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Center for Independence of the Disabled, NY

Testimony to the 2020 New York State Senate Manhattan State Budget Forum

February 28, 2020

Testimony by:
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Center for Independence of the Disabled

The Long-Term Care Ombudsman Program was created pursuant to the Older Americans Act. The mission of the New York State Long-term Care Ombudsman Program (LTCOP) is to serve as an advocate and resource for older adults and people with disabilities who reside in long term care facilities, such as nursing homes, assisted living and board and care homes. LTCOP is also charged with identifying systemic issues and addressing them through advocacy so that the State may address these issues and prevent related problems in future.

The State's program is one of the biggest in the country, but lacks commensurate funding.

- There are about 1,500 facilities in New York State, and more than 160,000 residents are entitled to ombudsman services.
- The Administration for Community Living (HHS) data shows that 61% of other states have a higher paid staff to resident ratio than New York State.
- The State has more long-term care residents than almost any state in the country (over 100,000), yet is 45th out of 50 in terms of percentage of State funding for Ombudsman services.
- LTCOP funding has remained entirely flat for over 10 years. This is true despite the imposition of additional mandates.

As a consequence there is inadequate staffing and residents do not have support of an independent conflict-free, trained and certified weekly presence.

- Only 40 percent of the 1,500 long term care facilities have an assigned volunteer Ombudsman leaving the remaining 900 facilities to be covered by a small number of paid staff.
- The number of paid staff is only 50% of the recommended minimum number established by the Institute of Medicine.
- More than half of the State's regional ombudsman programs fall short of the minimum standard for staffing.
- An alarming number of residents do not receive routine visits and programs are simply unable to maintain a regular presence in all long-term care facilities.

The State can and must do more to protect nursing facility residents. We are here to appeal for additional resources for this critical program. We understand that lawmakers are experiencing tremendous pressure to reduce spending, however, the modest amount of additional funding that we seek, $3 million, is no more than a rounding error when considered against the resources of the State.

Why is LTCOP so unique?

LTCOP is the voice of residents and families of those who reside in long term care facilities. Its State-certified ombudsman undergo rigorous training and retraining on legal and regulatory developments, information on trends in abuse of residents, recognition of systemic issues. They must investigate, negotiate with long-term care facilities, and report to authorities. They must provide a weekly presence.

- It finds cases that require intervention and ensures that these are known to the State Office for the Aging and the Department of Health,
- It identifies and can prevent discharges to homeless shelters,
- LTCOP is an independent conflict-free "watchdog" dedicated to preventing problems from arising, protecting individual's rights, and preserving the quality of life for institutionalized people with disabilities and older adults.
- Problems encountered can include:
    - staffing levels that are too low,
    - call buttons go unanswered and falls and bed sores occur,
    - financial exploitation of residents,
    - emotional and physical abuse and failures in care including malnutrition and pressure ulcers,
    - psychotropic drugging of individuals who do not need these agents and can be harmed by their administration,
    - unsafe discharges and evictions to homeless shelters or the street,
    - participated in 20 involuntary transfers/discharge hearings to shelters and other facilities away from family or other established relationships,
    - failure to provide due process,
    - lack of reasonable accommodations,
    - unsanitary facilities,

- poorly managed facility closings, and
- poor quality services.

LTCOP's Value

LTCOP can prevent costly harm to residents by identifying individual and systemic issues that must be brought to the attention of regulators to ensure correction of long-term care facility practices.

The New York City LTCOP is a lifeline for more than 55,000 residents residing in the 244 long term care facilities throughout the five boroughs. 134 nursing homes and over 30,000 residents do not receive routine visits due to the inadequate resources dedicated by the State to the program.

- LTCOP volunteers assist residents with filing complaints with the Department of Health regarding poor quality care, abuse and neglect, and other issues which can result in corrective action being taken by the Department of Health against a nursing facility.
- LTCOP assisted complaints can result in surveillance visits by the Department of Health to make corrections.
- When LTCOP volunteers are present in a facility they can help residents and their families meet with the facility to correct errors in care, poor quality care and other issues with care.

Uncorrected, these problems are life-threatening to older and disabled New Yorkers. They are also costly to the health system when they result in hospitalizations for preventable conditions.

New York City's LTCOP and long-term residents are dramatically affected by lack of funding.

However, there is more to be done but the program lacks the resources to do it.

- New York City has 33 percent of all residents in the State,
- It has one staff position for every 8,800 beds, less than 25 percent of the recommended level.
- If staffing were provided at the level established by the Institute of Medicine, instead of 5 paid ombudsmen in the field, the program in New York City were fully staffed, it would have over 25 paid staff.

In conclusion

Thank you for the opportunity to appear before you and your patient attention. We urge the Legislature to remedy the dangerous level of underfunding for the Long-term Care Ombudsman Program by adding $3 million to the program's budget to move us forward to safe staffing and coverage for long-term care residents who are daily at risk of harm.

Meri Krassner
370 E. 76th St. Apt. B303
New York, NY 10021

February 29, 2020

It is an inconvenient fact that people like my son will never be independent. He needs assistance for most activities of daily living, and he will continue to do so long after I am gone. There is no finessing the costs of keeping someone with a 40 IQ alive and well, forget happy. And for me there is no forgiveness for those who stand in the way of his being cared for properly.

Now we wait to see if the MRT2, with no representation from families, adds their cuts to the ones that the Commissioner has promised, 2% across the board July 1. He said this right after he said that there are 7,000 new people in the system. There is no money to cover the rising costs of keeping the doors open – rent, utilities, etc. this financial squeeze threatens the survival of the agencies we entrust to take care of people especially when parents die. The amount of agencies on the financial watch list is much longer than ever before because of this situation. State operated facilities have received trends every year. A proposal, the SIP-PL came out shortly after as a road map to move services into Managed Care for both medical needs & habilitative needs. There is no money in the Governor's budget for the administrative costs and no explanation of where it is going to come from but chances are – from services. Data from other states foray into Managed Care shows that the quality of care declines and there are no cost savings. Managed Care means paying for layers of administration and consultants is taking money from Direct Care. (See Daily News article about Maximus)

You cannot provide quality services and make cuts at the same time. Services are not only essential for people with IDD it is a serious employment program with opportunities for women. Empathy makes them hirable, not their graduate degrees. Taking apart this system by starving it hurts the person, the families, and the workers. Find the money

We recognize that there are real budget pressures, but this cannot supersede my son's right and others like him to be treated like a human being by caring people.

The state has also neglected the issue of housing for people with IDD. As of now the only beds available for people who need residential services are backfills – when the previous occupant dies. There is some money, in theory, for supported apartments, but the theory is not born out in practice. Families whose loved ones could live independently are still waiting to have it happen.

Borrowing the concept of zombie ideas from Paul Krugman I think we should add Managed Care. The zombie idea in this case is that Managed Care improves care and contains costs. Where is the data to back this up, especially given that Managed Care is a medical model being tortured into working for habilitative services? Where has Managed care demonstrated that it has any capacity to provide day programs, employment training, or any of the many many other supports agencies provide?

It is hard not to feel that the people making these decisions at DOH and DOB do not have any personal experience with what the day to day life is for a family with a loved one with IDD.

- Recent data justify growth in OPWDD's typically stagnant budget. Data collected through the Center for Disease Control's National Health Interview Survey show 1 in 6 children (17.8%) diagnosed with at least one developmental disability in 2017 (increased from 16.2% in 2009).[1]
- "While much research has been conducted on whether Managed Care delivery systems result in better outcomes than fee for service (FFS), there is no definitive conclusion as to whether managed care improves or worsens access to or quality of care for beneficiaries".[2]
- Results of a recent survey of fifteen states that moved some Long-Term Supports and Services (LTSS) for Individuals with Intellectual and Developmental Disabilities (IDD) to Managed Care found that "most states did not realize a cost savings..." and that "there are no commonly accepted measures of quality" for the IDD population.[3]
- Additional state funding is currently necessary to implement Managed Care of LTSS for individuals with IDD; however, the cost-benefit analysis is not necessarily beneficial. "While there are savings achieved on long term supports and services claims, the amount of increased administrative expenditures outweighs savings from claims".[4]
- Resources must be made available to address the ongoing workforce crisis which continues to compromise continuity of supports and services for individuals with IDD within the nonprofit sector. According to National Core Indicators, the average turnover rate for Direct Support Professionals in New York State is 33 percent.[5]

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[1] Official Journal of the American Academy of Pediatrics; Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009-2017, October 2019; 144 (4) e20190811.

[2] Medicaid and Chip Payment and Access Commission (MACPAC); Managed Care's Effect on Outcomes

[3] Pg. 35, Intellectual and Developmental Disability Care Evaluation, University of Texas School of Public Health. December 31, 2018

[4] Pg. 12 IDD LTSS Texas Health and Human Services Commission, Carve-In Cost-Effectiveness Evaluation Report. Deloitte, Jan11, 2019

[5] Pg. 17, NASDDDS, Human Services Research Institute; National Core Indicators 2017 Staff Stability Survey Report, Jan 2019

- Increased level of complexity within the IDD population with the growth in Autism diagnoses that can include seizures and behavioral problems.
- High needs individuals with IDD who require a more acute level of care are naturally more at risk of being underserved, due to the increased costs associated with their acuity. The budget does not recognize this reality.

- "While the goals of care integration, improving quality and encouraging innovation are important to IDD systems, there are only a few states who have fully embraced Medicaid Managed Care for all IDD services"… due to "lack of potential cost savings, limited experience serving people with IDD, limited state experience in setting managed care rates, need for meaningful quality measures, lack of managed care experience among providers, unique role of IDD case management and supports coordination, and strong advocacy networks and relationships."[6]

Pg. 1, Health Management Associates, Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities, prepared for ANCOR; June 11, 2018

Dear Senators,

I live in Forest Hills, Queens. I hope you will listen to my concerns.

My wife and I have two sons with autism who participate in the OPWDD. Our older son also participates in CDPAP.

(1) I am strongly opposed to the OPWDD managed care agenda. Here is my comment for MRT2: "The OPWDD managed care agenda should be called what it really is: underhanded privatization of services that must remain under complete control of the OPWDD state bureaucracy. The CCO/HH privatization is a fiasco that invites the scrutiny of the US Dept of Justice as a violation of the ADA and Olmstead. SIP-PLs are fiscally totally unrealistic. Partners Health Plan is tens of millions of dollars over budget. If the PHP model is scaled up to the entire OPWDD, costs will rise by hundreds of millions per year. SIP-PLs cannot operate except at a great loss and will have to be bailed out by the state when they fail, costing hundreds of millions of dollars. Who will profit from OPWDD privatization? OPWDD managed care is fiscally impractical, ethically dishonest, and morally indefensible. I am a managed care insider and I know what I'm talking about. The OPWDD has no expertise in managed care. SIP-PLs will only worsen the major problems at the OPWDD: severe shortage of direct service providers, underfunding of home- and community-based services, abysmal lack of transparency and non-existent communication, threats and bullying by the Acting Commissioner of families doing Self-Direction, chaos and neglect and mismanagement by CCO/HHs. The track record of completely new managed care health insurance plans, such as the proposed SIP-PLs, is very poor. Most new provider-led capitated health insurance plans either go out of business within a few years or are bought out by huge for-profit payer-led health insurance plans. This predicts that SIP-PLs will run huge deficits, will seek bailouts by the State, will fail to provide promised services, will drive hundreds of service providers into bankruptcy across the state, and will ultimately be offered in sale to New York's mainstream Medicaid managed care organizations (for-profit corporations). However, these MMMCOs have already demonstrated no interest in taking over the OPWDD – they know they would lose hundreds of millions of dollars. The OPWDD is a unique and fragile fee-for-service system. It must be incrementally improved from within. Managed care privatization is the worst possible agenda. The USDOJ is watching."

(2) I am fearful for the future of CDPAP. CDPAP originated to help people with physical disabilities. In 2014, Senator Simcha Felder got a bill passed to permit family members to be paid through CDPAP. It should be obvious that 1199SEIU was opposed to Senator Felder's bill, as 1199SEIU opposes any non-union workers being paid Medicaid dollars. Senator Felder was in an unusual position of negotiating power in 2014, and he got his bill signed into law. Since that time, Senator Felder's law has helped his intended beneficiaries — families of disabled adults. However, the law has also permitted CDPAP to grow far beyond families

with adult disabled members. Moreover, Senator Felder is no longer the swing vote in the Senate. 1199SEIU is now seeking to reverse Senator Felder's law — to put the genie back in the bottle, so to speak. 1199SEIU states clearly that it wants to unionize all CDPAP workers. The Governor's Dept of Health is the henchman of 1199SEIU, now creating a "problem" that 1199SEIU is tailor-made to "solve." The NYSDOH wants to consolidate CDPAP FIs. One large CDPAP FI in particular, Concepts of Independence, run by an unscrupulous dealer named Tony Caputo, appears to be conspiring with 1199SEIU on a backroom deal: Concepts permits 1199SEIU to organize Concepts' CDPAP workers in return for 1199SEIU inducing the NYSDOH to favor Concepts' application to become the statewide CDPAP FI. It's a naked power grab by both 1199SEIU and Mr. Caputo. CDPAP workers already have wage parity. The NYSDOH CDPAP changes will reduce CDPAP worker wages to the bare minimum wage, will eliminate overtime, and will cut worker benefits. These changes will give 1199SEIU an opening to campaign for unionization on a platform of restoring the workers' former wages and benefits, provided they pay union dues. Unionization, with its extensive job "protections" that make it very difficult to fire 1199SEIU workers, are wholly incompatible with the letter of the CDPAP law, which permits consumers to hire and fire workers at will. Therefore, it is unclear whether the 1199SEIU agenda will pass legal challenges. I encourage the NYS Senate to investigate the back-room deals behind the current assault on CDPAP. The Governor is vilifying CDPAP as a budget buster, which is directly taken from 1199SEIU's script. In fact, CDPAP has the lowest overhead and is the most cost-effective program for serving the needs of New York's disabled and aging citizens. If CDPAP is killed off, costs will rise as disabled and aging citizens will have to enter institutions, where they will cost more and die sooner. Not only is 1199SEIU gaming the NYSDOH for its naked self-interest (a desperate reaction to Janus v AFSCME), but also the hospital and nursing home operators would like nothing better than to see CDPAP cut or abolished. The Executive Branch has too much power over CDPAP. The Legislature must reclaim its oversight role.

Yours,
James Edmondson
Forest Hills, NY

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Yours,
James Edmondson
Forest Hills, NY

Community Habilitation:
An Essential OPWDD Service

My son, Eli, is a "high utilizer" of Community Habilitation, using over forty hours each week. This OPWDD service allows him to live a life of choice and community integration. OPWDD likes to celebrate the progress they are making with person-centered planning. Eli is fortunate to have person-centered delivery of services. This provides him with good quality of life at low expense.

Not everyone with a Developmental Disability needs or wants the same set of services. But there is a very diverse population of people who are using Self-Direction. For that group, cuts to the services which support them in the community will not actually save any money, since it will force them into more expensive settings. Take my son as an example. If his ability to purchase Community Habilitation were reduced, then he would need to move into a supportive IRA with Day Habilitation which costs 7% more. But then, he would likely be viewed as a discipline problem due to his desire to "do things his own way" and get transferred to a supervised IRA costing about 40% more. Even worse, if I were no longer alive to prevent it, he might get transferred to a State Services supervised IRA, costing almost **three times as much** as his current expenses.

Eli's current costs are lower than any of the desirable alternatives, despite the fact that he is a "high utilizer" of Community Habilitation. Please, preserve Community Habilitation and the other Community-based supports for people with Developmental Disabilities.

State and Non-Profit Services compared to one Self-Direction participant's costs

Category	**Description**	**Annual Cost**	**Ratio to Eli**
Wait list	When on a waitlist, no services are provided.	$ -	n/a
Individual Self-Direction	Residential only. Eli's rental subsidy plus cost of "supervision" from Live-In Caregiver	$ 19,867	0.24
Voluntary Non-profit	Residential only from a Non-profit: Supportive IRA (Individualized Residential Alternative).	$ 44,895	0.55
Individual Self-Direction	All-in-cost. Eli's residential plus all activities. Actual 2019 expense.	$ 82,162	1.00
Voluntary Non-profit	"All in" from a Non-profit: Supportive IRA plus 20-30 hrs/week of Group DayHab. Zero one-on-one.	$ 87,913	1.07
Voluntary Non-profit	Non-profit: **Supervised** IRA rates	$ 113,880	1.39
Voluntary Non-profit	Non-profit: Intermediate Care Facilities (ICF)	$ 172,038	2.09
State Services	State Services: **Supervised** IRAs	$ 233,873	2.85
State Services	State Services: ICF	$ 383,124	4.66

Managed Care provides no advantages when applied to Long Term Supports and Services

Jim Karpe, father of two young adults with Developmental Disabilities. jim.karpe@gmail.com

We must halt the transition of OPWDD services into managed care. There are no cost savings. There is no evidence of improvements to access or to quality. The Long Term Supports and Services (LTSS) provided through OPWDD are not avoidable expenses that can be prevented through clever management. Instead they are essential services which enable people to live in the community, and the alternatives to community care are more expensive.

No cost savings. Applying Managed Care principles to LTSS produces zero net gains, because the modest savings from reductions in services are overwhelmed by the large increase in overhead. This was the conclusion of a Deloitte report published in early 2019.

> "While there are savings achieved on LTSS claims, the amount of increased administrative expenditures outweighs savings from claims."
> pg 12. IDD LTSS Carve-In Cost-Effectiveness Evaluation - Final Report

Our experience here in NYS is consistent with Deloitte's conclusion. Partner's Health Plan (PHP) is in year five of the FIDA demonstration project, using Managed Care to provide LTSS to individuals with developmental disabilities. PHP results to date: On-going financial losses.

Access and quality might get worse. When looking at the entire landscape of Medicaid managed care, the congressional commission that evaluates Medicaid programs stated:

> 'While much research has been conducted on whether Managed Care delivery systems result in better outcomes than fee for service (FFS), there is no definitive conclusion as to whether managed care improves or worsens access to or quality of care for beneficiaries."
> https://www.macpac.gov/subtopic/managed-cares-effect-on-outcomes/

We have seen this play out in NYS. Care Coordination Organizations were rolled out in July 2018, and have cost hundreds of millions more than the Medicaid Service Coordination system that it replaced. So far, the increased costs have been covered by a temporarily increased Federal share-- but that ends this June. The disruption to the system has been self-evident, and there is no evidence of systematic improvements in access or quality. My family's personal experience is negative. Under the old system, we had the same service coordinator for five years, a dedicated individual who knew the details of my children's lives and needs. Under the new system, we have had a revolving door of eight care managers in eighteen months. Several of them were not with us long enough to figure out the gender of my children, much less learn about their service needs.

We were told that CCOs were needed to comply with the Federal mandate for conflict-free case management, separating the case manager from the provider of services. In reality, the CCOs are controlled by governing boards made up of provider executives. Under the current reimbursement model there is not much impact, but under MC there would be a financial incentive to pressure CCO personnel to reduce services. **If New York State continues to move forward with Managed Care for OPWDD services the result will be ever more waste of money, and an increase in conflict of interest. We must call a halt now.**