested to the Regents that if a school district seeks to terminate an educator based on an ineffective rating resulting from student performance on Common Core assessments during the 2012-13 or 2013-14 school years, s/he may raise as a defense an “alleged failure by the board of education to timely implement the Common Core by providing adequate professional development, guidance on curriculum, or other necessary supports to the educator during those school years.” The report to the Regents on these adjustments was adopted as of February 11, 2014. Department staff will implement the 19 specific initiatives as quickly as possible. The full report is online at: <http://www.regents.nysed.gov/meetings/2014/February2014/214p12hea3.pdf>

As a professional educator, I support increased learning standards for all students to ensure the opportunity to be critical and independent thinkers, which will increase chances for career and college readiness. However, as a parent of a child with disabilities, I see my son’s daily struggle with test anxiety and a “new style of learning.” I am fortunate to have the support of my son’s special education team to work with his unique needs and learning style. I encourage all parents to maintain a healthy rapport with your child’s teachers, to stay positive and encourage your child. Become an active participant in your child’s educational setting, and if unsure of the curriculum, ask the school for a list of supportive resources. Above all, keep lines of communication open.

If you are the parent of a child with disabilities, talk to your child’s special

education team about strategies for best meeting the individual needs of your child and safeguards which may be placed in his/her IEP (Individualized Education Program) or 504 Plan. It is imperative to remember that children with disabilities can succeed when provided proper instructional supports. For example, my son has dysgraphia, which makes it difficult for him to think or write in pictures. Many of the new concepts being taught in the math curriculum encourage children to write and think in pictures. He was finding it very difficult to complete his math homework, so I became a proactive parent. I met with his teachers and together we developed a strategy enabling him to complete his math assignments successfully. One such strategy which has been used by some school districts might be to allow the students to use circular magnets on a magnetic board, instead of drawing disks to represent numbers. A student may have an “amanuensis”, aka “a scribe”, built into his IEP or 504 plan as a safeguard. The scribe may then replicate on paper what the student has demonstrated on the magnet board. Other children may require extended time for testing. Be sure to talk to your district about what, if any, testing accommodations may be appropriate for your child in advance and have these accommodations placed in your child’s plan. Lastly, if you are a parent of a child with disabilities and have a question or concern about his/her educational program, please feel free to contact STIC at (607) 724-2111 (voice/TTY) and ask to speak with an Education Advocate.

Waivering Continues

The Cuomo Administration has been trying since nearly its first days to get federal approval for two huge new Medicaid managed care initiatives. The Centers for Health and Human Services (CMS) have balked on multiple grounds, including the OPWDD rate-setting and abuse scandals, and the Department of Health’s ongoing failure to answer questions from CMS about how the money being asked for would be spent.

The issue of the “Partnership Waiver” heated up in the media over the winter, not because of the disability community, but because

Cuomo apparently promised money from the waiver to some New York City hospitals. On one hand, the media has reported that some of these hospitals are in trouble and will close without the money, and on the other hand it’s been reported that these hospitals have excess beds that aren’t needed. CMS let it be known that it was irritated with Cuomo for trying to organize the state’s Congressional delegation to pressure the agency to approve the waiver instead of answering the agency’s questions. In February the sniping in the media stopped and it was announced that there is an agreement “in principle” to approve \$8 billion of the original \$10 billion waiver request, but that details must still be negotiated. Cuomo promoted this as a victory, but we won’t hold our breath waiting for actual results.

What’s important about the Partnership Waiver? It includes the Transformation Agreement that requires OPWDD to downsize and close all sheltered workshops, to downsize many small institutions known as ICFs, and to adopt the federal “Money Follows the Person” model for much of its new residential service development (especially, no facilities in which more than 4 unrelated people live together). It mandates that all Medicaid managed care programs must apply person-centered planning and offer self-directed services to participants. It enacts some aspects of the Community First Choice program, which, in theory, could be used to apply “community-first” needs-assessment and service planning to all long-term care in the state. (“Community-first” assumes that every person regardless of disability is best served in integrated community settings, and only if such services are tried and fail to meet the person’s needs will more restrictive options be considered.) So if this waiver does not get final, and real (not just “in principle”), approval from the feds, these initiatives to increase community integration and consumer control of services will grind to a halt.

Then there’s OPWDD’s “People First” waiver(s). That’s the program that will bring the “DISCO” managed care organizations into being. There is still no final CMS approval, no Request for Applications for DISCO demo projects, and only a weak belief by OPWDD officials that something might happen in late 2014 or early 2015.

courts watch

Better-Fitting SHUs? *Peoples v Fischer*

We reported on this case last summer. The NY Civil Liberties Union (NYCLU) brought a class-action suit against the NY State Department of Corrections and Community Supervision (DOCCS), charging that state prisons' reliance on extensive use of solitary confinement for minor infractions, and against people with mental illness, constituted cruel and unusual punishment. State prisons routinely place prisoners in solitary confinement "Special Housing Units" or SHUs, for things like unauthorized possession of cigarettes or documents, and for bringing charges of abuse against guards.

In February, NYCLU announced a potential settlement of the case. The lawsuit was suspended for up to 2 years while DOCCS agreed to some immediate policy changes, and to work with expert consultants to develop long-term alternatives to use of SHUs.

The agreement was promoted as making significant immediate changes in SHU policy, but that's not exactly the case. The most immediate measures include a "presumption" that pregnant inmates should not be placed in SHUs, and that people in SHUs should get more than one hour of "recreation" or other time (up to 6 hours for some inmates under age 18) outside the SHU every 24 hours. DOCCS also agreed to create alternate "rehabilitation" programs for people with cognitive or intellectual disabilities instead of sending them to SHUs. All of these proposals depend on whether funding is allocated to implement them. Beyond this, experts with experience in reforming prison solitary confinement policies will visit prisons and meet with officials and plaintiffs to develop further recommendations, to which DOCCS must give "full" consideration.

Advocates viewed the settlement as a positive, but small, first step. They support the "HALT" bill (Humane Alternatives to Long-Term Solitary Confinement), introduced in both houses of the NY Legislature. The bill would completely prohibit use of SHUs for people under 18 or over 55; people with disabilities including mental illness; pregnant women; and people who are lesbian/gay/bisexual/transgendered. Members of these groups would, if needed, be placed in "residential rehabilitation units" instead. Anyone else could not be kept in a SHU longer than 15 consecutive

days. Anyone in a SHU would have to be let out for at least 4 hours a day. Prisons would no longer be allowed to limit food to tasteless bread-like substances as a form of punishment.

We at STIC endorse the HALT bill, but we don't really think that being LGBT or in late middle age should qualify people for special treatment. The implication is that such people are somehow more vulnerable than others, which is a harmful stereotype. We do recognize that extended solitary confinement is dangerous to mental health and nobody should have to experience it. Prospects for passage in the bill's current state are poor, though it may be that when the experts issue their recommendations as described above, a bill containing them may be introduced.

Wages and Benefits

Disability advocates won a recent victory in the employment sphere. As part of his Executive Order increasing minimum wages paid under federal contracts, President Obama included people with disabilities. This means that although under federal law (Section 14(c) of the Fair Labor Standards Act) it is still permissible to pay people with disabilities less than minimum wage under some circumstances, contractors affected by the Order can no longer do so.

It's not a complete victory, though. The Order only affects "service or concession" contracts, such as operating a cafeteria in a government building. It does not affect manufacturing contracts—for things ranging from printing/packaging to production of parts for machinery—which is where most of the sub-minimum wage jobs are.

However, it is a significant symbolic turning point that could lead to production contracts being included down the road. Sheltered workshop operators are howling in pain, so it's clear they think they will be affected.

Disability advocates are not satisfied; they are working to repeal the entire 14(c) program. They support the "Fair Wages for Workers with Disabilities Act" (HR. 831), introduced in 2013 in the House by Gregg Harper (R) of Mississippi. Senator Tom Harkin, once thought an ally on this point, has turned against the proposal. We'll keep you updated.

NYAIL 2014 Disability Priority Agenda

(abridged)

The New York Association on Independent Living (NYAIL) is dedicated to removing barriers to the full community integration of people with disabilities of all ages. NYAIL represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs are controlled and primarily staffed by people with disabilities. 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.

Gov. Cuomo issued NY's long-awaited Olmstead Plan in October, detailing how the State intends to comply with the Supreme Court's *Olmstead v LC* decision to ensure people with disabilities get services and supports in the most integrated setting appropriate to their needs. NY is also preparing to implement the Community First Choice option and the Balancing Incentive Program under the Affordable Care Act, which create new opportunities for people with all types of disabilities to live in the community with services and supports. NYAIL's agenda supports the Plan by addressing barriers to community living and ensuring individual rights.

BUDGET PRIORITIES

Independent Living Centers

NYAIL urges the Governor to increase funding for ILCs to \$15 million, an increase of \$2.639 million. ILCs are essential community-based advocacy and service organizations that ensure people with disabilities have access to services and supports to live independently in their communities. ILCs are the "boots on the ground," making *Olmstead* a reality in communities across NY. Investing in ILCs is essential to ensure successful *Olmstead* implementation and will result in additional Medicaid savings to the state.

The state has an unprecedented opportunity to use ILCs to assist in implementing *Olmstead* and the Medicaid Redesign Team's reforms, including the transition to mandatory managed long-term care and implementation of Community First Choice and the Balancing Incentive Program. Data from the NYS Education Department, ACCES-VR, show ILC efforts to transition and divert people with disabilities from costly institutional placements **saved the state more than \$1.4 billion since 2001. ILC transition and diversion activities save the state more than \$9 for every state dollar invested in ILCs.** ILCs are well placed to assist

in implementing *Olmstead* by helping people with disabilities access the services and supports they need to live independently and fully integrated in their communities.

The Executive Budget proposes level funding for ILCs at \$12.361 million. Despite more than 10 years of flat or decreased funding, the demand for ILC services continues to increase. ILCs served 79,818 people with disabilities, family members, and others in 2008-09. In 2012-13, ILCs served 85,541 people, more than 7% above five years ago. As NY continues to implement Medicaid reforms affecting New Yorkers with disabilities, this number will surely increase.

NYAIL commends Governor Cuomo's proposal to pre-invest savings from institutional closures in the community mental health system. NY's *Olmstead* plan commits to reducing the long-term-stay nursing facility population by 10% across five years. **The state should pre-invest Medicaid savings in ILCs to support their efforts to transition and divert people with disabilities from costly institutions to fully integrated community-based settings. NYAIL urges the state to increase IL funding to \$15 million.**

Health/Medicaid

New York must broaden the proposed Nurse Practice Act (NPA) exemption to include critical changes necessary for the full implementation of Community First Choice (CFC). These changes will generate over \$150 million in Federal Financial Participation (FFP).

(Editor's Note: Changes to the Executive Budget proposals in the 30-day amendments removed most of NYAIL's concerns about this issue. However, the proposal's timetable is still a problem. As it stands, regulations for new "advanced aide" and other services would not be finalized before October 2015, and the federal government would then have to approve the proposal, delaying implementation of CFC until much later. Advocates continued working with the Governor's office on this issue at press time.)

NYAIL supports the restoration of the 2% Medicaid provider payment reduction. This restoration helps home care agencies and consumer-directed Fiscal Intermediaries to better support their employees who provide vital services to people with disabilities.

NYAIL applauds the proposed mental health systems changes that support *Olmstead* and the state's deinstitutionalization efforts and pre-invests funding in community-based services and supports. The Executive Budget pre-invests \$25 million in state resources connected to closing an estimated 400 state hospital beds over the next few years. These state dollars help create urgent walk-in, peer and family support, crisis support

and respite, transportation and other critically needed community services. The proposed budget includes an unprecedented \$120 million Medicaid reinvestment in community behavioral health service expansions. The \$120 million supports managed care readiness efforts by plans, hospitals and community providers, advances the integration of behavioral health and medical services, preserves critically needed access to vital safety net providers and dramatically expands community rehabilitation, peer, family and crisis. We urge the Legislature to support the Governor's proposals to invest in behavioral health and community based services and supports.

NYAIL supports Legislation to protect people from out-of-network surprise medical bills. The legislation would require insurance companies to meet provider network adequacy standards so fewer New Yorkers would need to see out-of-network doctors or specialists, whether planned or unplanned. It lets consumers go out-of-network when their plan's provider network lacks a specialist who meets their needs, and includes an external appeal right in disputes. It holds consumers harmless for surprise bills from emergency room or out-of-network charges outside of their control and sets a fair process for providers and insurers to negotiate coverage disputes.

NYAIL supports proposed expansion of the Medicaid Managed Care Advisory Review Panel (MMCARP), and recommends the proposal be strengthened to improve the panel's efficiency. MMCARP monitors enrollment and ensures access to care for Medicaid recipients. The proposal would expand the panel from 12 to 16 members, and require that new members represent both people with behavioral health needs and those eligible for both Medicare and Medicaid. NYAIL supports expansion and recommends the state improve efficiency of the MMCARP by: increasing MMCARP transparency; requiring evaluation of managed care providers, trends in service denials, appropriateness of program materials, data collection, and reporting on access to care for people with disabilities; and requiring that new panel members be experts in issues facing people with disabilities, including at least one Medicaid recipient.

NYAIL strongly supports increased funding to promote MRT "Supportive Housing" projects. The proposed 2014-15 budget includes \$260 million over 2 years (\$100 million in 2014-15 and \$160 million in 2015-16) to continue providing service funding, rent subsidies, and capital dollars to increase housing options for high cost Medicaid recipients. This is a \$14 million increase from last year's funding level. NYAIL strongly supports the additional funding to increase housing options for people with disabilities and older New Yorkers transitioning or diverting from institutions. NYAIL

urges adoption of the following strategies to increase affordable, accessible, and integrated housing through reinvestment of Medicaid savings.

1. Create a \$10 million housing subsidy program for people with disabilities who are institutionalized or at risk of unnecessary institutionalization due to lack of affordable, accessible, and integrated housing. This will support the Governor's *Olmstead* commitment to reduce the long-stay nursing facility population by 10% over the next 5 years.

2. Include \$5 million for the Access to Home program, a successful program run 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.

NYAIL supports the adoption of a Basic Health Program in NY, which will provide more affordable coverage to adults with income between 133% and 200% of the Federal poverty level. As proposed in the Governor's budget, there would be no premium for people with incomes below 150% FPL and a \$20 premium for people with incomes between 150% and 200% FPL.

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

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 last year. A prescriber, with clinical expertise and knowledge of his/her individual patient, should be able to override a managed care formulary or preferred drug when the plan and prescriber cannot agree on the prescription. Individuals may have very different responses to different drugs in the same class. Sometimes only a particular drug is effective or alternative drugs may have unacceptable side effects.

PUBLIC POLICY PRIORITIES

Health

- Amend due process for consumers in Medicaid Managed Long-Term Care. *A4996 (Gottfried)*

Implementation of Medicaid managed care for dual-eligibles in NY continues to be phased in aggressively. Two issues have emerged regarding

due process protections for enrollees: dual-eligibles in the MLTC program will have to go through all internal plan appeal processes before requesting a fair hearing, and dual-eligibles in the MLTC program can only seek continued services pending an appeal in limited circumstances. This bill seeks to protect due process rights and ensure that dual-eligibles mandated into MLTC have the same rights to notice and fair hearing as other Medicaid recipients.

- Increase the requirement for accessible diagnostic medical equipment in physician offices.

Physical barriers are common at hospitals, practitioners' offices, and community clinics. Recent promotion of guidelines for accessible diagnostic medical equipment by the US Access Board could help reduce health care inequities in NY if the state adopts federal guidelines. Amending NYS Human Rights law to address accessibility of medical equipment easily accomplishes this.

Housing

- Make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law. *A.2095 (Espinal) and S.168 (Squadron)*

Landlords often reject tenants with rental subsidies, such as Section 8 and subsidies tied to the Nursing Facility Transition and Diversion and Traumatic Brain Injury Medicaid waivers. Many people with disabilities rely on subsidies and other assistance programs to live independently in the community. Discrimination based on source of income is illegal in New York City. NYAIL has advocated for making it illegal throughout NY State for several years. **Governor Cuomo committed to make discrimination based on a tenant's source of income illegal in NY as part of the proposed Women's Equality Agenda legislative package in 2013.**

- Incorporate inclusive home design/visitability features in new housing that gets financial aid from federal, state, county, or local government. *S.3160 (Krueger) and A.5068 (Millman)*

Most existing housing stock was not built to meet the needs of people with disabilities, including disabilities acquired as one ages. Housing built with basic accessibility features—"inclusive home 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. Renovation of homes is much more expensive than including accessibility features at the start of construction.

- A tax credit for purchase, construction or retrofitting a principle residence to achieve universal visitability pursuant to standards adopted by HCR. *S.3956 (Grisanti) and A.7537 (Lavine)*

This bill complements NYAIL's Visitability bill by incentivizing private homeowners, who are not covered by the Visitability bill, to include visitable standards when building or retro-fitting their homes. Visitability is not usually considered when building homes and as a result, very few private homes have accessibility features. But as people age or become disabled, these features are highly desirable. This tax credit offers incentives to include these design features in new or remodeled homes. It also assists with 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.

Civil Rights

- Incorporate Title II of ADA into NYS Human Rights Law. *A.2070 (Paulin) and S.4093 (Marcellino)*
- Waive the State's sovereign immunity to claims under the ADA and Section 504. *A.828 (Lifton) and S.3249 (Krueger)*

The ADA and Section 504 of the Rehabilitation Act of 1973 provide comprehensive protection for the civil rights of people with disabilities under federal law. Under the US Supreme Court *Olmstead* decision, people with disabilities are entitled to services and supports in the community and to avoid unwanted placement in nursing facilities and other institutions. Title II of the ADA provides protections against discrimination due to disability in services provided by state and local governments. This bill clarifies the scope of protections against discrimination, including in provision of services, programs, and activities. Public entities would be required to make reasonable accommodations and people with disabilities would gain access to enforcement mechanisms of the State Division of Human Rights. To date, more than 30 other states have incorporated Title II into state law, and none have reported any increased costs as a result.

Employment

- Establish a small business tax credit for employment of people with disabilities. *A.570 (Cusick) and S.1907 (Addabbo)*

Working-age people with disabilities in NY have a 34.5% employment rate, resulting in an employment gap between people with and without disabilities of 40.9%. The poverty rate for New Yorkers with disabilities is 17% higher than nondisabled citizens. This legislation provides incentive for small businesses to hire people with disabilities, increasing their opportunities to achieve gainful employment and self-sufficiency.

Transportation

- Cap fares for paratransit at levels no higher than the base fares for transportation of nondisabled adults using the public transit system. *A. 943*

(Kellner) and S. 510 (Espallat)

- Require the appointment of riders, including seniors and riders with disabilities, to Transit Authority boards of directors.
- Require transportation service providers (taxis and limousines) to buy accessible vehicles.

Limited accessible transportation availability is a major barrier faced by people with disabilities across the state, often leading to unemployment, inability to get medical care, lack of access to voting sites, and isolation from friends, family, and full community participation. Many people with disabilities rely heavily on paratransit services; however public transit budget woes have led to an increase in cost for such services. The paratransit bill would cap paratransit fares, because charging people with disabilities more than nondisabled citizens is discriminatory. Participation of transit riders with disabilities on Transit Authority boards ensures that local decisions made on public transit and paratransit issues consider the needs of people with disabilities. Increased availability of accessible transportation will result in considerable savings to the state Medicaid program because demand for ambulettes to transport wheelchair users to medical appointments will decrease significantly. The need for accessible taxis remains an ongoing concern.

- Establish a visor communication card for people who are deaf or hard-of-hearing. *A.1320 (Zebrowski) and S.5301 (Nozzolio)*

This legislation would provide all deaf or hard-of-hearing drivers with a visor communication card through the Department of Motor Vehicles, for the standard auto registration fee, which details appropriate procedures for assisting a deaf or hard-of-hearing driver during a traffic stop.

Education

- Require the Commissioner of Education to expedite review of the unnecessary testing of students. *S.6006 (Flanigan) and A.8354 (Nolan)*
- Prohibit administering standardized tests to students pre-k through second grade, unless used for diagnostic purposes or required by federal law. *S. 6008 (Flanigan) and A. 8355 (Nolan)*

Some students with disabilities need testing accommodations as part of their Individualized Education Program (IEP). Increased numbers of tests, especially those that are not diagnostic or necessary to measure progress, creates additional stresses on students and teachers alike. This bill seeks to reduce or eliminate unnecessary tests, which ill-serve all students, but especially those still developing their motor skills and those with disabilities. **Governor Cuomo has recommended eliminating standardized testing for kindergarten through second grade.**



A Brief History of the STIC Navigator Program

by Chad Eldred

What does a navigator do? Ask ten different people and you will get ten different answers. The succinct answer is that navigators assist people in enrolling in health insurance plans sold through the New York State Health Benefit Marketplace. Okay, let's stop there. Before going any further I will provide some background.

The marketplace is essentially the health insurance exchange that the Affordable Care Act (ACA) mandates every state provide for their residents. Private insurers sell health plans through the exchange. Those plans must meet quality standards outlined by the ACA. Every state had a choice whether to set up an exchange or use the one provided by the federal government. NY ultimately elected to set up their own exchange, which they call a "marketplace."

The marketplace is not a place that you can go to, it only exists on the internet and is accessed through a web portal. In short, you create an account, input identity and income information for your household, and then you purchase a health plan that meets your needs. Depending on your income and household size there may be tax credits that assist in paying the health plan premium. That sounds simple enough. The concept, by itself is certainly clear and concise. However, the reality of calculating household income and deciding which health plan is appropriate for an individual or their family is a deceptively complicated matter. The enrollment process mechanics can be complex, and deciding which health plan is right is not a light decision. Assisting an individual through the input phase of the web portal and distilling the options available through the marketplace are among the critical functions of a navigator.

The ACA mandates both the marketplace and its navigators. Each state is required to have them. The navigator grants were awarded to private not-for-profit agencies that serve the communities of New York State. STIC was one of the agencies chosen for a grant (the second

largest awarded in NY). I came on board the STIC navigator program shortly after our Executive Director announced that we won the grant for a nine county region. Our ED and Assistant Director had done much of the heavy lifting to win the grant and to build the foundation of the program. Despite all that had been done, there was still a great deal to do and the calendar was nearing August. The health insurance marketplace was set to launch on October 1, with the web portal going live on that date. We needed to quickly assemble a team of navigators and get them trained before then. STIC had decided to serve Chenango, Cortland, Tioga, and Tompkins counties directly and subcontract services for Allegany, Chemung, Schoharie, Schuyler, and Steuben counties to other ILCs (Corning AIM and Catskill Center for Independence). The subcontractors faced similar challenges. However, ultimately the success of the subcontractors was the responsibility of STIC and the responsibility of getting the navigator program launched rested on our shoulders.

Things fell into place quickly and the process was relatively smooth. Looking back on it, I don't think that we could have asked for anything more. An enthusiastic and competent team of navigators was assembled and trained. Training consisted of intense, state-sanctioned, multi-day events at various locations statewide. Across the counties we serve, offices were furnished and equipped for business. Building infrastructure and establishing name recognition in counties where we previously did not have any footprint was a sizable task in itself. Learning the landscape, both literally and figuratively, and developing a rapport with the residents of the counties we serve has been pleasurable labor for me. By October 1 a great deal of work had been done in a brief period of time. I am extremely proud of the work done by those of us at STIC, grateful for our guidance from NY State Department of Health, and appreciative of the invaluable efforts of professionals and community members in the counties we serve in this endeavor.

Launch day arrived and we were ready for the challenge. As with any new program, and particularly one that is web-based, there were

glitches and bumps in the road. It was inevitable. Yet while these glitches complicated the function of navigators, they also made navigators an invaluable resource for the public. An anxious and under-informed public quickly began reaching out to navigators with questions and requests for assistance. Navigators were largely learning on the fly, as was the entire state. However, enrollments were happening. People were making it through the pipeline and getting insurance. Navigators successfully assisted individuals, families and businesses and became increasingly skilled and knowledgeable each day.

Geographical breadth makes keeping a team together a challenge. Thankfully technology has served to bridge this gap. Group texting helped by allowing navigators to share their collective knowledge in real time. Our team could ask questions of one another, communicate tips, and share knowledge. Some days the phone did not stop vibrating. Over time the texts have decreased as we've gotten the bugs out of the system. Some days I have to ask if anyone is out there, just to be sure that the navigators have shown up for work. Of course they had. While initially unsettling, I have come to embrace the lack of chatter. My still and idle cell phone does not indicate that the navigators are without tasks; quite the opposite is true. Silence indicates that navigators are busily and dutifully performing their intended function of assisting with enrollments.

The reception that I have received along this journey has been decidedly positive. I've met consumers who are proponents of the ACA, and others who are not. Ultimately this is irrelevant. My job, and the job of every navigator, is to provide impartial assistance and education for those wishing to enroll in a health plan through the marketplace. We are simply a resource available to the public. I believe that the neutrality of the navigator program has played a significant role in the favorable interactions that we navigators have experienced. The public has been overwhelmingly appreciative of our assistance and thankful for our availability. Navigators are trained to be, and required to remain, objective in all aspects of their job. We are not allowed to share our own views, nor are we allowed to advise consumers on what insurance to choose. We have no horse in the race. We do not work on commission; rather, our purpose is to serve. The neutrality of the navigator program is something that I have come to cherish. One benefit of impartiality is that being removed from the political fray is incredibly liberating. In my experience, partisanship encumbers a person and weighs on the work environment. Another subsequent benefit is that neutrality allows our team to focus on the assigned task: to assist, to the best of our ability, those New Yorkers whom we are privileged to serve.

STIC to Provide Prevocational Services

Doing the same old thing in a new way

by Lucretia Hesco

STIC has recently been approved to provide Prevocational Services through OPWDD's Home and Community-Based Services (HCBS) Waiver. However, STIC's Prevoc services will not be delivered in the same way they've traditionally been by other agencies. Services will be provided one-on-one in community settings that offer integrated opportunities for individuals, preparing them for future employment.

This service does *not* involve paid work. The purpose of this program is to assist individuals to gain the skills necessary to overcome barriers to employment. Skills may include, but are not limited to: interviewing, time management, using public transportation, filling out applications, and gaining volunteer experience. Competitive and supported employment are considered successful outcomes of this service. To be eligible for this service, individuals must be approved under the HCBS Medicaid Waiver.

STIC is in the process of implementing this service and is hoping to start services by late spring 2014.

For more information or to make a referral, please contact Lucretia Hesco at (607) 724-2111 voice/TTY) or email lucretiae@stic-cil.org.



Haunted Halls

by Bill Bartlow

After the holiday break, we're back at work on our Halloween fundraiser. This year will mark our 5th. annual event, and plans are as ambitious as ever.

If you like **Binghamton Senators Hockey**, we have tickets for a block of 50 seats. By getting your tickets at the usual \$19.00 price through STIC, we will receive a portion of the proceeds. It is an opportunity for you to enjoy the Senators in action and support STIC at the same time.

Tickets are available for the home matches scheduled:

Sunday, April 6 at 3:00 pm vs. the Wilkes Barre/Scranton Penguins

Saturday, April 19 at 7:00 pm vs. the Norfolk Admirals

Please contact Bill or Todd at STIC (607) 724-2111 (voice/TTY) for tickets.

Also, this year we will distribute a Haunted Halls program booklet containing information about STIC's mission and service programs, a history of our Halloween attraction, and articles about Halloween that tell about the Holiday's history—its Celtic beginnings and the history of traditional Halloween practices and characters, such as: Trick or Treating, Bobbing for Apples, the Jack-O-Lantern,

Navigational Aids

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Catskill Center for Independence

Schoharie County

(607) 432-8000

Witches, Werewolves, Vampires, Zombies, and Ghosts. We will also provide space to acknowledge our sponsors and advertisers, to make attendees aware of those invaluable organizations, benefactors, and businesses that help to make our event possible.

If you would like to participate in or sponsor our event, or if you're just interested in learning more, visit our updated Haunted Halls website: www.hhh-stic.com. Or call us at the above number.

Ruby Tuesdays Give Back Fundraiser for HHH

by Todd Fedyshyn

The Ruby Tuesday fundraiser is back! It runs all day on Thursdays in March and April. Mention the Haunted Halls of Horror/STIC give-back program when paying your check and Ruby will donate 20% of your bill back to STIC.

Ruby Tuesday

Oakdale Mall

601-635 Harry L Drive

Johnson City

Give Back Event Dates

March 20 April 10

March 27 April 17

April 3 April 24

ENJOY A MEAL WITH US AND WE'LL GIVE BACK.

Ruby Tuesday

COMMUNITY GiveBack PROGRAM

100% OF THE GIVEBACK AMOUNT IS DONATED DIRECTLY TO THE ORGANIZATION.

SELF HELP

Our Experience with NYU and a Cochlear Implant

by Luke Redmore

(Editor's Note: Middle-school student Luke Redmore's first article appeared in our Winter 2013-14 issue as "My Family's Journey through My Brother Dave's Deafness". We had promised, before we saw the article, to change names, places, and dates to protect confidentiality. I got started on it just hours before the printer's deadline, so when I saw what a joyful and positive piece it was, it was too late to contact Luke and his mom and get their permission to use real names. We have that permission now, and Luke's story continues here. He's promised to keep us updated in the future, too.)

We at STIC are aware of the views of people who are culturally Deaf concerning cochlear implants. STIC neither opposes nor advocates use of this technology. People need to make their own decisions, and they need to be aware that it does not always work for everyone.)

I've always wondered what her voice would sound like. Or how she'd react to our voices. Would they soothe her or scare her? Would she look at a phone and wonder how it could carry voices thousands of miles, but her own ears can't carry sound at all? I've always wondered if, when she's older, she would hold her processor in her hand and remember that day, all those years ago, when she finally entered a world of sound.

From birth, Ann Elizabeth Redmore was diagnosed with a potential hearing loss, but it wasn't until her second birthday that it was confirmed at The Children's Hospital of Philadelphia. Through an MRI and an Auditory Brainstem Response (ABR) test, it was determined that she had a 90 decibel loss in both ears. At Philadelphia, Ann got hearing aids this past October. We tried them, but they didn't seem to make much of a difference. Naturally, my parents began looking into getting her a cochlear implant.

At the time, I didn't know what a cochlear implant was. I soon found out how the ear works and how a cochlear implant works. When sound waves enter the ear, they travel down the ear canal and hit the eardrum. The sound waves cause the eardrum to vibrate, turning waves into vibrations. With the help of three tiny ear bones, the vibrations travel to the cochlea. Inside the cochlea are many microscopic hairs, and when the sound vibrations enter the cochlea, those hairs move. The movement is then translated into nerve signals that travel to

the brain through the auditory nerve. From there the brain understands the nerve signals as sound.

In many cases of deafness, the auditory nerve remains functional, but the microscopic hairs are damaged. A cochlear implant can stimulate those hairs with electrodes. The sound enters a microphone on the hearing-aid-like processor. The sounds are converted into electrical signals that are sent to the processor's magnet on the head. From there, the electrical signals enter the body from the magnet, through the skin, and into the surgically placed implant. The electrical signals are passed to electrodes in the implant, a wire placed in the damaged cochlea. The wire sends those signals right to the auditory nerve, skipping the damaged hairs entirely.

My grandma has a cochlear implant, so my parents began looking into one for Ann. My mom learned that once you got a cochlear implant, you get new doctors and nurses and audiologists. Originally, she wanted to stay with Children's, but once she learned that Ann was going to get new doctors, she wondered if she could find something even better.

She was looking up ear surgeons one night when she found Dr. Roland. He's a nationally renowned ear, nose, throat doctor and neurosurgeon in midtown Manhattan at the NY University Langone Medical Center. There were other potential surgeons on the East Coast, particularly at Johns Hopkins Medical Center in Baltimore, but we decided on Dr. Roland because he's the go-to guy if you have a problem with your implant. The only problem was that Binghamton, where we live, was four hours away from New York City, but we got over that.

As soon as we could, in mid-November 2013, we contacted NYU about Ann being a potential candidate for a cochlear implant. NYU got Ann's records from Philadelphia and Syracuse, where she had also had an ABR at 6 months old, and her local records from Lourdes Hospital. We scheduled an appointment with Ann's new audiologist, Janet Green, at NYU on December 5. Mom said that they sounded very nice on the phone and asked me if I wanted to come with Ann and her. I said "yes" immediately.

Ann, Mom, and I drove to New York City, where we met Janet Green and the Education Supervisor, Rose. They were both very nice and got right to work. Mom and Rose took Ann, who had her hearing aids on, into a soundproof booth, and Janet and I were in the booth's control center. Janet sent sounds of varying pitch and volume into the booth and watched Ann's reaction. After the test, she

determined that with the most powerful hearing aid on the market, Ann could hear starting at about 40 dB, still outside the speech range. Then and there, Ann became a cochlear implant candidate.

A week and a half later, Ann, Mom, Dad, and I were going back to New York to pick Ann's implant, have another quick evaluation with Janet, have a speech therapy session at NYU, and meet Dr. Roland for the first time. This time, we came for three days before Christmas break. After the Thursday evaluation, we went across the hall to see Nancy Geller, one of NYU's speech pathologists. Ann was taking speech at home, but this was her first session in New York. We played with cookies and trucks and Ann had a lot of fun. Before we left, we got packets of information on the three main cochlear implant companies: Cochlear, Advanced Bionics, and Med-El.

Later that day, we went over to Rockefeller Center to watch Saks Fifth Avenue's holiday light show and to see the 70-foot-tall Christmas tree. Ann loved the city. She waved to everyone on the street and wanted her stroller to go faster. When we got back to our hotel, Ann went to sleep instantly, so my parents and I were free to look at the brochures we had gotten earlier. I took Cochlear, Mom took Advanced Bionics, and Dad took Med-El. When we were done reading, we shared what we'd learned. In the end, Mom liked AB, I liked Cochlear, but Dad didn't really prefer Med-El too much.

On Friday we traveled back to the Cochlear Implant Center to meet with Dr. Shapiro and choose Ann's implant. Dr. Shapiro was really funny and nice and gave us the pros and cons of each implant. He explained that the internal implant itself has generally stayed the same, but the external processors change often. He also explained that, while all three manufacturers sound American, none of them are. Advanced Bionics is Swiss, Cochlear is Australian, and Med-El is Austrian. We had many questions for him and he had many answers for us. He reminded us that after the surgery, it would still be about a month before Janet turns the implant on, because the incision needs to heal. We liked that AB's Neptune processor was swimmable and could be clipped anywhere on Ann instead of hanging on her ear. And in addition to getting Ann two Neptunes, NYU would give us two of the standard AB processors, the Naida. We had all agreed that we probably weren't going to go Med-El—we liked their concept of the one-piece processor that fit behind your hair—but we all figured it would get lost too easily. Cochlear, Dr. Shapiro told us, was the first and leading implant brand, but AB wasn't far behind. He also said that there was no "best" option and that the hearing resolution was generally the same. In the end, we decided on Advanced Bionics. The waterproof Neptune would be perfect for Ann and the extra

processors wouldn't hurt either. Dr. Shapiro said we could change our decision any time before the surgery, but we didn't think we would. And we were right.

Next we were sent to meet with Dr. Roland at the main hospital. The hospital was so big that it had to be color-coded! We eventually found Dr. Roland's office in the back of the hospital. He was really nice and his office had a giant wooden model of the ear that Ann couldn't put down. Dr. Roland looked in Ann's ears (which Ann hated) and reviewed her MRIs from Philadelphia. For the first time, I saw what was making Ann deaf, her enlarged vestibular aqueduct, or EVA. On the MRI, we saw a little sack by Ann's ears that looked a little larger than it should've been. No one really knows how the EVA makes the hair cells non-functional, but they do know that a cochlear implant can help that. We discussed our decision to go with AB, then went across the hall to schedule Ann's implant surgery. We finally settled on January 29, a little over a month. When we left the hospital, we were all happy that Ann was definitely going to get an implant now.

The rest of the day, we mostly walked around sightseeing. I went to the Empire State Building's observation deck for the first time and the view was amazing. The next day we went to the Museum of Natural History by Central Park. When we got to the animal dioramas, Ann went crazy. We got her out of her stroller and she ran right up to every single diorama, knelt in front of it, and signed the name of the animal she saw. She ran around the animals nonstop, laughing when the animals wouldn't move even after making faces at them.

For the next month, we talked nonstop about Ann's surgery. Christmas was in a few days, and Ann's hearing would be our *really* late Christmas present, but a present nonetheless. We decided that my sister, Mary, would go with Ann, Mom, and Dad for the surgery. We made hotel reservations, scheduled babysitters, and prepped Ann for the big day.

The day before the surgery, Dad took my brothers—James, Johnny, and Mark—and me to school, then left for New York with Mary, Mom, and Ann. The three days they were gone, we at home couldn't think of anything else. I prayed for Ann every day during intentions at school, and I'm sure everyone else did, too.

When Ann got back the day after her surgery, she was very tired and cranky. I found out that the surgery started an hour or two later than expected and took about an hour longer, but everything was fine. When she finally let someone hold her other than Mom or Dad, she insisted on being carried. After a while, we thought she was able to walk on her own, but was too afraid to try. One day, though, we saw her walk a little on her own, but when she saw us looking, she put her head in her hands and became very shy. She's walking mostly on her own now, but is still cautious. In about a week, Ann will go back to New York to turn on her implant. Now, all we can do is wait, but we know that once it's on, Ann's world will never be the same.



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