



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

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Thirty years ago I began a journey that has moved over many types of terrain. I've traveled roads that were smooth and level, rough and rocky, steep and muddy, zig-zagging and curvy, and many others that I'll leave to the imagination. Along the way I encountered sheltered workshops, nursing "homes", group "homes", developmental and psychiatric centers, structured day programs, and many other configurations designed to "protect" people with disabilities, as they stifled independence, choice and free will. Of course I also discovered some excellent programs that promoted people's rights and assisted them to achieve their freedom and live the lives they chose. Some were independent living centers, others legal rights organizations, and, more rarely, very innovative agencies that worked diligently to establish creative alternatives to institutions.

STIC's vision, which has often seemed like an unachievable dream, has been for a barrier-free world where people with disabilities lived, worked and socialized in fully integrated settings. In fact, people would be such full participants in their communities that the words "integration" and "segregation" would disappear from the vernacular.

Take out all my rhetoric, and what it comes down to is that for all of our 30 years we have aggressively advocated for real community services, and closure of sheltered workshops, group "homes" and other segregated programs/settings. We put our money where our mouth is too, by offering alternative programs that are individualized and person-centered, respecting people's choices and helping them to achieve their goals. We provide one-on-one habilitation services, service coordination that works with people who want independent lives in the community, and supported employment that finds real, competitive jobs for people with

all types of disabilities. We don't cheat, either, by using "enclaves" and calling it "integrated".

We've demonstrated through our actions and services, and through the data collected from other such successful programs, that integration provides a higher level of safety for people, as well as a much improved quality of life. We responded to proposed regulations, laws, etc. by repeating the litany of equality, independence, integrated services, and advocacy over and over again. Occasionally, a slight flicker of hope would flare up, but then usually die again. Officials would talk the talk about "choice" and "community-based services", but they seldom if ever walked the walk. When they did walk, they were such baby steps that most people living today couldn't have achieved their dreams.

Then a few years ago, scandals of abuse and neglect of people with developmental disabilities in group homes and developmental centers hit the pages of the Poughkeepsie *Journal* and *New York Times*, and very sadly, all the things that we said would happen when people with disabilities were secreted behind closed doors, were proven to be true. Believe me, this was not an "I told you so" that gave me any pleasure, not when it was at the expense of human beings.

Soon after, things began to change, with NYS Office of People with Developmental Disabilities (OPWDD) Commissioner Ritter leaving, and Courtney Burke taking her place. The new Commissioner was faced with huge challenges. She was tasked to clean house, train staff and ensure that abuse and neglect were reduced/eliminated, as well as with reforming the OPWDD system. She had to implement a vision that included closing developmental centers, Intermediate Care Facilities (ICFs), and group "homes", and increasing employment opportunities for people with developmental disabilities.

I'm pleased to say that she has been very much up to the challenges, all of it coming to fruition with an announcement on April 1, 2013 of a "Draft Transformation Agreement" with the federal Centers for Medicaid and Medicare Services

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(CMS) that lays out a plan for downsizing segregated living situations and strengthening self-direction and person-centered planning. It includes stopping new admissions to sheltered workshops by July 1, 2013, and eventually closing workshops completely (see page 2). April 1 is my birthday, and this agreement was the best present I could have received.

The agreement isn't perfect, and it still has room for improvement, but it is a great beginning. Not only does it include many of the goals that STIC has worked for over the last three decades, but it also provides timelines for achieving them. STIC could have written this draft agreement, and we are pleased with its scope and direction.

Perhaps not so surprisingly, there are many who are refusing to support Commissioner Burke's efforts, and some who have actively vowed to oppose OPWDD's "Road to Reform". They are operators of segregated residential and day programs who see the lucrative payments they've received shrinking to much lower rates for integrated individualized services, eroding their bottom lines. They are angry because they have invested money in "bricks and

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

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mortar" (group "homes", etc.), and now they feel they are being left holding the bag.

The writing has been on the wall for the last few years, however, and the direction of OPWDD's People First Waiver has been there for all to see, if they chose to look. These providers buried their heads in the sand hoping that OPWDD would come to their rescue as they've done so many times before. So at the expense of the promise of new lives for consumers, they protest the changes, screaming to maintain the status quo. While I can have some empathy for their financial plight, I cannot feel any sympathy for their strategy to oppose the new model for service delivery. I urge these providers to embrace the changes, develop a plan for divesting themselves of their buildings, and begin to walk with their consumers along this new road. It will be difficult at first, but I'm betting the rewards in the end will be worth it.

I don't mean to paint every provider with the

same brush. I'm associated with many agencies, through my participation in iCircle, which have come out in support of Commissioner Burke's efforts and are already moving forward to implement reforms. I acknowledge that for some of them it won't be easy, but I applaud them for putting their consumers' interests before their own.

So how does the terrain ahead on the Road to Reform look? Well, it has pitfalls, some major bumps and slopes, but it is much less steep, much smoother, and leads eventually to a level and very accessible plateau.

Will we get there? The people who are opposed to this have a lot of money behind them and they are very capable of successfully lobbying lawmakers to get their way. Commissioner Burke needs your support, and your legislators need to know that you support her. Your voice will speed the journey, so please speak up.



TRANSFORMERS!

In April, the New York State Office of People with Developmental Disabilities (OPWDD) released a truly remarkable document. "Health System Transformation for Individuals with Developmental Disabilities", also known as the "Draft Transformation Agreement", finally commits the state to make measurable—and big—changes in how services are provided.

How big? For example, New York State:

- will **stop** admitting new people to sheltered workshops on July 1, 2013.
- will submit a detailed plan to **downsize and close** workshops by January 1, 2014.
- must transfer at least 30% of people from two closing developmental centers to residential settings housing **4 or fewer people** by January 1, 2014.
- must submit a plan to transfer people from **remaining DCs and "community ICFs"** by October 1, 2013.
- will offer self-direction to **all** people served under OPWDD's People First and DOH's NYS Partnership Plan Medicaid waivers.

This could be a massive victory in the decades-long struggle of New Yorkers with disabilities to achieve real systemic reform.

The Transformation Agreement is a set of requirements imposed on the state as a whole, and on OPWDD and the Department of Health (DOH) in particular, by the federal Centers for Medicare and Medicaid Services (CMS) during negotiations over three new or amended Medicaid waivers. They include OPWDD's two People First waivers and DOH's amendments to its NYS Partnership Plan waiver.

The agreement appears in the DOH amendments. OPWDD has a PowerPoint presentation called "Update: The Transformation Agreement" on its website. There are some differences between these documents (see links below). One of the most interesting concerns targets for moving people from segregated to more-integrated residential settings.

The agreement itself says: "By January 1, 2014, New York will transition a total of 148 residents from the Finger Lakes and Taconic [developmental centers already targeted for closure] in accordance with the following milestones: 7 residents will be transitioned prior to July 1, 2013, 20 additional people transitioned by October 1, 2013, and the remaining 121 by January 1, 2014..." All of them must be moved to "community-based settings" that meet the **new** definition of that term proposed by CMS. That means much more choice and privacy in, and control over, those settings than nearly all current so-called "community-based" residences

allow (see *AccessAbility*, Summer 2012 and Fall 2009, for details). Moreover, OPWDD is **required** to use that definition even though the new regulation has not been finalized (and may never be in its current form).

OPWDD's "Update" says these residences all must have four or fewer residents, but that is not in the actual agreement. The agreement says that at least 30% of the total, or 44 people, must move to such smaller settings. ("Four or fewer" is required by the federal Money Follows the Person (MFP) grant program, under which DOH is seeking funds for OPWDD; see below.)

Another important change is the requirement to increase availability of self-directed services. Currently OPWDD's only self-direction option is "Community Supports and Services" (CSS) under the Medicaid Waiver (the new "Front Door" initiative hasn't really rolled out yet). CSS can be very useful, but it's notorious for its difficulty to navigate and, as a result, is not used by many people. OPWDD's People First waiver plan required the new Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs) to offer self-direction to all participants, but that's about as much detail as we had. Until now. The agreement requires NY to increase the number of people who are self-directing their services by 1,245 by March 31, 2014. "Self-direction" is defined as offering people with disabilities or their designated representatives the option to have either or both "employer authority" and "budget authority" over how services are managed. "Employer authority" means the person or representative "fully controls the recruitment, training, hiring, discharge performance review, performance pay increases, and supervision of" people serving them. "Budget authority" means "decision-making authority over how funds in their individualized budget for waiver services are spent." And self-direction isn't just to be offered to OPWDD consumers; it's for everybody in Medicaid managed care.

There's more detail on employment too. Along with the sheltered workshop items, NY must show an increase of 700 people in supported competitive employment by March 31, 2014. "Only integrated gainful employment at minimum wage or higher will be considered competitive employment."

Some other items in the agreement could be very good, but they are described too vaguely for us to know for sure. Among these is a requirement that DISCOs provide "conflict-free case management" (OPWDD Update); that NY must have an "independent process for assuring that individual person-centered plans meet the needs of enrollees served in community-based settings" (Draft Agreement); and that DISCOs "do not determine eligibility and process enrollment" (OPWDD Update). We don't think this adds up

to genuine third-party needs assessment, which we continue to call for. OPWDD is required to provide a detailed description of how it will achieve these things, though, so when we see that we'll tell you what's in it.

Another new federal grant that the state is applying for is the Balancing Incentives Program. This program will give NY Medicaid matching funds if it raises its total percentage of "Medicaid medical assistance expenditures on non-institutionally based long-term supports/services" above 50% by October 1, 2015. It can only use the extra money to create new or expand existing "home and community-based services", and can't use any of it for "nursing home capacity building".

Unstated in these documents, but implied, is the notion that this is just the beginning. OPWDD is required to provide detailed plans on how it will meet some of these requirements. We hope the plans will show how the trend toward integrated individualized services will continue over time. But we must note that some of these early deadlines are only for submission of plans, not achievement of goals. There is no explicit requirement to implement the plans.

On the other hand, some of the goals are extremely ambitious. Achieving them in the next 6-9 months would require a wholesale turnaround in the operations of many service providers, as well as major changes in how OPWDD funds services. Right now, for example, STIC has a long waiting list of people who are eligible for, but can't get, habilitation services because OPWDD won't fork over the dollars. There are still huge shortages of respite services. Both of these services are critical to supporting people in integrated settings. And many local providers of employment-related services are allowed to "cream"—that is, reject people with high needs or who are considered difficult to serve. There appears to be a disconnect at OPWDD between the people who are promoting these changes and those who are running the current programs. In order for this to work, three things must happen:

1. Much more money has to flow to existing integrated services to handle the exploding demand that these goals will create. That has to start **now**. No more admissions to sheltered work on July 1 (as you read this, **in about 2 weeks**) means providers of integrated alternatives must have been given commitments by the state that they will get paid to serve the people who would have been sent to workshops on that date, and that includes a lot of people who will "age out" of public education all at once at the end of the school year.

2. Outreach to build capacity must be intensive. OPWDD needs to send representatives to every service provider it can find—not only current OPWDD service providers but those who serve

people with physical disabilities, brain injuries, and senior citizens—to convince them to create new integrated support services, for people who need: housing setup, including intensive service coordination to set up shared living situations; job exploration and/or volunteer opportunities; services to connect people with and without disabilities who have shared interests to develop supportive social relationships; and personal assistance and/or supervision so that family members who need to go to work aren't facing care crises. And that includes being ready to issue startup funds as soon as expedited contracts can be signed. If OPWDD sent out an army of people to do this tomorrow, the services wouldn't begin to be online for at least 9 months.

3. Existing providers must be forced to accept anyone who meets the state's eligibility criteria for a service, regardless of how "hard to serve" they are, as long as the money flows to serve them.

Despite the promotional efforts of some OPWDD officials, we don't see any evidence that these things will happen any time soon. So, perhaps, despite the tough language in the agreement, behind the scenes CMS, OPWDD and DOH have a "gentlemen's understanding" that failure *is* an option. We think it's good to put heavy pressure on state agencies and dawdling providers to make change happen; after all, the changes were first mandated pretty clearly by the US Supreme Court's *Olmstead* decision back in 1999. However, it will be **disastrous** if this agreement turns out to have no teeth; the reform effort would lose all credibility with providers and advocates. So you may be surprised to hear us say that we won't complain if the final version has somewhat more modest, but realistically achievable, goals and deadlines.

Meanwhile, questions and objections have been raised by advocates as to whether the existing state MFP program funds will be diverted to OPWDD; the existing program is supposed to focus on getting non-OPWDD people out of nursing facilities, a project that is already underfunded and needs to continue. (STIC currently has a nursing facility outreach program funded by MFP.)

We keep hearing that OPWDD officials are telling providers that there is no turning back. In the past, OPWDD published a lot of feel-good "vision" and "goal" stuff, but did not require providers to change what they do and did not stop helping them expand segregated congregate programs. Now, though, providers have been told that they need to get in line with meeting these objectives, and they should not expect any guaranteed "back-fills" for their segregated facilities.

This, as Samuel Johnson might have said, has, like the prospect of being hanged, concentrated their minds wonderfully. At various meetings with OPWDD officials some providers have put on

impressive displays of rage and defiance. This would be comical if they didn't have such big funding reserves and powerful lobbyists behind them. It is very possible that they will succeed in frightening, if not OPWDD Commissioner Courtney Burke, then higher-level Cuomo Administration officials and/or state legislators into backing down. Advocates need to be alert and vigilant, and express support for these changes to state officials at every opportunity.

There's a lot more in these documents than we

can fully cover here. If you want the full scoop, here's where you can get it:

OPWDD "Update" PowerPoint: www.opwdd.ny.gov/people_first_waiver/joint_discussion_board_provider_vcon_updates/Transformation_Agreement_4-9-13

DOH Attachment H "Draft Agreement":

www.opwdd.ny.gov/opwdd_about/commissioners_page/04012013_partnership_plan_stcs_attachment

And here's where you can let Courtney Burke know that you've got her back:

Send email to:

People.First@OPWDD.ny.gov

Or call the People First Comment Line at:

(866) 946-9733 (voice)

(866) 933-4889 (TTY)



Courts Watch

Health Insurance Runs Amok: NYSPA, et. al. v. United Health Group

This class action suit was filed in federal district court in NY in March 2013, by the New York State Psychiatric Association (NYSPA). The plaintiffs say that United Health Group regularly violates state and federal mental health parity laws, NYS insurance regulations, and the federal Affordable Care Act, by imposing limits on mental health coverage that it does not apply to coverage for physical health issues.

United Health Group administers many insurance plans across the nation, including the Empire Plan in NY, which covers state workers and employees of many organizations that get state funding. United also oversees "self-insured" health plans for large private employers.

United appears to be prejudiced against the use of psychotherapy to treat mental health conditions, regardless of whether it is used along with other forms of treatment, such as medication.

Significant mental illness often, but not always, responds to medication. Drugs do not "cure" mental illness and often serious symptoms remain even when medication produces improvement. Many people with significant mental illness need ongoing psychotherapy to understand their condition, cope with symptoms and drug side-effects, and stay motivated to keep taking the medication. This has been clearly shown by scientific research, and United's own promotional materials and procedural guides say so.

Yet United allegedly applies illegal pre-authorization requirements and service limits to psychotherapy, refuses to fully explain, or falsely describes, reasons for coverage denials, and follows illegal procedures regarding appeals.

According to NYSPA, United routinely denies coverage for intensive psychotherapy (more than one session every 1-2 weeks) for people who are

actively suicidal or frequently hospitalized.

For example, a person who needed 2 weekly psychotherapy sessions was only allowed 2 per month due to "undisclosed quantitative limits on coverage for outpatient mental health care". In another case, although the rules of the CBS plan run by United clearly say that psychotherapy is covered, subject to post-treatment review of medical necessity, United suddenly cut off all coverage for future psychotherapy sessions for a person who used that service a lot.

United allegedly allows its staff who initially deny coverage to decide on appeals of those denials, in violation of insurance plan rules and state and federal laws. In second-level appeals, the company has refused to respond directly to very specific medical evidence and detailed legal arguments describing United's violations of law. Instead, such appeals are often met with a brief letter simply restating the denial of coverage. This creates the impression that the company doesn't consider the substance of these appeals at all.

NYSPA also says that United frequently denies coverage for out-of-network mental health services on grounds that the provider failed to respond to requests for information from United, requests that the provider never received.

The Empire Plan covers services by out-of-network providers at a reduced rate. United, in overseeing this plan, allegedly requires pre-authorization of mental health services from non-network providers, in violation of New York State regulations.

United also excludes out-of-network inpatient mental health services but covers out-of-network inpatient physical health services.

Under Empire, United has a stricter definition of "medical necessity" for mental health services than for physical health services. For mental health, it requires that services must: "have a strong likelihood of improving [the patient's] condition";

be "in accordance with generally accepted mental health and substance abuse practices and the professional and technical standards adopted by [United]"; and "must be consistent ... with scientifically based guidelines of national medical research or health care coverage or organizations that are accepted by [United]". The latter two conditions let United decide completely on its own what is medically necessary, and reject any or all scientific data in making such decisions. United doesn't require any of this for physical health care. Physical health care can be delivered to maintain or prevent deterioration in the person's condition, and only must comply with generally accepted science-based standards. These differences clearly violate mental health insurance coverage parity laws.

Unfortunately, in discussing United's different coverage rules for in-network vs out-of-network inpatient services, the lawsuit appears to argue that requiring use of the most integrated setting for people with mental health disabilities is an illegal "fail first" or "step therapy" approach to treatment. The federal mental health parity law prohibits requiring such practices for mental health services by insurance plans that do not also require them for physical health services. The cases cited in the complaint do indicate that people were denied coverage for residential treatment even though they were clearly an immediate danger to themselves or others, which would be wrong. And of course, requiring step-therapy for medication when the doctor knows that the lower "steps" won't work, is always wrong.

But the notion that requiring the most integrated setting to be tried first for any mental health condition that doesn't create an immediate serious danger to the patient or others, is a discriminatory form of "step therapy", is medically wrong. Although the Americans with Disabilities Act (ADA) specifically excludes insurance underwriting practices from its reach, making such an argument in this case violates the spirit of

the ADA and the US Supreme Court's *Olmstead* decision. It is sad that a lawsuit seeking to stop outrageous illegal behavior by one of the nation's biggest insurance companies could end up creating a dangerous legal precedent that undermines the civil rights of the people it is trying to protect.

At press time there was no information on when the judge would hear the case.

Solitary Crimes: *Peoples v Fischer*

This suit was originally filed by the NY Civil Liberties Union on behalf of a single prisoner, Leroy Peoples, in NY federal district court in December 2012. In March 2013, it was expanded to a class action suit. Peoples and two other plaintiffs allege, on behalf of all people in NY State prisons, that NY, by "policy and custom", violates the 8th and 14th Amendments to the US Constitution in its use of solitary confinement to punish minor infractions in prison.

According to the complaint, "as of January 2012, approximately 14% of the individuals confined in [isolation rooms called Special Housing Units or] SHU were on [the State Department of Corrections and Community Services, or] DOCCS' mental health caseload; 35% of these individuals had been diagnosed with a serious mental illness." This continues to happen despite the "SHU Law" passed a few years ago that requires DOCCS to divert people with the most severe mental health disabilities from SHU into residential mental health treatment programs.

Mental health authorities regard long-term isolation as harmful for anyone; it is known to cause severe and persistent mental health problems even in healthy people. They recommend that it never continue for longer than 15 days and that it only be used as a last resort to control people who pose an immediate danger to others.

Yet NY prisons routinely isolate people for trivial infractions such as "smoking too much", littering, or having "unauthorized literature". These isolation periods are often much longer than 15 days, and back-to-back isolation "sentences" may be served for multiple minor offenses. The average sentence is 150 days. The three people cited in the case were isolated from 9 to over 24 continuous months for non-violent behavior. Two of them had serious mental illnesses before they went to prison and the third developed one while in isolation. All of their conditions got worse in the SHU.

The plaintiffs argue that long-term solitary confinement for non-violent and trivial offenses is "cruel and unusual punishment" outlawed by the 8th Amendment. They also claim that the way prison officials investigate and try infractions and sentence confinement violates the 14th Amendment's Due Process Clause, because the word of a prison guard always "trumps" testimony

and evidence provided by a prisoner, and because people have been sentenced to SHU simply for being unable to prove to the satisfaction of the prison guards who run the trials, that an allegation of serious misconduct, such as sexual abuse, against a guard, is true.

We didn't know, at press time, when the court would hear the case.

'Til Facility Do Us Part: *Forziano v Burke*

The official name of this case is *Frank Forziano, Paul Forziano, Roseann Forziano, Bonnie Samuels, Hava Samuels and Norman Samuels v. Courtney Burke, Independent Group Home Living Program, Inc., Maryhaven Center of Hope, Inc. and State of New York*. You may have already heard about it, and you certainly will in times to come.

Paul Forziano and Hava Samuels are two people with intellectual disabilities who live in two different group homes on Long Island. Not unusual, for sure, except that they are married—to each other. Neither facility will allow them to live together.

The widespread media reports have been somewhat contradictory, and since we can't see the complaint (at least, not without paying for it) we don't know what, specifically, is being alleged. Here's what seem to be the facts:

The other Forzianos and Samuels listed are the parents of Paul and Hava. Courtney Burke is the Commissioner of the NYS Office of People with Developmental Disabilities (OPWDD). Independent Group Home Living Program, or IGHLP, (*there's* a contradiction in terms) operates the facility where Forziano lives, while Maryhaven Center of Hope, which is run by Catholic Health Systems, houses Samuels. The State of New York is supposed to be in charge.

The marriage took place in April 2013, but the parents say that it had been planned since 2010, when they and their children began asking for a place to live together.

The Associated Press (AP) reported that, according to "the lawsuit", IGHLP said in a letter that its facilities "are not staffed or designed to house and supervise married couples or assist married couples with the dynamics of their relationships, sexual or otherwise." IGHLP's lawyer told the AP that there is no specific legal requirement for the facility to provide quarters for married residents.

The AP story also said that Maryhaven refused "because it believes [Samuels] doesn't have the mental capacity to consent to sex."

It was variously reported that OPWDD officials claimed that there were no other nearby facilities that would accept married couples, that there were such facilities nearby but they had no openings,

that OPWDD had "sided with" the group "home" operators, and that OPWDD had no comment on the lawsuit other than to say that married people seeking to live in group "homes" are a "small minority" of residents of such facilities.

New York State law requires that people considered to have limited intellectual abilities who are in the "custody" of state-certified residential facilities must be evaluated on their ability to consent to sexual activity if they seek to have any sexual relationships. OPWDD has often used a written "test" for these evaluations. Some of the questions on the test require a very sophisticated understanding of the nature of relationships; others appear to require "applicants" to agree with, or at least understand, concepts of conventional religious sexual morality. We would wager that many so-called "normal" people could not pass that test.

But a facility that lets residents have sexual relations without both parties having "passed" the evaluation can be charged with neglect and/or sexual abuse, and its employees can be subjected to criminal charges. So this is not a matter that any certified facility can afford to take lightly. It is also not a matter of OPWDD "taking sides"; that agency has no choice but to enforce the law. Only the state legislature, or a very specific court decision, can change this.

As for what group "homes" are required to do:

All such state-certified facilities operated, or funded, by OPWDD are required to provide whatever individualized support each resident needs while in the facility, including help with building and maintaining relationships with peers. If the facility is an "Individual Residential Alternative" (IRA), the funding it receives is supposed to be calculated specifically from the costs of meeting those individual needs. ICFs ("Intermediate Care Facilities") are funded differently but are still required to provide individualized supports and services to residents. We don't know what types of facilities are involved in this case.

There are some limits to this. The needs, and services to meet them, must be in the resident's individual service plan. A facility that doesn't have physical capacity to meet a need (other than accessibility, which is required) probably can't be forced to take in someone whose needs it can't meet. For example, if the facility only has single-person bedrooms, it can't be required to let two people live in one room, and it probably can't be required to tear down walls to create a larger room for two people. And, of course, it's unreasonable to expect a facility to violate the rights of one resident to meet the needs of another, so a facility that is full can't be expected to kick out someone who doesn't want to leave, in order to make room for the spouse of another resident.

However, capacity to consent to sexual activity is not a matter of personal opinion, religious or otherwise, under state law. If the parties can pass a valid evaluation, they have the capacity to consent, period, as well as the right to act on their desires. OPWDD has a responsibility to ensure that these evaluations are done in a uniform, objective, and scientifically valid way.

As a law professor quoted in various media reports said, “This is a case that is moving into uncharted territory. If a state licenses the couple to be married, they are afforded all of the protections and privileges of marriage. The most fundamental right is to be able to live together as a married couple.” The court could decide whether a marriage license trumps the state law regarding capacity-to-consent determinations in certified residences.

However, it is clearly illegal for a group “home” that has a vacant two-person bedroom to refuse to let an otherwise-eligible married couple that “passed the test” live in it merely because they are a couple. And it is also illegal to refuse to provide staff to “supervise” and “assist” that couple “with the dynamics of their relationship, sexual or otherwise”—if they need any.

The question that hasn’t been raised in all this media coverage is, why would a married couple want to live in a group “home”? Why wouldn’t they want the privacy and freedom that living in their own, real, home provides?

We don’t really know what Forziano and Samuels want. The media has portrayed them as very unhappy that they aren’t allowed to live together, but that’s all we know. The rest of the information comes from their parents and attorneys.

The parents seem to believe that the couple aren’t capable of living in their own home. But we don’t know if any of these people have been told that the couple has a legal and civil right to get the supports and services they need in any residence they choose, including their own home; that such services and supports can be provided effectively and safely and have been provided to others; and that Paul and Hava have a right to make reasonable decisions about it themselves.

When it comes to sexuality, people get very uptight. Even disability rights advocates can get it wrong. The New American Movement for People with Disabilities released a statement that said, “the suggestion that the couple can simply move if they are discontent with ... their service provider ignores both the complexity of disability support services and the desires of all romantic couples with disabilities who receive supports. ... Moving to another provider would uproot their social capital and deliberately discounts the value of the couple’s friends, job and families in their lives. Furthermore, [the suggestion] completely

eliminates the responsibility of the provider agency to make reasonable modifications as [required] by the ... ADA.”

The two facilities in question are about 3 miles apart. These advocates don’t seem to be aware that nobody would have to move further than to the nearest available rental unit, and that all of the support and supervision they need could be provided there. The couple see each other every day at a “performing arts education center”. Leaving a provider’s residential facility would not change how they spend their time during the day, nor would it deny them access to their friends, even if those friends live in the group “homes”.

Nondisabled American married couples don’t usually live in communal settings with friends, but sometimes they do. In such cases, it is a matter of choice, not only for the couple, but for the friends. Perhaps some friends would rather not live in such close quarters with a married couple if they had a choice.

We would certainly like to see NY’s draconian legal restrictions on sexual activity by people with intellectual disabilities lifted. But we don’t think taking this case to court will do that. The court will try very hard to avoid that controversy. It can resolve the case by saying what we’ve already said here—if the couple can “pass the test”, the facility operators have to accommodate them if they have suitable vacancies—and that’s what it’s likely to do.

The real solution to the problem for Paul and Hava is indeed to move—not only out of those group “homes”, but out of any state-certified program that requires them to submit to “capacity to consent” evaluations. All of the services they need can be provided in their own non-certified home, with state funding, and that is the way for them to finally be united in matrimony.

Still, we’ll watch this case with interest because it’s sure to be interesting for a long time.

Budget Post Time

We were close to being right on the money when we said, last time, that “we’d wager that the Legislature won’t approve anything it didn’t approve last year, and everything else we’ve described will go through mostly unchanged.” Here’s how all the entries in the race finished:

Dogs

Cuomo’s proposals to curtail “Spousal Refusal” and convert the Early Intervention program to managed care were rejected wholesale.

His plan to end “prescriber prevails” for anti-psychotic drugs was also rebuffed, and see below!

Following the deal with the feds that cut \$500 million in federal funding out of Medicaid, some Republicans resurrected their (usually) annual attempt to cut “optional” Medicaid services. (“Optional” means the state isn’t required to offer them under federal law; it does not mean the state can have a rational or cost-effective Medicaid system without them.) This went nowhere.

Photo Finishes

The housing picture looks better than expected—to the extent that we know what it looks like at all. As we’ve reported, there are various state housing programs and it is never clear how the published budget numbers actually affect availability of housing.

Still, officially the Medicaid Redesign Team (MRT)’s “Supportive Housing Development Program” was funded at about \$86 million for 2013-14, which looks like a \$5 million loss over the original projection. Last year a lot of money under this project went to one nursing facility to build a new segregated congregate facility, and a lot of it was allocated to the state “mental hygiene” agencies (OPWDD, OMH and OASAS) to (mostly) do what they usually do—build or renovate group “homes”. We don’t know what the plans are for this year’s MRT funds.

Then there was Cuomo’s “new” proposal to “invest \$1 billion over 5 years to preserve and create 14,300 affordable housing units statewide.” As we reported last time, most of this money seems to be targeted to repair existing “affordable” housing; not for new low-income housing. It is not clear what, if any, overlap, there is between this and the MRT housing program.

And finally, separate from this is the continued development of supported housing “beds” mandated by two lawsuit settlements involving people with mental health disabilities, as well as ongoing work on housing for homeless people in New York City.

Complicating the issue was an announcement in May by the Cuomo Administration of \$91 million worth of “awards” for “shovel-ready” housing development projects. Since these awards followed a “rigorous application process” that must have started well before the current fiscal year, at least some of this appears to be MRT, or mandated lawsuit settlement, funds budgeted for FY 2012-13 that is finally being spent (see page 8).

It looks like the new Medicaid Managed Care Ombuds program will get started in the current budget. The original proposal was for \$3 million; we heard it had been cut to \$1.5 million, then later that it was being put off until FY 2014-15. We don’t know if it’s fully funded or not.

Also-Rans

Cuomo's proposal to require nursing facilities to use state Medicaid funds to pay special higher minimum wages to various kinds of workers was rejected.

The Access to Home program, which pays for home modifications for people who can't afford them was maintained at an entirely inadequate \$1 million.

The state funds administered by the New York State Adult Career and Continuing Education Services – Vocational Rehabilitation agency (ACCES-VR; formerly VESID) to be provided to Centers for Independent Living like STIC were maintained at current levels.

Out of the Running

Cuomo's proposed \$120 million cut in funding for "voluntary" (that is, other than state government) providers of developmental disabilities services was reduced to \$90 million. This was originally presented as an across-the-board cut. But state legislators got, and continue to get, a lot of publicity by pointing out that Cuomo could have reduced this even more by dropping his (apparently successful) plan to pay a \$5 million dollar bribe (er... incentive) to the producers of the *Tonight Show* to get them to return the show to New York City. OPWDD announced that who gets cut by how much will be determined by a committee that will look at individual provider organizations and try to eliminate things such as excessive executive compensation, excessive or "fraudulent" charges for services, and high administrative costs. Officials claimed that none of this would reduce services, and on paper it appeared that STIC might not be cut at all. But state agencies constantly squeeze us on "administrative costs", by refusing to pay for computers or to make empty space in our building suitable for use, and without considering the growing costs of compliance with tighter documentation and "quality assurance" requirements. No state agency pays the full cost of any service that it contracts with us to provide. The pressure on our unreserved funds (the money that you donate to us, and which we need to save for things like roof and HVAC equipment repair and replacement) is increasing. Eventually services jolly well will be cut. Either that or the roof will collapse.

Cuomo partially succeeded in killing the open competitive bidding requirement for OPWDD's DISCOs (and the newest wrinkle in managed care, FIDAs—the Fully Integrated Duals Advantage demonstration project—which are managed long-term care organizations for people who have both Medicaid and Medicare). Instead of issuing full-blown Requests for Proposals, OPWDD and DOH only have to post a notice on their website of their intention to establish these programs,

give interested vendors 30 days to submit some kind of offer to run them, and then consider those submissions along with those of whoever they really want to award contracts to.

As the state legislature considered this legislation to enact DISCOs and FIDAs, some segregated congregate service providers got the bill changed to say that regardless of what an objective scientific needs assessment says about what people with disabilities need, their "wishes" to be segregated will be respected. STIC and other advocates saw this and went to work. In the end, that dangerous language was somewhat changed. The final law says that the needs assessment and service planning process should take account of people's wishes that are consistent with their needs when determining how services will be provided—which is what "real person-centered planning" means, and has always meant. We think that people whose actual needs don't include segregation will not be able to demand it just because they "wish" it, but time will tell.

As we reported last time, due-process protections for Medicaid managed care enrollees are under siege (see page 12). Unfortunately, the bill sponsored by Assemblyman Gottfried to restore due process protections to Medicaid managed care went nowhere, though he, and we, are still trying.

Dark Horses

Cuomo didn't just lose on "provider prevails"; he lost big. As of July 1, 2013, most types of drugs are back under "prescriber prevails" in Medicaid Managed Care. Doctors got the last word back on 8 categories of medication: antidepressants; antiretrovirals; antirejection (including those used to treat various autoimmune diseases); seizure/epilepsy; endocrine (including hormones and anti-diabetes meds); hematologic (including anticoagulants); and immunologic (vaccines as well as things like interferon for the flu and anti-shingles drugs).

NY's "prompt payment" requirements for insurance companies were extended to include fiscal intermediaries. What does that mean? STIC's CDPA program is a fiscal intermediary: we collect time sheets from consumers and their attendants, bill Medicaid or managed care insurance companies, and then pay the workers. NY Medicaid has always been pretty quick to pay when bills are submitted electronically. But although managed care for homecare is in its infancy, already problems have arisen with insurance companies taking months to make payments to organizations like STIC. So this was a welcome win that we frankly didn't expect.

Lame Dark Horse

Unbeknownst to us, a bill was proposed to change NY's "scope of practice" law to allow some types

of "traditional" homecare workers to administer medications to people. This bill did not pass. CDPA workers can already do this. However, OPWDD habilitation workers cannot, and it doesn't appear that they would have been affected by this bill anyway. This is a big gap in what's needed to provide fully integrated community supports and employment; right now people in STIC's one-on-one integrated habilitation programs who need meds during the day have to return home to have someone (sometimes a CDPA worker) administer them.

Managed Care is Everywhere!

There are several types of mandatory Medicaid managed care being introduced in NY. DISCOs, FIDAs and Health Homes are among them, but this article focuses on two other types: Mainstream Managed Care and Managed Long Term Care.

Don't ask us why these are two separate categories. We don't know, and even the experts don't seem to be able to clearly explain them. They overlap in some ways but not in others.

"Mainstream Managed Care" (MMC) is for people of any age who have Medicaid but not Medicare, whether they have disabilities or not. "Managed Long-Term Care" (MLTC) is for adults over age 21 who have Medicaid, and some, but not all adults, who have both Medicaid and Medicare, and who need more than 120 days of long-term support services, including homecare and/or other forms of medical care for what appear to be chronic health conditions.

Then there are "exemptions" and "exclusions". If you're "exempt" from mandatory managed care, it means you can voluntarily enroll but don't have to. If you're "excluded", you are not allowed to be in managed care. If you think you're exempt, you have to apply and have the state say you are. You typically don't have to apply for exclusions, but sometimes the state will "mistakenly" enroll you anyway, and then you'll have to take formal action to disenroll. It's also possible to be required to enroll in managed care temporarily until you get approved for a program that is exempt or excluded, after which you'll have to disenroll. (See page 12.)

If you live in STIC's service area and need long-term care, you're probably eligible for both MMC and MLTC, but not yet required to enroll in either. That will change. Many exemptions and exclusions are already gone, and the only thing that is stopping many people from being forced into managed care is that their counties haven't come up on the roll-out calendar yet.

Here are recent and upcoming milestones on the road to full mandatory Medicaid managed care:

April 2013

The following exemptions and exclusions for mandatory participation in MMC ended: people in the Long Term Home Health Care Program (LTHHCP, or “Lombardi”) waiver; people in the Medicaid Buy-In; upstate children living in community foster care. People in LTHHCP will be able to opt out of MMC and enroll in MLTC instead. Mandatory managed care applies only to LTHHCP participants if they live in areas where “capacity exists”; that is, where there are managed care organizations available to enroll them.

New MMC-covered benefits include Medical Social Services and Home Delivered Meals for people transitioning from LTHHCP to managed care.

New MLTC benefits include Adult Day Health Care and AIDS Adult Day Health Care.

June 2013

MLTC begins to move upstate from New York City and Long Island; the first new counties are Rockland and Orange.

July 2013

New benefits added to MMC: Adult Day Health Care, AIDS Adult Day Health Care, and “directly observed therapy for TB inpatient”.

October 2013

Nursing facility residents will be subject to mandatory participation in MMC.

Hospice is added to the list of benefits for both MMC and MLTC.

December 2013

New MLTC counties include Albany, Erie, Onondaga and Monroe.

April 2014

MMC exemptions/exclusions end for residents of long term chemical dependence programs and state psych centers.

New MMC benefits include some specific lab tests, comprehensive Medicaid case management, OASAS services through “Behavioral Health Organizations” (BHO) statewide, OMH BHO services in New York City, and some additional medication coverage.

Some specific lab tests are added to the MLTC benefit.

FIDA demonstrations begin for people who have both Medicaid and Medicare. FIDAs are a more comprehensive form of managed care; they offer Medicaid-waiver-like services as well as strictly medical and home-care services. There will be separate FIDA demonstrations for people with and

without developmental disabilities. DD FIDAs are expected to look a lot like DISCOs and probably will become DISCOs eventually.

June 2014

Mandatory MLTC managed care rolls out to the rest of the state, “where capacity exists”, for almost everybody else, except people in the NHTD and TBI waivers, people in nursing and assisted living facilities, and dual-eligibles who don’t need “community-based” long-term support services.

A House is Not Always a Home

In May the Cuomo Administration announced that it had awarded some \$91 million to new “affordable” housing initiatives.

Availability of housing that people with disabilities can afford and which, if needed, is accessible to them is a huge issue all over the state. The floods of the last few years destroyed a lot of this kind of housing in our area, and “super-storm Sandy” did the same in New York City and Long Island. Virtually none of it has been replaced. Meanwhile, the state’s initiatives to increase integration for people with disabilities will create a huge new demand for more housing.

Our officials are hearing this but not very well. They keep pushing segregated or “supported” housing for people with disabilities, when what we need is just cheap ordinary housing, scattered across typical neighborhoods or housing complexes, that can be made accessible if needed.

Full details on how the \$91 million will be spent were not provided. What we did see indicates some bias toward segregation and an inadequate response to the needs of low-income people. Out of some \$32.2 million to be spent on projects Cuomo chose to highlight, over \$7.5 million will be used for 93 apparently segregated disability-only units. Not only are most of these units to be grouped together, but in some cases they are to be segregated *by disability*; some for people with hearing disabilities, others for developmental disabilities, others for “frail elderly” people, and so forth. \$8.2 million is for “elderly”-only units, including those with disabilities.

The highlighted projects include a total of 620 units; about 91% of them appear to be new, with the rest being renovated existing housing.

Income-eligibility was harder to determine. Of the 10 highlighted projects, 6 will include units for “low-income” housing; 5 will serve people with “moderate” incomes. Those are official terms that equate to hard numbers based on family size which change from year to year. Most people with disabilities are unemployed and live on fixed very

low incomes, but “very low income” is another official category that was not mentioned at all.

One of the projects is nearby. The Norwich Shoe Apartments will have 34 low-income units, including 7 for people with developmental disabilities. It covers an area previously occupied by “four blighted buildings”; we don’t know if those 7 will be scattered or grouped together.

Obamacare Comes to NY

On January 1, 2014, major provisions of the Affordable Care Act (ACA, or “Obamacare”) take effect. It’s time to start understanding how they will affect us now.

We must remind readers that STIC never endorsed the ACA; we said that single-payer national health insurance based on an expanded Medicaid program would be the way to go. When the law was attacked we defended some of its provisions, but our opinion of it hasn’t changed.

Anyway, each state must have a Health Insurance Exchange to offer insurance to people who don’t have it, and they are being encouraged to expand Medicaid eligibility to more people.

In NY, Medicaid income eligibility rules will be “simplified”, and eligibility is being expanded for most nondisabled people to 133% of the federal poverty level (FPL). Pregnant women and infants under 1 year of age will be eligible at up to 200% of FPL. Also, eligibility for Medicaid, once established, will continue for 12 months regardless of changes in income for this group.

Unfortunately, most people with disabilities will still have to have incomes at or below 100% of the FPL, meet “spend-down” requirements, or be enrolled in the Medicaid Buy-In, to qualify for Medicaid. When we say “most people with disabilities”, we mean those who are eligible for SSI or who meet Social Security definitions of “blind” or “disabled”, and people over age 65.

Family Health Plus (FHP) is being phased out. No new applications will be accepted after December 1, 2013, and it will cease to exist on January 1, 2015. Many people eligible for FHP will be eligible for ordinary Medicaid under the new income limits. But families, and children aged 19 and 20 with incomes between 133% and 150% of FPL will have to enroll in one of the new health plans to be offered by the Exchange; those plans will have higher premiums, deductibles and co-pays than FHP. These people will be able to apply for help to pay premiums, but in the near future there won’t be help for deductibles or co-pays.

As more details emerge on how this is going to work, we’ll keep you informed.

On the Horizon

The Cuomo Administration is set to release some news on New York's Olmstead Plan at the end of May. That's too late to cover in this issue, but we will certainly feature it in the fall.

The activities of Cuomo's "Olmstead Cabinet" have been closed to us. However, the state's Most Integrated Setting Coordinating Council (MISCC), which was created to produce an Olmstead Plan more than a decade ago, still exists, and while we don't know what purpose it really serves any more, it did meet in April. There was a lively discussion at which a number of topics were mentioned. Perhaps it provided some clues on what to expect from the Olmstead Cabinet.

Roger Bearden, the former disability rights lawyer turned CQC Chair turned *Olmstead* "guru", did a PowerPoint presentation and asked MISCC "public" (non-state-agency) members how they can help hold him and other state officials accountable for the plan. NYS Association of Psychiatric Rehabilitation Services Executive Director Harvey Rosenthal said there are three vacant public seats on the MISCC; people have applied for them but none have been appointed.

Pat Fratangelo of Onondaga Community Living, the developmental disabilities service agency in Syracuse that does shared living, said the MISCC needs to define "most integrated setting". Bearden noted that the federal Centers for Medicare and Medicaid Services (CMS) have proposed a new definition but haven't released the final regulation. There was a discussion about somehow transforming segregated facilities into "community" homes; perhaps ownership of places like adult "homes" could be transferred to the residents. ADAPT activist Bruce Darling said that we don't want to see another mere name change like those in the past, when places like ICFs were renamed "Individual Residential Alternatives" so "now you're in the community." OPWDD Commissioner Courtney Burke grinned at this. Rosenthal said, "No, we don't want adult homes, even if you claim they are owned by the residents." Mark Kissinger, representing DOH, said, "On Friday nights people are pushed from hospitals into nursing homes as the quick default. We need to make the community the default, the first option." This came as a surprise; Kissinger has not so far been known as an advocate for integrated services.

Meanwhile, the new Justice Center for People with Special Needs seems to be on target to open in June. Although we at STIC continue to have strong reservations about how this new state agency, which will take over some of the functions of the now-defunct Commission on Quality of Care, will work out, we can report some good news.

Leah Farrell, a tireless and effective advocate

for people with disabilities at Rochester's Center for Disability Rights, has been hired to work at the Justice Center. We are absolutely certain that Leah will continue to be a forceful advocate for maximum integration in her new position.

Getting Old isn't for Sissies—But it's Great for Crooks

Recently there was a news story about how managed care companies are defrauding New York State by enrolling spry and active elderly people into new "Social Adult Day Care Centers" in New York City. These new programs are supposed to be only for people eligible for Managed Long-Term Care; that is, people who have Medicaid and/or Medicare and need permanent assistance with basic tasks of self-care and self-preservation. But there were reports of seniors riding bicycles to the center or walking away carrying heavy bags of free food. These programs are cheap to run, and it was reported that managed care insurance companies were colluding with them. Apparently the centers recruit elderly people, who then sign up for managed care in order to get into them, and this brings in fat fees to the managed care companies. As the *New York Times* reported, "It is being gamed," said an executive at a managed care company, speaking on the condition of anonymity. "There are just plums in the payment system. And the state will choose to be blind about this until something happens, which is what they did with nursing homes." Top NY Department of Health (DOH) Medicaid official Jason Helgerson appeared to be upset about the bicycle story, but he also said that managed care companies should police the program, not DOH. Nevertheless, the NY Medicaid Inspector General said he would investigate.

There is a need for the assistance with nutrition, supervision and activities that such programs provide to those who are truly eligible, though, and that highlights a very important issue. In Stephen King's novel *Insomnia*, elderly Bill McGovern says, "Getting old is certainly no job for sissies, is it?" We agree.

Not only that, but it's a genuinely new thing under the sun, at least in the huge numbers of people who are now living to very old ages. Life expectancy is increasing rapidly, and people are staying healthier longer into old age, but even so there are an unprecedented and growing number of elderly people with disabilities in the world, and a smaller and shrinking number of younger people available to assist them. Society has not figured out what to do about this.

It's not enough to say, "Well, in the old days, when somebody got old they lived with their

adult children and they took care of them." Yes, that's true. One thing that many people don't realize is that our increased average life expectancy is largely a result of better conditions for infants. Life expectancy was low hundreds of years ago not because most people didn't get very old, but because a whole lot of babies died. If you made it past the first couple years of life you had a good chance of getting your "three score and ten" (70) years.

But in the "old days", families in general tended to stay together in multi-generational groups, each playing an active role in maintaining the extended family. Everybody worked, almost all the time, until they just couldn't any more. Adults of what we now call "working age", and even children above the age of 5 or so, worked very long hours on farms or factories. Grandparents didn't do most of the cooking, cleaning, and care of younger children out of the goodness of their hearts, they did it because it had to be done and they were the only ones available to do it.

That old social "contract" has been broken by *all* parties. Today the expectation is that when you become an adult, you go away, and perhaps very far away, on your own. This isn't just what young adults want; most parents want their adult kids out of the house so they can finally have some peace and privacy. Older people tend to view helping with child care as doing a favor for their kids, not fulfilling a natural expectation. It is unfair when modern parents who pushed their kids and grandkids out complain that nobody is there for them when they get old.

Beyond that, the rate at which the health of elderly people improves is much slower than the rate at which their life expectancy increases. In the "old days" seniors with disabilities didn't live very long after they lost the ability to do many things for themselves. Today they can live for decades.

Things have been trending in this direction for only about a hundred years, and it's only in the last 30 years or so that a crisis has begun to emerge. So it's not surprising that we, as a society, haven't figured out how to deal with it yet. But we'd better, because this is not going away.

Here are some things we need to start thinking seriously about.

1. Long Retirement Periods are Not Natural

People in the United States have grown up with the idea that they are entitled to spend the last 2 or 3 decades of their lives not working for a living. Of course, if you're one of the relatively few people who are wealthy enough to put aside enough money to support that, feel free. But most of us are not that rich, and we have no right to expect the rest of society to feed, clothe, and house us when we're still capable of working. Nor can

the shrinking number of younger people afford to do that even if it was right. We need to raise the minimum Social Security retirement age, and raise all of our expectations about how long we will need to keep working. It's not just a matter of money or personal responsibility; the longer you remain active doing useful work, the longer you'll stay healthy. We're sorry; we at STIC support a lot of progressive causes and ideals, but the knee-jerk lefties who insist that nobody should dare to touch this issue are just wrong.



STIC NEWS

2. Old People Need Young People

Lots of elderly people have convinced themselves that they will be happier if they don't have to associate with younger people, and they have begun to believe they have a right to that. They've gotten federal and state housing authorities to set aside funds to create elderly ghettos (also known as "senior housing"), where rowdy younger adults or children are not allowed to disturb their quiet, peaceful lives. The problem is that if the only people you interact with are elderly and more or less in decline, you will age faster. You will get depressed and feel less able to do things, so you will do fewer things, and then you will lose the ability to do those things. Being with younger people helps older folks keep in touch with the world at large, provides opportunities to pass on wisdom, and "keeps them young". A little noise and rowdiness is a small price to pay for those benefits. Government has to stop supporting segregated "senior housing".

3. Old People Need Old People

If you are the type of senior citizen who prefers the company of others your age, there are lots of opportunities to get it. The whole point of the Social Adult Day Care Centers is to ensure that elderly people who need some help or a little watching can get it. Why wait around for the government to form a club to do that for you? How about you and your cronies get together and meet up with some other seniors in your neighborhood and give them a little help yourselves? It will save tax dollars, keep you busy, and probably be a lot of fun.

The Baby Boomers began reaching their "official" retirement age a couple years ago. They are a big group, but the biggest is the generation in their 20s and 30s right now, and that generation isn't having enough children to replace them, let alone to pay for their care when they get old. Meanwhile, euthanasia and "right to die" laws are becoming more popular. This problem is not going to go away. We cannot keep on going the way we are. It must change, and, without a doubt, it *will* change. We need to take pro-active steps starting now to change it, or the change that economics imposes upon us may be very harsh indeed.

Something to EAT

by Sue Ruff

The Education Advocacy Team (EAT) is a group of parents, education advocates, service coordinators and others who meet monthly (usually the last Monday of the month, from 2:30 - 3:30) at STIC. In addition to trying to stay abreast of educational needs for local students with disabilities, the committee also reviews changes at state and federal levels.

Recently the committee submitted comments on the New York State Regents Work Readiness Credential that is being proposed as a replacement for IEP diplomas. Our local NYS legislators have long supported Early Intervention services and negative changes proposed in the Governor's budget were denied by the legislature again this past Spring. Members of this committee have also advocated with federal legislators about the loss of federal dollars for Head Start, Title I, Early Intervention and Special Education as a result of sequestration. For over seven years this committee has worked with others around the state and nation on the issue of restraint and seclusion.

In May, California Congressman Miller introduced the Keeping All Students Safe Act, HR. 1893, in the House of Representatives. Congressman Miller has fought for many years to protect all students nationwide from restraint and seclusion. Southern Tier ADAPT and STIC were among the 200 organizations that co-signed a letter in support of this bill:

<http://democrats.edworkforce.house.gov/sites/democrats.edworkforce.house.gov/files/documents/HR1893-SandR2013-Support-AutCom.pdf>

The text of the bill can be read at

<http://thomas.loc.gov/cgi-bin/query/z?c113:H.R.1893>:

Injuries, trauma, and death through restraint and seclusion have been documented for many, many years. Civil Rights Data Collection (<http://ocrdata.ed.gov/>) showed that nearly 40,000 students were physically restrained during 2009-10. Restraint and

seclusion are disproportionately used on students with disabilities and minority students.

In the words of Jessica Butler, Congressional Affairs Coordinator for The Autism National Committee, "America today is a tattered patchwork of state laws and guidelines, where some students receive comprehensive protections only to lose them if their parents move across a river, down a highway, or to the next town. Only 19 states have statutes/regulations providing meaningful protections against both restraint and seclusion for all children."

The only New York Congress member currently signed on to HR. 1893 is Louise Slaughter. Please call or email your member of the House of Representatives and ask them to co-sponsor the Keeping All Students Safe Act, HR1893. Here is a link to email addresses:

<http://www.house.gov/representatives/find/>

Or call (202) 224-3121, ask for your representative's office, and then ask for the education aide.

Congressman Miller had one minute to introduce his bill but his words reflect the damages done:

<http://www.youtube.com/watch?v=tgOTwD-UcOo&feature=youtu.be>

If you would like to join with others from the community to work on educational systems advocacy, please feel free to contact Susan Ruff at (607) 724-2111 (voice/TTY).

At Your Service

The Community Services Advocacy Committee at STIC was formed to work to ensure that as more and more people leave segregated settings, there will be enough integrated supports and services available for them.

The single most important support for integrated living is a place to live. Unlike many big cities, STIC's service area does not have a serious housing shortage of the sort most people think of. But our area has thousands of people living in segregated facilities that they don't need to be in, and there

is not enough suitable housing available for them when they leave.

“Suitable” means ordinary homes and apartments scattered through typical neighborhoods, where the rent and utilities are affordable for people who are either on government-provided fixed incomes like SSI or Social Security, or who work at entry-level, often part-time, jobs. Much, but not all, of this housing also needs to be either already “handicapped accessible”, or more-or-less easily modifiable to make it so.

There are lots of federal and state programs to provide these sorts of homes, but they are mostly underused, or not used at all, by the people in our region who develop housing. The problem got worse in recent years as two major floods destroyed a lot of low-income housing in the region.

STIC can't solve this problem alone. It can only be solved with a concerted effort by all of the people who are responsible for planning and developing housing in our region. What STIC *can* do is organize this effort.

We started with our well-attended housing conference last fall, at which we invited major players to join a housing coalition. Since then we've hired a Housing Educator, Seekia Morrison, who has been researching and collecting information on housing needs and opportunities. She will take the lead on building the coalition. Our goal is to

make sure that every person who is in a position to increase the availability of suitable housing for people with disabilities in Broome, Chenango, and Tioga Counties knows about, and fully uses, all of the options and help available for doing so. By the time you read this, we will have sent out invitations to join the coalition to those who signed up at the conference. If you didn't receive one and you believe you can help, please contact Seekia Morrison at (607) 724-2111 (voice/TTY) or housing@stic-cil.org.

Housing isn't the only topic for the Community Services Committee though. We've also been talking about the impact that Medicaid managed care will have as more people with disabilities are forced to enroll. One aspect of that is OPWDD DISCOs. They are expected to provide more opportunities for non-traditional support services for people with developmental disabilities in the coming years, because those services will be more cost-effective than segregated congregate facilities. We are working on ways to increase the availability of services such as:

Shared Living—In which people with developmental disabilities are paired up with other people to live together and help each other out. The person with a disability gets support and supervision, when s/he is not working or otherwise busy outside the home, from a housemate; in return the housemate gets a break on rent and utilities. This can be an

STIC's Loan Closet in Space-Time



Recently the Cider Mill Playhouse borrowed an electric wheelchair and a communication device from our loan closet to use as props in their production of Deborah Zoe Laufer's "End Days". Pictured are Mark Roth as renowned physicist Stephen Hawking, and Amoreena Wade as Rachel. We're star-struck!

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important piece of providing up to 24-7 support in integrated community settings. Setting up these arrangements, though, is time-consuming. Funds need to be available to hire staff to do that.

Job Exploration and Readiness – Supported employment is supposed to include enabling people with disabilities to visit and learn about different jobs, and also to learn skills, such as time management and use of public transportation, that they will need to hold a job. Over time though, government has cut much of the funding for such services, and made supported employment less effective for people with the most significant disabilities. Meanwhile, OPWDD habilitation services are restricted from offering much of this sort of work-oriented training. We're trying to find ways to help more people get ready for jobs that they are interested in doing.

Habilitation and Respite – These are not new services, but there aren't nearly enough hours available to meet the current need, let alone expected growth in demand.

Then there are the civil rights aspects of all the new forms of managed care that are coming to NY: Mainstream and Long Term Medicaid managed care, DISCOs, FIDAs, Health Homes and Behavioral Health Organizations. How do we ensure that managed care companies respect the laws and regulations governing them? Can we help people being forced into this new medical insurance system become informed consumers? We have just hired a new Health Information Specialist to work on those issues. In the coming months, Elizabeth Berka will research the complex laws and regulations, and the characteristics of various managed care plans. She will eventually be a resource for individuals who have questions, but she will also work on educating the public and on systems advocacy to make sure people with disabilities don't lose vital services and supports. She's just getting started, but by this fall you should be hearing from her.

As the Community Services Advocacy Committee continues to work on diverse issues related to maximizing integration for people with disabilities, we'll keep you informed of our progress.

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SELF HELP

Managed Care Gotchas

As mandatory Medicaid managed care ensnares more people in its ever-widening noose, we are beginning to see the problems that we predicted appear. We intend to follow this from now until doomsday (or until we get a better healthcare system), and in future issues we hope to bring you "report cards" on how specific managed care organizations in our service area are behaving.

Meanwhile, there are some emerging trends that we want to warn you about:

BOGUS!!! "You Might as Well Enroll Now"

People who are not yet required to enroll in Medicaid managed care are being told by various sources that since they will eventually have to do so, they should just get it over with.

THIS IS BAD ADVICE!!

Some managed care insurance companies are playing fast and loose with the rules. We hope, that with time and vigilance, these issues will get reported to the state Medicaid authorities, and to the new Medicaid Managed Care Ombuds program, and that they will straighten these companies out. We hope, but we aren't holding our breath.

In the meantime, if you enroll in Medicaid managed care you may get jerked around. If you do, you won't have the same legal rights to appeal care decisions or receive "aid continuing" that you have under ordinary Medicaid. Under managed care you have to jump through whatever hoops the company sets up for its internal appeals process, and get a final decision, before you can get an impartial Medicaid Fair Hearing. And once you have completed the transition from "ordinary" to managed care Medicaid, you'll no longer be able to get "aid continuing" while you appeal a decision. You could have your homecare cut to the point that you are forced into a nursing facility and lose your home before you get a fair hearing judge to reverse that cut.

Also, it appears that if you use a spend-down to maintain Medicaid eligibility, under managed care you won't be able to apply receipts for paid medical bills to the spend-down. As best we can tell right now, the only way to make a spend-down under managed care is to pay cash directly to the insurance company.

So DO NOT sign up for Medicaid managed care

until you are absolutely forced to.

How will you know when you're forced to? Well, you can't rely on what your county DSS or the state Department of Health tell you, because those agencies have "mistakenly" sent out letters telling people they had to enroll when they didn't. If you get such a letter, DO NOT just do what it says. Contact the person you work with at STIC. We can help you find out if it's genuine. If it is, we can help you learn if you're eligible for an exemption, and show you how to apply for one.

Don't Dawdle

People who are on any Medicaid Home and Community Based Services waiver except the Long Term Home Health Care Program (LTHHCP, or "Lombardi" waiver) are exempt from mandatory managed care, and will remain so for quite some time. The exempt waivers include the OPWDD HCBS waiver, the TBI waiver, and the NHTD waiver. If you're already enrolled in any of those waivers, you can sign up for managed care but you don't have to. As we've said above, DON'T. If you already did, you can opt out, and you should do that immediately.

But there's a catch. If you have "community" Medicaid but are not yet on a waiver, then you must be in managed care, and you will be automatically enrolled in a plan. Once you're on a waiver, you can then opt out of managed care.

You can't apply to be on a waiver until you are first approved for Medicaid, and this stuff takes time. So our advice is, don't delay! While you're waiting for approval for Medicaid, work with the agency that administers the waiver you plan to enroll in to get your waiver application ready. Submit that application the day you get your Medicaid.

Pay Attention

In most areas of the state you have a choice of at least two different plans for managed care Medicaid. These plans may be very different, not only in what they cover, but in whether they follow the rules for determining medical necessity, hours of service, and other things.

So as soon as you know for sure that you are required to enroll in managed care, you need to research the plans available in your area and make an informed decision. Unfortunately, there is no single website that you can visit to learn about and compare the different plans.

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STIC has just hired a Health Information Specialist who will be putting together the information you'll need on this topic, but she isn't ready yet (see page 10). So if you need help with this, talk to the person you work with at STIC.

Medical Necessity

Medicaid only pays for things that are a "medical necessity" for you. That's always been true. However, we are starting to get reports that some managed care companies are playing games with this. So be an informed consumer:

"Medical necessity" means the service, medication, or device is recognized in the medical community as being needed and effective for the particular condition(s) you have, either to improve the condition or maintain your existing abilities. It is only about your medical diagnosis and personal functional abilities—that is, what you are able, or

not able, to do yourself.

Medical necessity has nothing to do with your environment. It's not about whether you have a live-in boyfriend or spouse who can help you. It's not about whether you're a child with a parent who doesn't currently have a job. It's not about making value judgments about what the people in your life should or should not do for you.

If a Medicaid managed care company tells you that, for example, 30 hours of homecare per week is not a medical necessity for your child because, as a mother, you should be taking care of the child, they are flat-out dead wrong. They are violating Medicaid law and regulations. Do not accept such a decision ever. Immediately file an appeal, and pursue it until you win. Tell the person you work with at STIC about it too, so s/he can help you.



Sarah Norris, seated, at the May 9, 2013 Binghamton University Celebration of Design, and, from left to right, student team members Jonathan Dinces, Nithin Dandamudi, William Bailey, and Ryan Terracciano.

WANT TO JOIN THE FUN?

Binghamton ADAPT meets on the first Tuesday of each month from 4 pm to 5 pm at STIC, 135 East Frederick St.

All are welcome

An Unlikely Partnership

by Sara Norris

In the past twelve years, I have had many negative experiences with trying to find assistive technology devices that work for me. As many individuals with disabilities know, the process for obtaining assistive technology is long and the amount of paperwork is extensive and repetitive. This is true whether you are attempting to get it through health insurance, a waiver program, or other funding source. You could end up waiting six months to a year, minimally. To complicate the process further, it may be difficult to find a durable medical equipment company that is willing to complete the paperwork and accept

the reimbursement rate, so you may never get the equipment or you may get a poorly made product with fewer features.

All of this time, effort, and aggravation to get something that may not work as expected or advertised and may just become a dust collector. I have tried environmental control units, voice-activated remote controls, speech recognition software, various types of switches and mobility devices, with varying degrees of success and frustration. In addition to the disappointment I've experienced, I have wasted my money on products that have

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failed. When I was approached about coming up with ideas about product designs for the bioengineering class at Binghamton University, I was eager to share my thoughts and ideas.

For their senior year, the bioengineering students are required to apply their formal training to develop a real-world product. This process, known as Senior Design I & II, spans over their last two semesters and is worth eight credits. The first semester includes all of the planning involved in designing the product, including several interactions with the client who will be using the finished product. Among other requirements, the students must work in groups, stay within the allotted budget, meet with a faculty member throughout the project, consider ethical and safety issues, and determine the impact on the environment. Led by Professor George Catalano, the students are encouraged to take a humanistic approach to engineering by choosing projects that really matter.

For the past two years at the request of Professor George Catalano, Cheri Robinson (STIC's TRAIID Coordinator) has solicited project ideas from STIC's employees and consumers. Individuals are encouraged to challenge the student teams by proposing that they invent a new product to meet a need or improve upon an existing product. All of the ideas generated from STIC are designed to improve the functional capabilities of individuals with disabilities and no idea is too big or too small. Cheri compiles the ideas and then during the fall, Cheri and some of the individuals who propose the ideas, present them to the Senior Design I class. The students are assigned to a project taking into consideration the top three projects they would like to work on.

I have submitted project ideas and have been privileged to work with the student groups during both years. Of all of the different projects to choose from, they chose to work with someone with a disability. In fact, for both years more than half of the projects chosen were designed to benefit individuals with disabilities. In a world where I often feel that individuals with disabilities are underrepresented, it is an honor to see young people taking an interest in us and trying to make our lives better.

Throughout the process, the students weren't afraid to ask questions about my condition and needs, which put me at ease because I felt listened to. This open communication also contributed to the successful development of the products. Last year, I received an environmental control unit with four functions including turning on and off my fan, turning on and off my light, communicating with my parents, and contacting emergency services. The device exceeded my expectations and I can access it independently by using a sip n' puff switch.

This year, I proposed an adaptive pill dispenser, which I thought might be impossible. The higher tech medication dispensers I have seen don't meet my needs and are cost prohibitive. On May 9, I attended the senior presentation and demonstrated my finished medication dispenser, which not only has the capability to dispense all of my medications and includes water, but most importantly, I can access the dispenser independently.

With my desire to live independently in the near future, I truly value products that will help me reach my goal. I am grateful to Professor George Catalano for being empathetic to individuals with disabilities and for being a mentor to his students. I am also thankful for the students for diving into the world of disabilities, which may have been unfamiliar to them before now. I am hopeful that the students will carry this experience with them in their future endeavors and change the way products are designed.

Glossary of Abbreviations

We try to define every abbreviation the first time it appears in every article. Sometimes there isn't space to do that, so here's a list of some of the most common ones.

ACA – Affordable Care Act, also known as “Obamacare”

ACCES-VR - NY State Adult Career and Continuing Education Services – Vocational Rehabilitation; formerly “VESID”

ADA – Americans with Disabilities Act, federal civil rights legislation

ADAPT – A national grass-roots disability rights organization with many local chapters, including one in our region

BHO – Behavioral Health Organization; a form of Medicaid managed care for people with mental health disabilities

CDPA – Consumer Directed Personal Assistance program; “self-directed” personal attendant services where the consumer hires, trains, schedules, supervises and fires his/her attendants, with paperwork and billing help from an agency; available in NY under ordinary and managed-care Medicaid, and some OFA programs

CIL – Center for Independent Living; a not-for-profit local consumer-controlled cross-disability service and advocacy agency like STIC

CMS – Centers for Medicare and Medicaid Services; the federal agency that oversees those programs

CQC – Commission on Quality of Care; a now-defunct NY State agency that was supposed to oversee the compliance of OPWDD, OMH, and OASAS with various “quality” requirements; it has been replaced by the Justice Center for People with Special Needs

DC – Developmental Center; one type of large institution for people with developmental disabilities

DD – Developmental disability

DISCO – Developmental Disabilities Individual Support and Care Coordination Organization; OPWDD's proposed new managed care organization

DOCCS - NY State Department of Corrections and Community Services, which administers state prisons

DOH – NY State Department of Health

FHP – Family Health Plus; a NY State form of limited Medicaid coverage for families with incomes above FPL; it is being phased out

FIDA – Fully Integrated Duals Advantage program; a federal managed care demonstration grant program to offer a broad array of HCBS services to people who have both Medicaid and Medicare

FPL – Federal Poverty Level; an amount of income, adjusted for family size, below which people are considered to be impoverished

HCBS – Home and Community-Based Services, a category of Medicaid-funded services for people with disabilities defined by CMS, intended to support people in settings other than nursing facilities, DCs, ICFs, and psychiatric hospitals

ICF – Intermediate Care Facility (sometimes called “ICF/ID”); a segregated congregate residential setting of any size for people with developmental disabilities which meets certain CMS regulations to provide intensive medically-oriented supports and services; all DCs are ICFs, but not all ICFs are DCs

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ID – Intellectual disability, a type of developmental disability

IDEA – Individuals with Disabilities Education Act; a federal law that requires school authorities to provide public-school-age children with disabilities a free, appropriate public education in the least restrictive environment

IEP – Individual Education Plan; a plan to ensure that a child with disabilities gets a free, appropriate public education, as required by IDEA

IRA – Individual Residential Alternative, a residential program for New Yorkers with developmental disabilities; it can range in size from one resident to 12 or more and can be provided in any type of residence; it must be designed and staffed to meet the specific needs of the individuals who live in it; almost all IRAs are group “homes” with 6 or more beds and owned and operated by OPWDD or not-for-profit agencies

LTHHCP – Long Term Home Health Care Program (also called the “Lombardi” program), a Medicaid HCBS waiver available to elderly New Yorkers with relatively limited support needs

MFP – Money Follows the Person; a federal systems change grant program that gives NY extra Medicaid money to promote getting people out of nursing facilities

MISCC – Most Integrated Setting Coordinating Council; a committee of NY State agency heads and interested others charged in 2002 with creating an “Olmstead Plan” for the state

MLTC – Managed Medicaid Long-Term Care; a form of mandatory managed care for people with significant permanent disabilities; already in use in New York City and slowly being expanded to the rest of the state

MMC – “Mainstream” Medicaid Managed Care; currently available to and required for all nondisabled and many disabled New Yorkers

MRT – Medicaid Redesign Team; a group established by the Cuomo Administration to devise its Medicaid “reform” plan

NHTD Waiver – Nursing Home Transition and Diversion waiver program; a federal HCBS Medicaid waiver intended to enable people with physical or cognitive disabilities not served by other waivers to leave, or avoid entering, nursing facilities

OASAS – NY State Office of Alcoholism and Substance Abuse Services

OFA – NY State Office for Aging

OMH – NY State Office of Mental Health

OPWDD – NY State Office of People with Developmental Disabilities

SHU – Special Housing Unit; a name given to “solitary confinement” cells in prisons

SSI - Supplemental Security Income; a federal stipend for people with certain disabilities who have never been employed or are very under-employed

STIC – Southern Tier Independence Center; hey, that’s us!

TBI – Traumatic Brain Injury

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