Testimony to the New York State Legislature
Joint Hearing of the Senate Finance and Assembly Ways and Means Committees
THE 2019-2020 EXECUTIVE BUDGET
TOPIC: MENTAL HYGIENE

February 7th, 2019
Submitted by
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Dear Senators and Assembly Members,

My name is Amber Decker I am a Family Peer Advocate, Parent and a Caretaker. My son has a Developmental Disability. I am a caretaker for my elderly parent who has a serious mental illness who has struggled throughout her adult life. I grew up homeless with my single parent in NYC, who was always in and out of Hospitals. We never had access to supportive housing and other community services, they did not exist during the 1980s. With a long history of voluntary and involuntary hospitalizations since 1987 for both medical and psychiatric illnesses my parent was never able to hold down a job and receives social security for her mental health impairment. Currently I live in Brooklyn New York but work with many families across the state of New York many of which are dealing with loved ones whose lives are seriously impacted by their disabilities.

I want to bring your attention to the millions of dollars that we as parents and caretakers for the severely disabled save the state of New York and tax-payers everyday by utilizing self direction.

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 steamrolled 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, supports, 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. MRT is the great sell out.

Health And Recovery Medicaid Managed Care Plans (HARPS) Gross Under Utilization of Behavioral Health Home and Community Based Services:

When my seriously mentally ill parent with Bipolar Disorder now age 63 was forced into mandatory managed care in 2005 almost 14 years ago, she lost so many services including day treatment services. Was psychiatrically hospitalized at least six times from 2005 -2010. The Medicaid managed care plan said she could not see a therapist and psychiatrist on the same day. The Medicaid managed care plan that she was auto enrolled in bit by bit besieged my mentally ill parent with many restrictions on mental health treatment and life became again a revolving door in and out of the hospitals, no one ever explaining or helping her assert her rights under the Mental Health Parity Act, we can never get that time back. Clearly this population's mandatory enrollment into a Medicaid managed care plan did not go as the MRT expected, because in 2015 there was the creation of a new Medicaid Managed Care Plan called Health and Recovery Plans (HARP)[1] into which almost 100,000 individuals were auto-assigned. My parent was again without notice or education auto-assigned by the New York State Department of Health into one of these plans with the hope of accessing BH HCBS (Behavioral Health Home and Community Based Services) which have been described as the following[2]:
Behavioral health HCBS benefits for the member:

1. Psychosocial Rehabilitation
2. Community Support and Treatment
3. Habilitation Service
4. Family Support and Training
5. Short-Term Crisis Respite
6. Intensive Crisis Respite
7. Education Support Services
8. Peer Support Services
9. Non-Medical Transportation
10. Pre-vocational Services
11. Transitional Employment
12. Intensive Supported Employment
13. On-going Supported Employment

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[1] https://www.health.ny.gov/health_care/medicaid/program/update/2015/jul15_mu_speced.pdf

[2] https://www.health.ny.gov/health_care/managed_care/plans/docs/hiv_care_management/2016/hiv_cm_report.pdf

14. Self-directed Care

I spent over one year trying to get answers and access for my loved one to receive these new BH HCBS services of which she was entitled. No one knew how or what BH HCBS were or how they actually worked, not even the HARP Medicaid managed care plans and yet managed care plans were now receiving even more Medicaid monthly capitated payment funds. Not even Medicaid Choice run by Maximus, paid with taxpayer dollars in " *Helping you make smart decisions about your future health care*", when I called them to ask for their help, they knew nothing about BH HCBS and HARP plans all they could do was assign a plan to her.

The New York City Regional Planning Consortium's lack of Consumer and Stakeholder Engagement of Families and Parents:

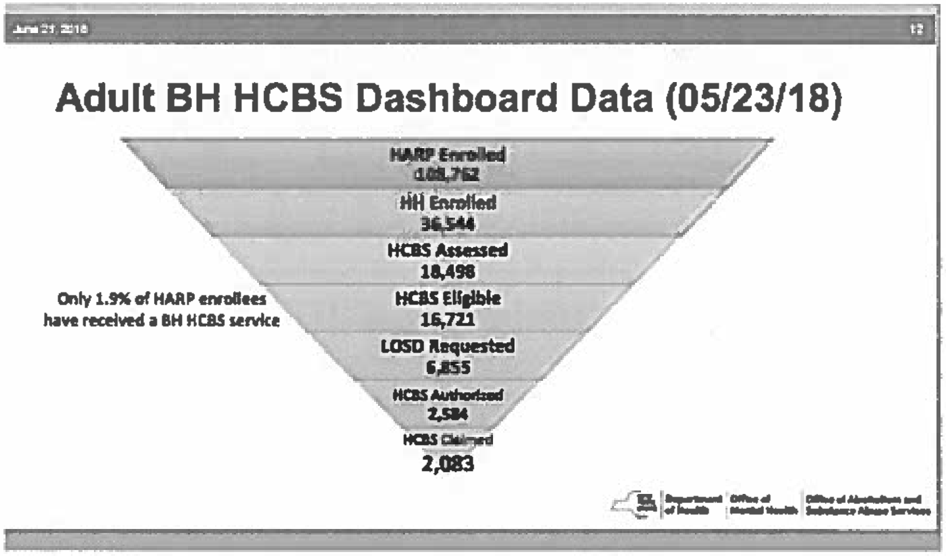
I attended countless meetings at the (RPC) New York City Regional Planning Consortium http://www.clmhd.org/rpc/ filled with hope that I has finally found the contacts that could help my loved one to access BH HCBS. At these meetings I asked numerous times where the funds for BH HCBS were being diverted to for NYC residents? No one there could ever answers any questions.

It's important that you know that the NYC DOHMH (New York City Department of Mental Health and Hygiene) never solicited parents or families in these discussions. It is unclear who has oversight of the DOHMH. They were never able to give answers as to how the New York City's Health and Mental Hygiene Department was utilizing state Medicaid dollars or any other funds for the STC (Special Terms and Conditions) populations. Furthermore The OPWDD never once came to the NYC Regional Planning Consortium (RPC) meetings despite claiming to work together on the CLMD website: http://www.clmhd.org/rpc/

State Run Government Entities like the OMH and the OPWDD all have a piece of the pie but cannot answer simple questions about medicaid managed care plans who are now responsible for delivering services, nor can they troubleshoot access for vulnerable populations in any meaningful capacity. I contacted OMH (Office of Mental Health) who has a dedicated website just for managed care issues and complaints:
https://www.omh.ny.gov/omhweb/bho/complaints.html
with zero response to questions about access and oversight of Health Homes, HARP plans and BH HCBS services. The Seriously Mentally ill who need mental health services are placed on long waiting lists for services like ACT (Assertive Community Treatment). No one helps these individuals assert mental health parity laws and most of the medicaid managed care plans do not offer single case agreement or out of network options.

Health Home Care Managers Have No Idea or Ability To Connect The Vulnerable To Services For Which They Are Entitled:

The Health Home Care Manager [3] did not even know my parent was auto-assigned to a HARP plan and no assessment for BH HCBS was done until 2017 almost two years later, and during that time the hospitalizations did not stop, the mental illness was not treated and my loved one continued to be a danger to herself and others. After I took every free webinar and read every single thing I could about the HARP plans and BH HCBS[4] for the Serious Mental Illness (SMI) population, I was able to assert her rights to at the very least the HCBS assessment. Which was all for nothing because even after being approved for Tier II BH HCBS we were unable to access them, networks new nothing, many of these BH HCBS providers told me they were not being paid or that they canceled their program. The utilization numbers of BH HCBS services for this population reveal this, and even after four years is extremely low only 1.9% of HARP enrollees have received any BH HCBS services.



June 21, 2018 12

Adult BH HCBS Dashboard Data (05/23/18)

HARP Enrolled 108,762
HH Enrolled 36,544
HCBS Assessed 18,498
HCBS Eligible 16,721
LOSD Requested 6,855
HCBS Authorized 2,584
HCBS Claimed 2,083

Only 1.9% of HARP enrollees have received a BH HCBS service

Department of Health | Office of Mental Health | Office of Alcoholism and Substance Abuse Services

For this reason it has become my full time unpaid job navigating layers of bureaucracy. That includes hours of dealing with impersonal Medicaid managed care plans customer service agents. The learning curve for accessing benefits and services is so steep many people simply give up or never even get started. Enrollment in a HARP plan did allow for one positive thing and only very recently, and after years of emails, research and phone calls; I was able help my SMI loved one to be apart of a pilot program that allows access to "Self-Directed Care", she is

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[3] https://www.health.ny.gov/publications/1123/hh_brochure.pdf

[4] https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/docs/hcbs_poc_workflow.pdf

one out of a handful of individuals enrolled in this most-enlightened and person-centered of options. The Medicaid Managed Care plan did not help with securing this service, the Health Home care manager did not help to secure this service either. I on my own with an unyielding effort found and helped to ensure that she received approval for this service. In spite of the state's promising "self directed care" in its 1115 Waiver Amendments[5], sadly this still just a pilot program in New York State and is only in two regions with just a handful of participants. Mandatory Medicaid managed care enrollment imposed in 2005 for the seriously mentally ill has been completely flawed in New York State, if not a total failure. Behavioral health provider claims have been denied repeatedly. Ask yourself how this affects those that need these services? The misappropriation of Medicaid dollars and capitated payments to Medicaid managed care plans for services not delivered for the SMI population and the clinical providers that serve them can only be described as fraud and abuse. New York is at high risk of being audited for clawbacks by the federal government.

Therefore the Legislature should do everything in its power to strengthen access to "self directed care" for those who are passively enrolled into HARP plans and ensure that Behavioral Health providers are paid timely and appropriately for services rendered to this population. And that HARP plans have true network adequacy when it comes to BH HCBS services.

The Transition to Mandatory Medicaid Managed Care for the Intellectually and Developmentally Disabled Under the Office for People With Developmental Disabilities (OPWDD) and The New York State Department of Health:

My son who is now 13 was diagnosed with Autism at age 3. He has been enrolled in the Office of People With Developmental Disability Waiver since he was 8 years old. He has been in receipt of Home and Community Based Services, specifically self-direction services which has allowed him to remain in the least restrictive environment where he interacts with typically developing peers. With OPWDD's self direction program my son is able to participate in meaningful classes in the community with the support of his self hired community habilitation life coach and has access to transportation to and from these programs, has physical health and fitness opportunities, community engagement experiences and socialization opportunities that he would not have without the OPWDD Medicaid waiver. My personal experience with watching my parent lose services under Mandatory Medicaid Managed Care, the poor roll out and under utilization of HCBS services for the SMI population makes me fear the same fate for the Intellectually and Developmentally Disabled population. Will my son too to be denied access and services that he needs under managed care? What about all 100,000 OPWDD participants?

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[5] https://www.health.ny.gov/health_care/medicaid/redesign/2016/2015-10-01_1115_waiver_sdcs.htm

Will the providers that have been working with them to deliver HCBS services vanish and be forced to close due to denied payment from Medicaid managed care plans in the future?

The steady and fast changes that have been underway will jeopardize access to OPWDD waiver services for this population including my son. The OPWDD describes three Phases of its Transformation Agenda. Of these, Phase One was abruptly launched on July 1, 2018, with shockingly inadequate and misleading claims of readiness. Not that you would know anything is amiss from what the OPWDD itself says in public. I advise the Legislature not to trust one word out of the OPWDD mouth regarding managed care. I urge the Legislature to make its own inquiries and to listen to the stories of its own constituents, how they are being neglected, are losing services, are getting months of run-arounds, and how their care managers are quitting in droves. I collected over 40 testimonies and circulated a CCO/HH survey[6] of which 170 participants revealed that the roll out of care managers for the I/DD OPWDD population has been a complete and total failure for many families. In spite of high rates the lack of service coordination and support before the Phase One rollout, the service gap has grown under managed care. The survey results have been shared with OPWDD and New York State Department Office Health with little to no response. The survey revealed very serious concerns and issues with the CCO/HH roll out on July 1 2018 including issues around access, privacy, competence and fair treatment.

Many states are precipitously forcing their intellectually and developmentally disabled populations into ill-conceived and deeply flawed private managed care plans, and the same horror stories are repeated in every state: services cuts, service denials, bankruptcy of service providers, disabled people left high and dry. After a few years of the nightmare, the respective legislatures must step in and stop and/or reverse the managed care runaway train. People die preventable deaths. New York State's OPWDD is falling down the same rabbit hole.

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 intellectual and developmental disabilities:

The Legislature cannot sit idly by and be a rubber stamp for the Governor's reckless and heartless assault on people with disabilities. The Legislature must open its eyes, reach out to its constituents, and learn the ropes in order to properly regulate the new private bosses of Medicaid managed care for disabled New Yorkers. The Executive branch is pulling a very fast one on everybody, and it is the duty of the Legislative branch to serve as a check and balance on the imperial Governor.

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[6] **CCO/HH Participant Survey** https://goo.gl/forms/Bc7SDXVgHfaqf3ws2

The DOH and OPWDD are now a major propaganda operation, selling glittering lies about managed care and covering up any hint of trouble. The DOH and OPWDD are shaking in their boots lest the federal HHS OIG get wind of the systemic government-sanctioned Medicaid fraud occurring as we speak at the OPWDD and its Seven Care Coordination Organizations/Health Homes. Participant families are completely stonewalled by the OPWDD. Sadly, the federal Center for Medicare and Medicaid Services simply signs off on the Governor's MRT agenda, even though Uncle Sam is paying 90% of the first two years of CCO/HHs. Nobody represents the voiceless disabled people who are directly affected.

The Legislature must do its duty to represent The People in Albany. I ask the Legislature to ignore the bureaucrats and the lobbyists, because they are selling out people with disabilities this very minute. The OPWDD managed care timeline indicates the rollout of Phase Two of OPWDD managed care this year. Ignoring the disinformation propaganda campaign, each phase of the OPWDD managed care rollout is nothing less than right-wing privatization and market consolidation. But the joke will be on the State, because it is a hard-and-fast rule of the basic economics of supply and demand that a monopoly provider can name his price, and the payer will be over the barrel and have to pay it. The Governor's MRT scheme will consolidate disability service providers into a single private plan, and the costs to the State will skyrocket. The State is needlessly giving up all of its negotiating strength and leverage - why? Was it for campaign contributions? The OPWDD is an $8 billion dollar budget item, and lots of private operators would like to get the fingers into that money. The State must not simply give away the farm.

The logical outcome of monopoly private Medicaid managed care plans is service cuts, which will fall hardest on Home and Community Based Services across the board for the Special Needs populations. This will drive disabled people out of their homes and into institutions. It does not take a genius to perceive that the operators and unions of those institutions bought access to the reins of power and control of the MRT. The 100,000 OPWDD Intellectually/Developmentally Disabled participants are pawns and sacrificial lambs in a massive power and money grab. This was the Great Sellout. Unless New York's HCBS sector is prioritized over institutions, New York's intellectually and developmentally disabled population may be a future subject of a US Department of Justice Olmstead enforcement lawsuit, similar to the one recently concluded for the seriously mental illness population with a deinstitutionalization consent decree.

The OPWDD Phase Two on managed care has not yet been fully authorized. Phase One is currently a disaster. Phase One must be repaired completely before there is any talk of moving to Phase Two. The Legislature CAN and MUST stop any talk of Phase Two immediately. The

Legislature must hold hearings on Phase One to discover the full extent of the OPWDD deception and mismanagement going on across the state right now.

The OPWDD's Transformation Agenda did not do anything beneficial for the real problems: inadequate housing for people with intellectual and developmental disabilities and a desperate shortage of direct service providers due to inadequate wages. To the contrary, Phase One has made each of these problems worse. Make no mistake, the changes proposed in Phase Two will multiply those core problems, not fix them.

Conflicts Of Interests Are Rampant At The OPWDD For the last four years OPWDD has had an "Acting" Commissioner only, named Kerry Delaney. If anyone is wondering where she went you can now find her sharing insider information to a for profit managed care plan called Partners Health Plan (PHP). Soon PHP will be the largest Medicaid Managed Care Plan for the OPWDD population. We hope that Kerry Delaney will not forget those that have waited and gone without services under her authority for the last four years.

The OPWDD at this time has no way of knowing how many individuals are in receipt of HCBS services. Many of those with eligibility are simply waiting for services for years. The OPWDD loops all of its enrollment and service authorization protocols through a non-functioning information technology system called MediSked. The Legislature must create a rational procurement pathway for healthcare information technology, because MediSked is killing the OPWDD. Despite numerous attempts at FOIA requests and emails, the public has no idea how MediSked was chosen to run all of OPWDD service functions. There is reason to suspect insider profiteering. The OPWDD and DOH have failed to justify the current rates that it pays for Group Homes, Certified Residences, Intermediate Care Facilities, including Day hab services. Nor have they published utilization numbers, on the delivery of Home and Community Based Services, Some of these Include the following:
Camp
Counseling
Crisis Intervention
Day Services/ Day Habilitation
Environmental Modifications (E-Mods)/ Adaptive Equipment
Employment Services
Evaluation, Intake and Referral
Family Care
Family Support Services
Financial Assistance
Forensic Services
Health Care

Housing/ Individual Support Services
In-home Services
Parent Advocacy and Training
Recreation
Respite Services
Residential Services
Service Coordination
Transportation
Waiver Services

The successful delivery of these services is a vital in order to establish and understand what access looks like currently. This needs to be done prior to any further discussion of Phase Two of Managed Care. The absence of this information opens the door to a huge mismanagement and further exploitation of Medicaid dollars.

The OPWDD Fails To Adhere To Open Meetings Law & Fails to Respond to Stakeholders, Self-Advocates and Families Questions:

To be clear the once Interim Acting Commissioner of the OPWDD Kerry Delaney for the last four years has failed to produce any "Status Reports" or feedback from families in spite of New York State Laws, Rules and Regulations that require the OPWDD's Commissioner to do so. Delaney failed to engage stakeholders meaningfully even worst denied access to those who ask for meaningful participation. Parents and Families spend countless unpaid hours navigating services from an unresponsive system. Money did not following the person under Commissioner Delaney's watch. And now there is another interim Acting Commissioner. OPWDD cares so little about keeping it's families informed and did not even publish the name of their newly appointed Commissioner anywhere. Families were told the name of Kerry Delaney's replacement from the news media, but we have no official introduction from the OPWDD or any public statements from him.

The Developmental Disabilities Advisory Council and the Family Support Service Committees are both councils that are established under New York State MHL § 41.43 and MHL 13.05. Both are subject to Open Meetings Laws. None of the members have been provided any training nor is it clear that they understand their own roles as stakeholders and advocates. It would be great to ask the OPWDD for clarification on how families and self-advocates are selected to participate on these public advisory bodies. There are members remaining on these councils for decades who are either being stonewalled, manipulated or profiteering. For example, one appointee happens to also be the CEO for Life Plan http://lifeplanccony.com/about/ which is one of the new Care Coordination Organization/Health Homes; while also sitting on the JAC[7] (Joint Advisory Council for Managed Care) and the DDAC. This CEO has not recused himself from the position of Chair to date.

These advisory bodies are established in what appears to be an un-democratic, vague process. There is very little movement or progress on them, vacancies are not announced and the population is not represented. A great deal of profit being made under the disguise of "stakeholders" from the OPWDD and it's various advisory bodies. Those that do speak up are excluded or railroaded. It is unclear why there is so little opportunity for meaningful engagement of parents and self advocates. The New York State Department Of Education has School Boards, PTAs (Parent Teacher Associations) and these appointments are decided through a vote, but the OPWDD allows for no such process. In fact it is the complete opposite.

Phase One Of Managed Care for the OPWDD Population and Care Coordination Organizations Health Homes (CCO/HH):

The OPWDD and the DOH have failed to give authorization numbers for many of it's services and now because of MediSked[8], a new IT System that been imposed and adopted by all Seven New Care Coordination Organizations, Health Homes has proven to be a useless waste of taxpayer money. Currently Medisked is the only IT system in use by all seven CCO/HH. While Medisked has existed for some time, the CCO/HH are new and yet all of them use this system which was not a requirement listed in the original applications see: https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/idd/docs/hhidd_application_part_2.pdf The word Medisked is not listed anywhere in the application and yet each and every CCO/HH uses Medisked. This gross monopoly and misuse of taxpayers money remains unchecked. Medisked is not regulated by the OPWDD or the DOH and is undermining LTSS data, falsifying information crashing, is not fully operational. It went through zero readiness reviews and has caused a number of problems for the OPWDD population and providers. Yet they have no choice but to rely on this cheap and useless platform. Rather than invest in a true Electronic Health Record (EHR) the OPWDD has imposed that all CCO/HH use an unchecked EHR, which is Medisked. In order become a CCO/HH all of them had to use this system. The OPWDD has yet to respond FOIA requests concerning their 2017 EHR RFP: https://opwdd.ny.gov/opwdd_resources/procurement_opportunities/OPWDDEHRRFP

The Legislature should ask who is regulating Medisked?

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[7] https://opwdd.ny.gov/opwdd_services_supports/people_first_waiver/opwdd-joint-advisory-council-managed-care

[8] http://www.medisked.com/products/medisked-coordinate/

Many questions remain unanswered from the OPWDD. The Legislature should ask the OPWDD one question about Phase One of managed care for the OPWDD, the aim of which is to create over 100,000 "Life Plans" between 7/1/18 and 6/30/19: **"How many Life Plans have been completed since 7/1/18?"**

The OPWDD brazenly refuses to give any information on the Life Plan agenda. Is this because the OPWDD simply does not know? Is this because the number, which should be nearly 60,000 by now, is embarrassingly low? While there are many unanswered questions the answer to this one would reveal the current disaster. If the number is too low, then the federal government will have every reason to claw back hundreds of millions of dollars already paid to CCO/HHs: money was paid but services were not provided, which is the definition of fraud. The OPWDD is skating on very thin ice with Phase One of its deeply corrupt managed care agenda. Phase Two will only compound the instability and risk of fraud.The legislature and the public need to know who is in charge of the CCO/HH? Who is accountable for the ongoing care mismanagement disaster that is now costing more money to taxpayers?

Housing Issues Are Overlooked For Individuals With Developmental Disabilities Specifically The OPWDD Population:

Recently The New York City Human Resources Administration/Department of Social Services (HRA/DSS) was the subject of discrimination in the news media. What you do not hear about is what it is like for someone who cannot move, speak or understand, to access Services at these places.The truth is because this work is done by families and parents which is why the number one concern from us is: What will happen when we die? Who will advocate and navigate services for my adult child when I am gone?

CCO/HH Care Managers do not have the training and capacity to navigate housing issues for the Individuals with Developmental Disabilities population. CCO/HH Care Managers do not know how to advocate with of the Local Department of Social Services. Many individuals with I/DD and their families simply have no one to assist in navigating the Office of Temporary And Disability Assistance (OTDA) services. If parents and families of those caring for an I/DD adults died, there are very few who would assist them with accessing supports and services to meet their basic needs in order to remain in the community. Parents of this population are breaking ground and working countless hours to create programs for those with I/DD and are never compensated. Even worst are ignored and left out of the conversation. Many parents of those using Self Direction under the OPWDD say they are the real care managers.

All that we want is to ensure that our loved ones needs are met, that our children (including adult children) are not subject to repeated abuse, neglect and exploitation.

Group homes across the state have closed in favor of an integrated model and yet subsidy amounts have not been increased in over a decade and in some counties (like Manhattan) the rent subsidy is too low as compared to actual housing costs.The Live In Caregiver function is almost impossible to use the way it is currently designed. Most of the OPWDD Financial Intermediaries will not even accept a case that has the Live In Caregiver in the budget

Ideas that are innovative and cheaper for the taxpayers are usually developed by parents and caretakers. They do the everyday groundbreaking work and problem solving for their loved ones and at great cost.

Thank you for the opportunity to submit this testimony.
Please feel free to contact me with any questions.
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NEW YORK STATE BUDGET FORUM - Hearing 3/2/19,

New York Academy of Medicine 1216 5th Ave. at 103rd Street, New York City
Comments of Catherine Skopic

Greetings. Thank you for this opportunity to comment on our State Budget. My name is Catherine Skopic. I live in New York City - Tribeca - am an artist, educator, activist, Vice Chair of Sierra Club New York City Group and Chair of Shut Down Indian Point Now.

As the climate crisis is the greatest existential threat to our planet, this issue needs to be first and foremost in the Governor's budget. Although he has increased offshore wind from 2,400 megawatts by 2030 to 9,000 megawatts by 2035 and solar from 3,000 megawatts by 2023 to 6,000 by 2025 that is highly commendable, I did not see anything about eliminating fossil fuel infrastructure such as pipelines and gas compressor stations. We continue to be harmed by the negative health and environmental impacts of fossil fuel infrastructure.

The Governor's goals of New York State being 100% carbon neutral by 2040 and 70% of the State's electricity being generated from renewable energy by 2030 are also commendable, however, I share with the Governor, as he has included it in his energy mix, that nuclear power is NOT emission-free. In fact, considering the full life cycle of nuclear power from the mining of uranium to its transformation to yellowcake to its transportation and the over 30 steps in between, nuclear power is highly fossil fuel intensive.

Secondly, nuclear power creates thermal pollution. Water from rivers and lakes used to cool the reactors is circulated through the plant and then ejected back into the source, only now, it is at 110 o or more, killing fish, plant life and emitting this extra heat into our atmosphere, causing more global warming. Nuclear is deemed by many to be the other great existential threat to our planet. And no one knows how or where to safely store nuclear waste - why make more of it? Right now we have 4 aging nuclear power plants that are costing us, the ratepayers, $7.6 Billion over 12 years to bail out. This money is going to owner, Exelon, and is not available for the renewable energy we need.

On the plus side, the Governor has budgeted, if I have this correct, $70. Billion for communities to transition from fossil fuels to renewable energy. This is a joy to hear. Although we have not seen the details of how this money is to be allocated, I hope it will be fair and transparent, as this budget states is necessary for the increased education funding.

As a parent who wants to see a livable world for my daughter, all children and future generations, I commend the Governor for his renewable energy increases, urge him to go even further in this direction, end nuclear energy in our state, eliminate all present fossil fuel infrastructure while allowing no new infrastructure and to actually realize his admirable renewable energy goals as soon as possible - the planet can't wait, nor can we!

Thank you, PEACE, Catherine Skopic

March 6, 2019

New York, New York

NY State Legislature Hearings on the 2019-20 Executive Budget Proposal

Senate Finance Committee, Senator Liz Krueger, Chair; Senators Robert Jackson, Brad Hoylman, Brian Kavanagh, Jose Serrano, Brian Benjamin.

More detailed written testimony of Sandra Radoff
(As follow up to 2-minute oral testimony delivered at the March 2 hearings.)

I am a wife, mother, small business owner, political activist, and constituent of Senator Krueger's. I am here not only for myself but for my son and daughter, my husband, my friends and family and fellow activists. I am here for the communities who are suffering because we have neglected our environment far too long: I am here to communicate the urgency of now because if we don't do something substantial and soon to mitigate the effects of climate change, there will be no need to discuss any of the other issues on the legislative agenda.

80% of Americans believe that climate change is human caused. 70% are somewhat or very concerned. 49% are downright alarmed! These numbers would likely be higher if we could look at New Yorkers alone. Our own governor has said: "Climate change is a reality, and not to address it is gross negligence by government and irresponsible as citizens."

We already spend billions per year on climate-related catastrophes. What will it take to get us to act?

Nobel prizing winning social scientist and behavioral economist, Daniel Kahneman, has said that if one went about trying to construct a problem that human beings are not designed to address, it would be the environment. It is remote, abstract, and, for the most part, something that happens to someone else (though that is changing). This is why we desperately need our elected officials to take action on our behalf and do what is needed to address this urgent crisis. Individual efforts will not be enough. We need strong action via legislation now.

The real question before us in NY State is how far and how fast we will move to make progress on the environmental front. The Governor has proposed his Climate Leadership Act. Senator Kaminsky has sponsored the Climate and Community Protection Act or CCPA. CCPA is the stronger of the two. The Governor's act has some key weaknesses. Cuomo's act says NY's electricity would be 100% carbon neutral by 2040 but carbon neutral standards actually include biofuels, natural gas facilities and nuclear power. These are unacceptable standards. Cuomo's plan, unlike the CCPA, is not legally binding making it essentially toothless. And, his plan doesn't address the agricultural sector at all. Cows emit methane which is 86 times more potent than CO2. Finally, while the Governor's act includes language about prioritizing investments and jobs in disadvantaged communities, the extent of this investment is vague and unenforceable.

By mandating a move off of fossil fuels, the CCPA will protect New Yorkers' health and lead to the creation of 150,000 new jobs every year for a decade and beyond. In addition, the CCPA mandates and specifies that 40% of state energy funding be directed into environmental justice communities and low-income households, making the equity and justice component central to the law.

Some ask, why should New York State propose such dramatic environmental legislation? Isn't this something that should be dealt with at the national level? The answer is, yes, it would be best to address this at the national level. However, Washington is broken. There is little hope than anything will be done nationally for at least two years. We can't afford to wait. On the other hand, if New York leads the way with what Heather MGhee and Robert Reich in The Nation have described as "the most progressive climate-equity policy we've seen." , other states will follow. And, New York will be ahead of the curve when legislation finally does come at the national level.

Some cite the cost of transitioning to an emissions-free economy as too much and too disruptive. However, the cost of NOT doing this is even more expensive and more disruptive. It is estimated that New York state alone could be spending $10 billion annually by mid-century to deal with climate-related catastrophes.

Any budget item requires spending on one thing which means not spending on something else. There is a bit of sacrifice involved in any decision we make. Sacrifice is defined as an act of giving up something valued for the sake of something else regarded as more important or worthy. Aren't our children, our grandchildren, our friends, and our communities worthy of some sacrifice to save our planet? We must act now and forcefully and include the CCPA in this year's budget. This would be a good start toward progress in solving the existential crisis we must face together.

CCPA is not just a Green Deal; it's a Good Deal for NYS.

Testimony of Sharifa Abu-Hamda
New York State Senate
Public Forum on 2019 NYS Budget
New York City
March 1, 2019

I appreciate the opportunity to comment on the 2019 New York State Budget. My testimony will address the problem of insufficient funding within the managed care program of services required for people, like myself, with high needs who want to remain in their homes and communities. .

My name is Sharifa Abu-Hamda. I live in Brooklyn, New York. I have a degree in accounting, work full time and serve as President of the Civics League for Disability Rights.

As a woman with a progressive, degenerative disability that limits my movement and affects my health in many ways, I receive 24 hours of personal care in 12 hour split shifts, 365 days a year.

Without 24/7 personal care, I would not be able to live independently and would be confined to bed, in an institution. I would not be able to work and would be dependent on SSI.

In 2012 it was determined that due to my disability my body was not getting sufficient oxygen and my doctors prescribed a ventilator for me to use at night in order to remedy this. My nighttime personal care worker makes sure that my ventilator is working properly and that I am breathing properly. She also changes the tubing and heats water for the humidifier needed to keep the air I breathe moist. If my home loses power she can replace it with a backup battery, ensuring that I am able to continue breathing.

I also require a cough-assist machine in order to keep my lungs clear. This equipment is expensive but it is needed, especially during the change of seasons when people are prone to getting sick, to prevent me from getting life threatening pneumonia and other infections. My nighttime personal care worker manages the machine and puts the mask on my face every night and morning in order to keep my lungs clear.

In addition, my nighttime worker turns me multiple times each night to protect me from getting pressure wounds and assists me in using the bathroom. Without these services at night I would be at great risk of illness, injury and death.

Having personal assistance during the day allows me to work, travel to medical appointments and take part fully in the life of my family and community, none of which would be possible without this assistance. As my condition progresses the need for these services will only become more pronounced.

My condition also mandates that I have expensive mobility equipment. This includes a properly fitting wheelchair, customized seating that protects me from pressure wounds and back pain, and that allows me to sit for long periods of time so that I can work, travel and live my life.

All of this costs a lot of money, which is not taken into account in the State's long-term managed care funding formula. As a result, Guildnet closed and the State is planning to close my plan, Independence Care System, as well. I believe that these closures represent a failure, not of the plans, but of the State's funding formula.

Back in 2011 when the State moved to require mandatory enrollment into managed care plans for people needing long-term services, individuals with disabilities and disability advocacy groups warned that the proposed funding mechanism did not protect the rights of people who need ten or more hours of personal care each day. It was suggested that a different payment structure was needed for our population and the State was warned that without an appropriate funding structure, plans would cut services for high needs people like me.

What has happened since is twofold. Plans have indeed cut homecare hours without regard for actual need and plans that have not followed this illegal and immoral course have been reduced to financial ruin, as the closure of Guildnet and the imminent closure of Independence Care System illustrate.

This problem is not going to go away. As the population ages, more and more New Yorkers will need high home care hours. People with disabilities are not going to go away either. We are not going to go back to institutions and we are not going to die without a fight.

The State must address this as the systemic problem it is. As has been said many times, people with high needs, like me and thousands of other New Yorkers, require an appropriate funding structure to ensure that we are able to remain healthy and live in the community, as is our right under local, state and federal law, and the U.S. Supreme Court's ruling in Olmstead v. L.C.

Home care has always been the most expensive part of long-term care and it will only get more so. It recently became much more expensive when home care workers gained parity with most other wage laborers after decades of being excluded from the Fair Labor Standards Act. In addition, these workers are covered by the State's recently enacted minimum wage law, as they should be.

Governor Cuomo seemed to recognize the justice of fully funding community supports for people like me when his administration announced in the summer of 2017 a program called Able New York, which was described as a multi-agency initiative "aimed at supporting community living for New Yorkers with physical disabilities." Noting the state's history of leading on disability rights as she joined the governor in announcing the initiative, Lieutenant Governor Hochul said, "New York is committed to building off that progress and increasing resources and support for people living with disabilities."

We have heard not a word about this initiative since the election. We can only hope this was not an empty gesture couched in empty words. There is one sure way to keep the governor's promise to people like me.

The State must take its head out of the sand and create funding streams that actually work for honest, effective, long-term managed care providers and those of us they serve.

Thank you.

Sharifa Abu-Hamda

NYS Senate Budget Forum Testimony
By David Kallick Fiscal Policy Institute

Thank you for the opportunity to submit the Fiscal Policy Institute's budget priorities for consideration in the Senate's budget proposals.

The Fiscal Policy Institute's priorities on immigration are:

ª **$4.5 million for the New York State Enhanced Services for Refugees Program.** This is an increase over the $2 million in last year's budget.

* **$40 million for community-based organizations to ensure a complete count in the 2020 Census.**

* **$15.3 million for Adult Literacy Education,** an increase of $8 million.

* **Driver's Licenses for Undocumented Immigrants.** This is a revenue gain, not an expense. Allowing undocumented immigrants to apply for driver's licenses can be expected to add $57 million in recurring annual revenues and will add $26 million in one-time revenues.

New York State's Enhanced Services to Refugees Program is a leading example around the country of countering the hostile federal stance toward refugees. New York State allocated $2 million in 2017 to help resettlement agencies get through the federal cutbacks. At the same time, it provided more flexible terms that allowed the agencies to provide extended job training, English language, and other integration services that improved the outcomes of refugees in our communities. The funding has been particularly critical in upstate cities—Buffalo, Rochester, Syracuse, Albany, and Utica—where refugees are also important to helping population growth. It has also made a real difference in New York City and on Long Island, where it allows resettlement agencies to address the strains of serving both refugee and asylee communities. The projected decrease in the number of refugees, and the corresponding decrease in federal funding, justified a $2 million allocation in 2017. The actual decrease today—more than double the initial projection—justifies an expenditure of $4.5 million.

Community-based outreach for the 2020 Census is going to be critical to ensuring a complete count in New York State. Trusted voices are going to be a key to getting all New Yorkers to feel confident about filing out the Census forms in this highly polarized environment. The Fiscal Policy Institute's research shows that $40 million would allow for basic outreach to all hard-to-count populations, moderate outreach to ten percent of those who are hard to count, and intensive outreach to five percent. Among those who are hard to count are immigrants, parents with young children, low-income New Yorkers, people in rural communities, Muslims, Native Americans, and people of color. Having a community-based organization reach out to the people in their community is a proven way to increase participation in the census. Having a full Census count is important to New York's apportionment, to federal funding that is often driven by Census-based information, to planning of schools and public services, to businesses, and to our basic understanding of who we are as New Yorkers.

Adult Literacy Education (ALE) has long been at a level that is far below the need. Last year $7.79 million was allocated to ALE. This year, the Executive Budget absurdly proposes a $1.5 million decrease in ALE funding which will reduce the total to an even more insufficient amount of $6.3 million. Both state and federal changes are shifting the emphasis and priorities of funding to educating higher-skilled immigrants. Program goals have shifted for the Workforce Innovation and Opportunity Act (WIOA) system and the English Language and Civics program, so that their focus is now on post-secondary and workforce education. Added attention to these more advanced students is welcome, but it should not come at the cost of taking funding away fromhelping those with even greater needs. It is estimated that as some 17,000 lower-skilled students may no longer be able to benefit from these programs as a result of the shift to higher-skill students and the repurposing of $8 million worth of WIOA funding in New York. New York should increase the funding for Adult Literacy Education by $8 million, to $15.3 million to help address the gap.

*** Driver's Licenses for Undocumented Immigrants.** New York should do what 12 other states already do, and what New York did until 2003: allow undocumented immigrants to apply for drivers licenses. Our roads are safer for everyone if all drivers are tested, licensed, and insured. Having to pass a driving test can make people better drivers. And when everyone has a license, it reduces problems when traffic incidents occur When everyone can drive, it benefits employers and local economies. Access to licenses would relieve a big challenge for the upstate farm industry. And across the state it would improve the job match between employers and employees, improving the local economy. And this proposal will more than pay for itself. In New York, driver's license fees, by design, cover the cost of producing the license and eve n generate some revenue to public transit agencies. As more people buy cars, they would also pay more in gas tax and other taxes. State and local governments and transit authorities could expect $26 million in one-time revenue, and $57 million in recurring annual revenue. That would more than cover costs, even after investment in training and outreach.

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March 8, 2019

Hon. Carl Heastie
Speaker
New York State Assembly
Legislative Office Building 932
Albany, NY 12248

Hon. Andrea Stewart-Cousins
Temporary President and Majority Leader
New York State Senate
Legislative Office Building 907
Albany, NY 12247

Re: 2019-2020 Executive Budget – One House Budget Proposals

Dear Speaker Heastie and Senator Stewart-Cousins:

In advance of your respective chambers release of their one-house budget proposals, I wanted to reiterate the New York City Bar Association's positions on various provisions of the Governor's budget proposal.

- **A.2007-A/S.1507-A (Health & Mental Hygiene)**
  - **Part G § 1: OPPOSED.**[1] This section would provide that, for Medicaid eligibility, the income and resources of a legally responsible relative (including a spouse) would only be deemed as unavailable if the relative was both absent from the home *and* refused to provide care and assistance. If enacted, this change would force couples to consider separation and divorce in order to avoid the loss of their home and impoverishment of the well spouse (as well as removing an important caregiver from the home), or compel the ill spouse to forego in-home care and enter nursing home care prematurely in order to prevent financial ruin.

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[1] https://s3.amazonaws.com/documents.nycbar.org/files/2019502-SpousalRefusalBudget.pdf

  - **Part C, §§ 2-3: <u>OPPOSED</u>.**[2] This section would reduce financial assistance for services provided to low-income Medicare beneficiaries. This threatens access to care by reducing the amount of cost-sharing assistance provided by the Qualified Medicare Beneficiary Program (QMB) and Medicaid, which will cause providers to refuse to treat Medicaid or QMB patients altogether and thereby reduce access to health care for hundreds of thousands of low income seniors and people with disabilities. Furthermore, other providers who must accept Medicaid, such as outpatient clinics and community health centers, will be hurt by the proposal, which will result in an elimination of services to the low income patient community.
  - **Part R: <u>SUPPORT</u>.**[3] This provision would establish a Maternal Mortality Review Board (MMRB) in New York. The MMRB would "review maternal mortality and morbidity, analyze their causes and disseminate strategies for reducing the risks of maternal mortality and morbidity." The United States experiences a disproportionately high rate of maternal mortality, with New York at 30th among the states. Moreover, poor women and women of color are victims of maternal mortality at far higher rates than are their affluent and white counterparts. We support the MMRB both as a means to improve health outcomes for New York's female population and to rectify the economic and racial disparities in those outcomes.

- **A.2010-A/S.1510-A (Good Government & Ethics Reform) – Part R: <u>OPPOSED</u>.**[4] This provision would lower the monetary threshold for JCOPE disclosure to $500 from $5,000. While we understands the underlying transparency goals, we believe that the burdens that would be imposed by this change far exceed these negligible and perhaps illusory benefits. Registered lobbyists are subject to extensive reporting requirements. For small, grassroots organizations, compliance would be onerous and potentially cost-prohibitive, effectively silencing their voices. According to Lawyers Alliance for New York, the current threshold covers 98% of lobbying activities in the state, which calls into question the benefits of the proposed change. Filings would undoubtedly increase, but many highly active local organizations will dissuaded from engaging with their government.

- **A.2005-A/S.1505-A (Public Protection & General Government)**
  - **Part QQ: <u>SUPPORT</u>.**[5] We support efforts to lift restrictions on compensated gestational surrogacy within the state and to clearly

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[2] https://s3.amazonaws.com/documents.nycbar.org/files/2019503-MedicaidCostSharingBudget.pdf

[3] https://s3.amazonaws.com/documents.nycbar.org/files/2019487-MaternalMortalityReviewBoardBudget2020.pdf

[4] https://s3.amazonaws.com/documents.nycbar.org/files/2019499-JCOPEThresholdBudget.pdf

[5] https://s3.amazonaws.com/documents.nycbar.org/files/2017382-Child_Parent_Security_Act.pdf

recognize the parentage of children born via surrogacy arrangements and donor conception. New York's current donor conception statute applies only to married couples who have conceived through sperm donation and meet specific conditions. Families falling outside of that construct do not receive the benefit of the statute and face a legal ambiguity regarding recognized parentage. Further, New York should join nearly every other state in the U.S. that permits the practice of compensated gestational surrogacy.

- **Part OO: <u>SUPPORT</u>.**[6] This provision, also known as the One Day to Protect New Yorkers Act, would amend the penal law to reduce the maximum potential sentence for A misdemeanors by one day. Currently, the maximum potential sentence for A misdemeanors is one year; this provision would reduce that maximum to 364 days. This one-day reduction would have profound immigration consequences for many New Yorkers who otherwise may face deportation under federal laws that provide for deportation of individuals convicted of crimes for which a sentence of one year or longer "may" be imposed -- even if the person was sentenced to probation or incarceration for a period of less than one year.
- **Part U: <u>SUPPORT</u>.**[7] This provision, also known as the Domestic Violence Survivors Justice Act, would allow judges greater discretion when sentencing defendants who are survivors of domestic violence. The provision would enable the court to take account of such circumstances, and would equip judges to effect justice for all parties in such cases in a manner not available under existing law, without permitting the offender to escape responsibility for having committed the crime. This change would represent an important step forward in achieving justice for victims of domestic violence by recognizing the role that abuse can play in the commission of crimes. It would return a small number of appropriate candidates to the community earlier than dictated by general sentencing provisions, thereby strengthening families without jeopardizing public safety.

- **A.2006-A/S.1506-A (Education, Labor and Family Assistance) – Part K; A.2003-A/S.1503-A (Aid to Localities Budget): <u>CONCERNS</u>.**[8] We are concerned about (1) the disparate support New York State provides for the children and families of New York City compared to the rest of the state when it comes to juvenile delinquents in placement (the "Close to Home" program) and Raise the Age implementation, and (2) the state's proposed Persons In Need of Supervision (PINS) reform that will negatively impact the safety and stability of youth and families in NYC and statewide. While New York State supports 50% of the placement costs for all youth adjudicated as juvenile delinquents outside

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[6] https://s3.amazonaws.com/documents.nycbar.org/files/2019490-OneDayProtectNYersBudget.pdf

[7] http://documents.nycbar.org/files/2019489-DVSurvivorsJusticeBudget.pdf

[8] https://s3.amazonaws.com/documents.nycbar.org/files/2019505-PINSChildWelfareJusticeBudget.pdf

New York City, the City's youth in placement (Close to Home) receive no state support in the Aid to Localities Budget. Part K of the Article VII Education, Labor, and Family Assistance Budget would eliminate the family court's ability to place a PINS youth in foster care (except when the court determines the child is sexually exploited). Although placement of PINS youth in foster care should be rare, since most youth are best served in their communities, we oppose the wholesale elimination of this option, even with the sexually exploited youth exception. Part K would also eliminate the state's support for the PINS diversion services currently strengthening parent/child relationships so children remain safely with their families through uncapped child welfare preventive dollars.

- **Funding for the Communities First Program: <u>SUPPORT</u>.**[9] We urge continued support for New York homeowners and communities by providing funding in the Budget for the Communities First program. The Communities First program is an initiative that focuses on providing services that help "homeowners avoid foreclosure and build strong neighborhood preservation efforts" and is the product of a statewide effort to mobilize legal resources to mitigate chronic housing-market issues that fuel foreclosure, e.g. zombie properties, distressed mortgages, and municipal tax debt. As long as foreclosure persists in New York, preserving the Communities First program will remain critical.

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We recognize that a number of these provisions are also the subject of standalone legislation under consideration by the Legislature. While we have indicated support for the provisions in the budget here, we are also supportive of their passage outside of the budget process. We urge that those bills be passed regardless of whether that is accomplished through the budget or regular legislative process.

We would welcome the opportunity to answer any questions you may have or discuss these issues further. Thank you for your consideration of these positions.

Respectfully,

Elizabeth Kocienda

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[9] https://s3.amazonaws.com/documents.nycbar.org/files/2018457-CommunitiesFirstFunding.pdf