JOINT LEGISLATIVE BUDGET HEARING - HEALTH
Albany, New York Wednesday January 29, 2020
Submitted by
Amber Decker Family Peer Advocate, Parent and Caretaker
Amber@specialsupportservices.com

Senators, Assembly Members,
My name is Amber Decker, I am a Family Peer Advocate, Parent and a Caretaker. My child has a Developmental Disability. I am a caretaker for my older adult parent who has a serious mental illness who has struggled throughout their adult life to remain in the community.

As a Family Peer Advocate, I feel compelled to help people navigate the MAZE of systems, many of which continue to become convoluted, complicated and inaccessible. I find myself having to coach families, caregivers and parents through the bureaucratic nightmares that they face in order to access services and support. So many of these services have become too complicated for families to navigate on their own. In order to access services, you need to be able to climb a huge wall of chaos, claw through a rats nest, eat pounds of baloney and trust no one at their word.

The Governor's Medicaid Redesign Team is a flagrant give-away to large institutions and unions who will reap billions in profits while destroying what was once the country's best social safety net for people with disabilities including those with intellectual and developmental disabilities The New York State's Medicaid Redesign Team (MRT) is a catastrophe, too privileged and far removed from the public and those they allege and claim to represent. The Medicaid Redesign Team is already proceeding with secrecy and zero transparency. At these secret meetings handshake deal making and conflicts of interest all go unchecked and unbalanced. Of note is the total absence of the LGBTQ and Caregiver/Parent community on the MRT 1 and MRT 2.
The MRT has failed to improve access to health care for the Medicaid population; including but not limited to those you consider an issue the SMI, SUD, I/DD and other STC (Special Terms and Conditions) Populations. We know that access to health care, including behavioral health care, long-term care and home and community based services has not improved. Nor has there been any evidence of "Quality" improvement since the MRT was imposed, there has been no reporting on any "Quality" from medicaid recipients at all.

The New York State's Medicaid Redesign Team was created through an executive order that they did not even follow has destroyed medicaid, an endless migraine.
One needs a GLOSSARY to just to understand and translate DOH's "reform initiatives" into plain English. Medicaid should not be **so difficult** to understand that it must be explained to our

legislature.. There's something inherently wrong about this if our Medicaid Director spends half of the Budget hearing just ***explaining*** HOW Medicaid works to our Reps. The MRT is not a Team - it's not even a Redesign, It is an end run around public accountability and sanity given that the Governor has sacrificed the biological basis of medicine for a set of specific special interests. Executive Order NO. 5 is unethical and should be illegal as it is an attack on Medicaid and those who need Medicaid to remain in the community and out of institutions. The MRT has not made any substantial or clear attempt to "*engage and solicit the input of a broad and diverse range of groups, organizations and individuals*". The MRT has not fulfilled its own "Duties and Purpose" as outlined in the MRT Executive Order One being:

> "*The Team shall engage Medicaid program stakeholders for the purpose of conducting a comprehensive review of and making recommendations regarding the Medicaid program, which shall include specific cost saving and quality improvement measures for redesigning the Medicaid program to meet specific budget reductions for Medicaid spending"*

It has failed to improve the quality of services delivered to the medicaid population; including but not limited to the SMI, SUD, I/DD, Medically Fragile Children and other STC (Special Terms and Conditions) Population. Much of the DSRIP "data" available on the public-facing dashboard not only shows little change, but is essentially ***meaningless***. Speaking of dashboards, much of the data is gathered using counterfeit tools; "Participating entities" are forced to enter data that has no way of being verified or validated. The DSRIP entities "**self-report**" the data, *(with no consumer input)*, so it is skewed towards their OWN interests. Since 2011, over 389 Medicaid Redesign Team **"projects"** have been launched with the specific goal of improving care and increasing the efficiency of the Medicaid program. Most of those "**projects"** have truly failed to have any impact on the lives of the most vulnerable and on the lives of those for whom they claim to have been created for.

There is no one representing consumers, parents, caretakers or families on the MRT I nor will the governor and the NYSDOH promise to allow any consumers, parents, caretakers or families on MRT II. The Medicaid Redesign Team I and the MRT II are set up to act in a corrupt and unjust fashion, even those appointed have revealed the discombobulated, unbalanced control of decision-making to be in the hands of a select few resulting in an overriding, of any democratic discussion; voting or stakeholder process They do not have anyone on the Team who is in fact a Medicaid Consumer, but do have Members who work for organizations, managed care plans and that benefit from the agreements and decisions that were made in secret from the public view and from those who are directly impacted. It is clear that the Medicaid Redesign Team is all about "agency-centered planning" not "person-centered planning."

NYSDOH has left out utilization numbers of CFTSS "EPSDT Expansion of Behavioral Health Kids-OLP, CPST, PSR, FPSS- Effective January 1, 2019: Children and Family Treatment and Support Services No relief in sight for Children and Families

The MRT's "Care Management For All" **is actually "Neglect for All" and Exploitation of all People who are in need.** The promises that were made compared to the funding that has been spent do not pass muster. New York State's Medicaid Redesign Team vision has **manipulated** resources generated through managed care quote-on quote "efficiencies" that actually actively exploit low-income and disabled New Yorkers. LDSS, OTDA, OPWDD, OASAS, OMH, OCFS, DOH are not complying with Olmstead, ADA or person-centered service planning. Managed care plans are committing fraud and failing to provide medical, behavioral health and home and community based services all the while collecting Per Member Per Month Payments, sometimes up to $5,000 per month. Real "Care Management" does not exist**.** The whole "Care management for All" initiative was supposedly the REASON why DOH moved Medicaid populations into "managed care arrangements" in the first place. Yet, there is really NO real care or "care coordinating" happening at all.... Groups like legal aid and ICAN are over-flooded with calls because all "managed care" did was make services harder for folks to access!

Health Homes replaced TCM

The Health Home program which replaced targeted case management is not working.
It is exploiting individuals and not providing service plans to these individuals. So much blame is placed on those that they serve for being transient, homeless and not available, yet no direct information, or actual "quality measures" has been collected from Health Home **recipients** or their **families**. With all the "Waivers" and "regulatory flexibility" that is going on in this new Medicaid territory, we can't even, as a public, help to identify what a real "conflict of interest" is, what fraud is, and where or how to even who to report the massive disorganization, exploitation and mismanagement that we are seeing on the ground because it's all happening with a DOH's rubber stamp of approval.

MRT Project: Behavioral Health Transition to Managed Care

https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/index.htm
The behavioral health "transition to managed care" project continues to show, not only no impact on the SUD & SMI Population, but less access to services! Yet Money is being spent more and more on the health home program while having no effect on the populations for which they are supposedly serving. No direct data is being collected from individuals whose lives are impacted. The Table below shows that Behavioral Health HCBS services continue to be inaccessible.

Adult BH HCBS Access Dashboard Data for 8.27.19

The Trend of HCBS Access for HARP Members							
Progress in Unique Recipients Count	Unique Recipients of HARP Enrolled	Unique Recipients of Health Home Enrolled	Unique Recipients of HCBS Assessed	Unique Recipients of HCBS Eligible	Unique Recipients of LOSD Requested	Unique Recipients of HCBS Auth Received	Unique Recipients of HCBS Claimed
8/28/2019	140,179	38,084	33,757	32,819	12,531	5,004	5,454
Compare with previous month report	328	-900	1,046	1,038	811	515	365
Compare with previous month report (by %)	0%	-2%	3%	3%	7%	11%	7%

NEW YORK STATE | Department of Health | Office of Mental Health | Office of Alcoholism and Substance Abuse Services | Office of Children and Family Services | Office for People With Developmental Disabilities

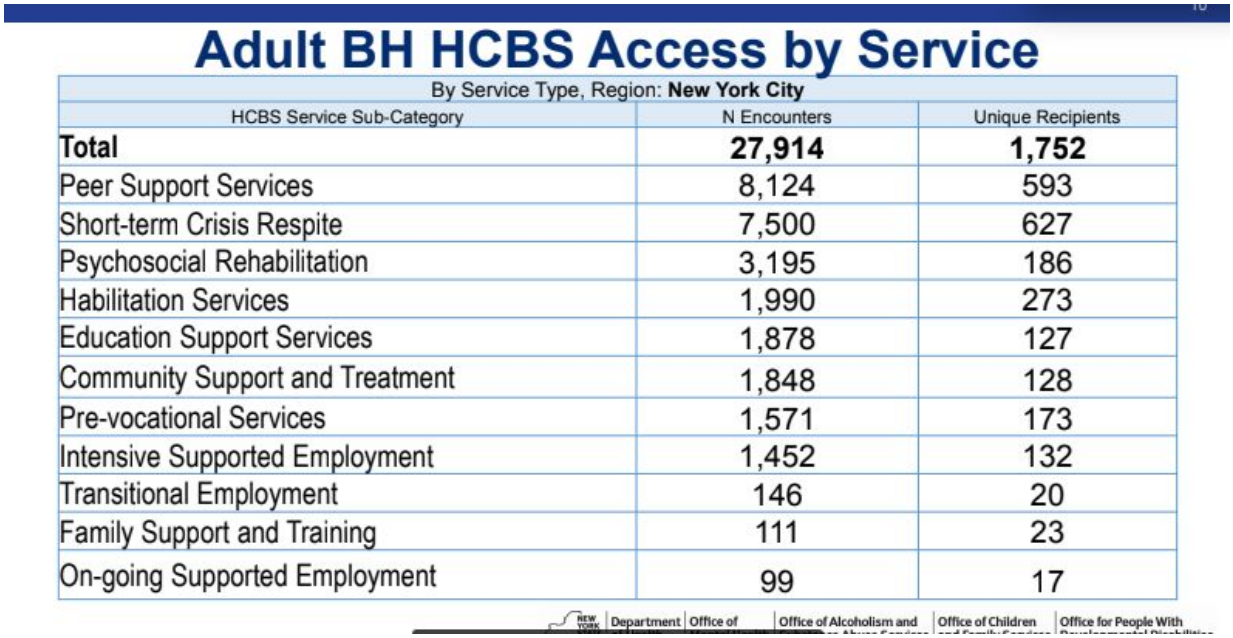
Since 2015 Health & Recovery Plans (HARP) (a Medicaid Managed Care Plan Product) continues to show a gross **under-utilization** of "enhanced services" which they call Behavioral Health Home and Community Based Services (BH HCBS). The utilization numbers of BH HCBS services for this population reveal this, and even after five years is extremely low
As of August 2019

11

Adult BH HCBS Access by Service

By Service Type, Region: **Rest Of State**		
HCBS Service Sub-Category	N Encounters	Unique Recipients
Total	**62,007**	**3,702**
Peer Support Services	22,233	1,788
Psychosocial Rehabilitation	12,732	752
Habilitation Services	7,591	570
Education Support Services	7,579	840
Community Support and Treatment	4,000	285
Pre-vocational Services	2,923	354
Intensive Supported Employment	2,581	341
Short-term Crisis Respite	939	196
Family Support and Training	801	92
On-going Supported Employment	427	40
Transitional Employment	184	32
Intensive Crisis Respite	17	10

NEW YORK STATE | Department of Health | Office of Mental Health | Office of Alcoholism and Substance Abuse Services | Office of Children and Family Services | Office for People With Developmental Disabilities



Adult BH HCBS Access by Service

By Service Type, Region: **New York City**

HCBS Service Sub-Category	N Encounters	Unique Recipients
Total	**27,914**	**1,752**
Peer Support Services	8,124	593
Short-term Crisis Respite	7,500	627
Psychosocial Rehabilitation	3,195	186
Habilitation Services	1,990	273
Education Support Services	1,878	127
Community Support and Treatment	1,848	128
Pre-vocational Services	1,571	173
Intensive Supported Employment	1,452	132
Transitional Employment	146	20
Family Support and Training	111	23
On-going Supported Employment	99	17

New York State Department of Health Ombudsman Programs are an Adjudicator of no one, A lovely Idea without Any teeth : NYSDOH Ombudsman Programs by the very nature of their funding are unable and unwilling to advocate for any population. NYSDOH funded Ombudsman Programs are ill equipped and spend most of their time working with NYSDOH via conference calls versus helping those who need services actually access them. Please call them yourself. ICAN is the New York State Ombudsprogram for people with Medicaid who need long term care or behavioral health services **(844) 614-8800** try to get a straight answer on their "process". There have been no clear metrics or data on what they are collecting on behalf of the individuals whom they are tasked with helping to *navigate the behavioral healthcare system!*

NYSDOH Funded Ombudsman programs cannot and do not provide oversight, access to direct consumer training actively. Not one public report has been forthcoming on their impact. Thus, Families and Individuals have no one, no outside impartial oversight to help them enforce their rights and protections because no one can keep up with the Mountain of Bull Crap, that has been created. They have nowhere to turn when Medicaid managed care plans deny and fail to pay for services including even basic mental health and medical treatment.
A REVIEW AND ANALYSIS OF THE 2020-21 EXECUTIVE BUDGET YELLOW BOOK says,

> *"Behavioral Health Parity: The Executive proposal would create a new fund to collect penalties from insurers that violate State or federal parity laws. Up to $1.5 million of these funds would be used to increase support for the Substance Use Disorder and Mental Health Ombudsman Program, which helps individuals and their families navigate the behavioral healthcare system." (Page 62)*

For the record, this Substance Use Disorder and Mental Health Ombudsman Program already began in 2019-20 and the Long-Term Care one began in December 2014!
There has yet to be any evidence or report on its impact concerning the hundreds of thousands of people including children in New York State who are without to date access to services!

Some of these undelivered inaccessible services and supports are induled but not limited to:
Substance Use Disorder Treatment
Mental Health Services, Home and Behavioral Health Home & Community Based Services (BH HCBS):
Children & Families Treatment Support Services
Applied Behavior analysis (ABA)

Local Governments: Including County, City, Town and Village, are not and do not know how to keep up with the steadfast New York State Department of Health changes. Other State Government Agencies are often too little and too late in offering guidance to Local Governments:

New York State Government agencies like the OMH, OCFS, OASAS and OPWDD all have a piece of the pie but cannot answer simple questions about Medicaid or Medicaid managed care plans who are also responsible for delivering services, nor can they troubleshoot access for vulnerable populations in any meaningful capacity because they do not seem to know how managed care works.
The same holds true for Medicaid Managed Care Organizations who do not have the care, capacity or knowledge of services in which they are supposedly responsible for paying! There are several plans of care for disabled individuals, not just home care and consumer directed personal assistance programs. The Medicaid Director's failure to explain to the legislature any details on how local municipalities will participate and determine care plans is alarming. Many individual's home care services are determined by MMMCP (Medicaid Managed Care Plans) and are never considered or reviewed by the local municipalities. The LDSS including the local counties have no part in what MMMCP determine as far as home care hours and plans of care go. They also have no oversight of these plans, which is how MOST Medicaid recipients in their counties access Medicaid.

Local Counties and Local Health Departments are being asked to act like ACOs
Soon "Local Health Departments" will be part of "SDOH providers" and VMOs or VDEs in VBP and if you don't know what the heck that means, then really, we have to wake up here and DEMAND more transparency in these new Medicaid financing games.
It seems that DOH would like to turn "local districts of social services" and counties into ACOs, "Accountable Care Organizations" of some sort, using a carrot and stick approach. If the

counties 'cooperate' with DOH and push folks off of Medicaid, then they get to "share in the **SAVINGS**". You know what? That's not the way local districts of social services are supposed to work. They are NOT "Business entities", and DOH should not be putting counties in a position to act like them. THAT would be a true "conflict of interest", violation of their fiduciary duties (?) and should be a cause for concern for **all of us** New Yorkers. NYSDOH's financing games are confusing because their new catch-phrase and initiative is "Value-Based Payments"... But, do we actually know what "**VALUES**" they are promoting though? According to this current Budget Proposal, the underlying Values are: non-transparency, $$ to big hospital systems, $$ to managed care organizations, etc. Look at the Global cap reports that were just published! The BIGGEST expense is to "Medicaid managed care". Are these the **Values** we want to see?

Public Consulting Group Inc. is driving this train

I ask you all to question and challenge what kind of "**Professional Assistance**" that DOH is receiving from ***Public Consulting Group Inc***.

This contract was entered via an "Executive Order" in 2017, which will last until 2021. According to the Office of the State Comptroller's database, PCG is providing "**Professional Assistance**" to DOH for the Department's 1115 Waiver and "Professional Assistance for the NYS Medicaid Programs" and a slew of other services via contracts including but not limited to:

- *"(HCBS) Waiver Final Rule - Statewide Transition Plan Implementation"*
- *"Person-Centered Planning Training"*
- *"NYS DelivSys Reform Incent-new" <--- "Independent Assessor!"*
- ***"Medicaid Administration Cost Allocation Plan"***
- *"COST ALLOCATION & RATE SETTING" (Office of General Services)*
- *Technology-based Information Technology consulting (Office of General Services)*
- *"Independent verification and validation for Statewide Financial System" (Division of the Budget)*
- *...among others*
  SEE HERE

It's subsidiary, Public Partnerships LLC, handles the NHTD and TBI housing subsidy. While there is no word yet on if PCG is going to be on the MRT II or one of it gazillion workgroups. It seems that *they have already written the script for the MRT II meetings:*

At the National Level, THIS is the group that is doing "studies" in Alaska for a Medicaid Block Grant, NYC controversial contract for Education consulting (2018), in **NJ**, OIG said that PCG improperly "altered" records, Indiana: Revolving door similar to Delaney, In New Mexico, the state relied on PCG's allegation of "fraud" and drove BH providers OUT OF BUSINESS!! **Why aren't we questioning these contracts?**

Nursing Home Transition Diversion (NHTD) Waiver:

New York has the Nursing Home Transition Diversion (NHTD) Waiver, however it eligible individuals are unable to access it, and it is never discussed at any public hearing or forum, this is a shame since more and more elderly are and should be diverted to this type of support.

In fact, there is such a lack of oversight of this program, that its NYC contractor Visiting Nurse Association of Staten Island (VNA) is involved in an ongoing lawsuit about the failure to provide any due process protections to those who are deemed eligible. The NYSDOH has not explained the total failure to allow access to this support. The NHTD Waiver is supposed to divert individuals from being stuck or forced into Nursing homes, which can cost up to 300-500$ per day or more to the Medicaid program. Yet there are approximately 2000 individuals state-wide enrolled in the NHTD Waiver and it is not widely advertised. The NYSDOH has not published any numbers or conducted any outreach on who else might benefit from this waiver.

People in Nursing Homes "Long -Term" Will be Disenrolled from MLTC Plans and No New Enrollment in the MLTC for People in Nursing Homes. Obviously there are serious concerns here because that means that managed care plans will have a conflict of interest and a very high incentive to avoid care planning and to decrease authorizing hours of home care, such as 24-hour/day care, for those with extensive needs -- allowing folks to wither away in expensive Nursing Homes and denied access to more appropriate supports in the community like home care. Before MMCP had to pay the high cost of nursing home care, there was an incentive to help folks maintain themselves in the community: MLTC plans were willing to pay for home care which costs much less than nursing home care, but now that incentive is gone. Now that the high cost of nursing home care is no longer charged to the plan, the plan can avoid high costs altogether by denying increased home care services, forcing the member into a nursing home. After 3 months, the member is dis-enrolled from the plan – and the plan, washing their hands clean, can and will **remove a high-need person from their rolls.** It will become even harder for people with disabilities – old and young -- to stay out of institutions or leave nursing homes… especially if they do not know about the NHTD Program, because DOH doesn't make that program known and available to the public very well.

<u>CDPAP under Fee For Service and CDPAP under MMCP</u>

Lastly, we must make something clear: There is a difference between CDPAP hours authorized by a Medicaid Managed Care Plan and CDPAP hours authorized by the LDSS

For some reason, DOH and its collaborating media outlets are perpetuating the myth that they function the same way. Furthermore, DOH and the media perpetuates the myth that MLTC=CDPAP. It does **<u>not</u>**. MLTC is a PLAN. *(CDPAP is a service; a certain MODEL of home care)*. CDPAP is not a "Health Plan"... In fact, one doesn't even need to be in MLTC to access a CDPAP program-- it is a model of home care that is also available in Mainstream

managed care, and via FFS through the local districts. Thus, it is **inappropriate** to rhetorically condense "MLTC" with "CDPAP" to obscure the facts about what they are in order to **blame** disabled and elderly folks, for such 'high spending' costs-- essentially using them as a political scapegoat.

The "figures"

When DOH is attacking the "local districts" and all their "spending", what we must understand is that MOST folks **do not** use the LDSS or HRA for their Medicaid determinations. The scope of Medicaid eligibility determinations that the LDSSs and HRA processes are for those "complex" cases… namely, the original, Non-MAGI (pre-Obamacare) populations: disabled, blind, elderly, former foster care cases, Dual eligibles who also have Medicare etc. The New York State comptroller's Office notes that this compromises of a merely **21.4%** of the Medicaid population. https://www.osc.state.ny.us/finance/finreports/fcr/2019/public_health.htm Furthermore, according to DOH's newly published figures for December 2019, of the approximately **6 million** people in Medicaid in NY, only **281,836** are in MLTC. Yes, this is a larger figure than years prior, but remember that DOH has **pushed** and **mandated** *more and more* folks to be managed care over the years. **Page 10:** https://www.health.ny.gov/health_care/medicaid/regulations/global_cap/monthly/sfy_2018-2019/docs/april-december_2019_report.pdf

Along with "mandating" managed care, DOH created incentives to enroll in Medicaid MLTC Plans including but not limited to :

a. Partially capitated MLTC plans do not restrict your access to doctors or specialists. That's because those benefits are "carved out" of the package. One is only subject to the "network" of long term care benefits: home care agencies, physical therapy, etc.

b. If one comes out of a nursing home, DOH encouraged enrollment into an MLTC by allowing a higher "housing disregard" for income calculations, so that folks may be able retain and be able to pay for their housing costs.

c. Federal programs have ENCOURAGED the use of home and community-based services. These are programs like: *Balancing Incentive Program*, *Money Follows the Person*, *CFCO*, etc. New York has taken advantage (rightly so) of the increased FMAP available by participating in these programs. Furthermore, laws like the ADA and Olmstead encourage HCBS for the sake of civil rights.

d. In 2016, Governor Cuomo allowed family members to be considered a "Personal Assistant" to folks enrolled in a CDPAP model of home care. DOH even wrote it explicitly on their website: *"The law was intended solely to **expand** the pool of who can be a CDPAP aide to include parents of adult children."* MLTC plans prefer to recipients to use CDPAP instead of traditional agency-model home care because it is ultimately

cheaper for the plans…. But not everyone wants to have the responsibility to hire, fire and train their own home care workers, and it is **not** an appropriate model for everyone. See: Clarification to the New Law in Relation to the Consumer Directed Personal Assistance Program (CDPAP)

For all of these reasons and more, NYSDOH cannot simply pretend to be "shocked" by all the increases in Medicaid MLTC enrollment!

The NYSDOH has unleashed a "Roadmap" for VBP called: A Path toward Value Based Payment: Annual Update June 2019 A Year 5 New York State Roadmap for Medicaid Payment Reform available in only one language and riddled with contradictions and fantasy. Based on the Roadmap content alone it is obvious that the DSRIP & VBP enterprise has been an ungoverned, unproductive and impractical plan; in which even those responsible cannot explain, comprehend or envision.

The NYSDOH alleges that the "Starting Point" is a Question: **"How Should an Integrated Delivery System Function from the Consumer/Member's Perspective?**" Ironically No "Consumer/Member's" perspective is inserted collected, quoted or considered. Instead the "Roadmap" goes on to claim that "The fundamental vision of NYS DSRIP is the creation of integrated delivery systems capable of meeting the diverse needs of Medicaid members." and that "Different types of members require different types of care. As foreseen in DSRIP, a high performing care delivery system encompasses three types of integrated care services, with optimal coordination between them" (page 9).

While sentiment is appreciated, it is obvious that the "Consumer/Member's Perspective" is not the starting point of NYS VBP vision, but rather a pretentious facade. One would think that VBP should start with asking medicaid members/consumers what they envision directly, which NYS has failed to do even though NYSDOH has had more than enough time to directly engage consumers/members about DSRIP since 2014 and yet nothing has been done to 1 educate consumers/members about DSRIP or VBP. The Roadmap goes on gaslighting and declares that it "aims to act as the primary source of care for the majority of everyday care needs." (page 9).

While this pitch of a utopian fair system, there has been no real work to see what access looks like for medicaid members including those who are disabled and whose lives are already being seriously impacted by such a careless impersonal automated landscape. Providers who serve this population cannot and will not be able to keep up with such a vague and disorganized objective, This is especially true for the many underfunded, misguided CBOs & Behavioral Health Providers who refuse to provide electronic health records, and direct access

to members because they themselves are not familiar with the technology and process and who simply are unable to retain the impersonal webinars and youtube videos that state entities provide "guidance and oversight". The public and stakeholders have yet to be provided with any meaningful juncture that allows for the review information about the VBP "pilot opportunities" including those obscure pilots aimed at specific I/DD arrangements. No one knows if and when these "pilot opportunities" will be known or even start.

Parents and caretakers are often left out of budget considerations, no one factors the cost of our lives. I can tell you we pay with our lives to keep our loved ones out of the most restricted settings like nursing homes, hospitals and prisons. We pay with our lives advocating day and night for services that we know they are entitled to, that we know that they need in order to be afforded the same rights as those without disabilities. We pay with blood sweat and tears everyday. Many of us have no choice and cannot work full time jobs with benefits due to the demands of advocating for our loved ones. Clearly the nursing home operators and union lobbyists are very unhappy with Olmstead, Money Follows Person, the ADA, and the HCBS Settings Final Rule because the deinstitutionalization trend takes money away from nursing homes. How many of those living in an institution would prefer an opportunity at a meaningful life? Parents and caretakers make that happen everyday for our loved ones until we are broken.

The Governor's Medicaid Redesign Team has and will continue to steam roll managed care for the severely disabled with little to no thought on how it will affect the voiceless, vulnerable, disabled New Yorkers who look to the State as their only source of services, support, and protection. Managed care is a code-word for privatization, plain and simple.

The Governor is attempting to get the State out of the business of caring for society weakest members and turning that moral duty over to for-profit investors who only care about share prices. The MRT is and continues to be the great sell out.

Thank you for the opportunity to submit this testimony.
Please feel free to contact me with any questions.

Amber Decker, Brooklyn, New York
amber@specialsupportservices.com