Downstate New York ADAPT

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Image description: "Downstate NY ADAPT" text over & under image of PWD in wheelchair with arms raised, breaking handcuffs' chain overhead, under arching text "Free Our People"

February 8th, 2022

Honorable Liz Krueger
New York State Senate
Chair, Committee on Finance
Email address: financechair@nysenate.gov

Honorable Helene E. Weinstein
New York State Assembly
Chair, Committee on Ways and Means
Email address: wamchair@nyassembly.gov

Re: 2022 Joint Legislative Budget Hearing on Health

These comments are submitted on behalf of Downstate New York ADAPT, a chapter of the nation's largest grassroots, non-hierarchical community of disabled people that fight for the right to live and fully participate in the community. **We are not a provider organization, we are a coalition of disabled consumers of home care services through Medicaid.**

ADAPT's main goal is to fight against the institutional bias that slants nursing home care over home care. **We therefore demand that the following bills be included in the upcoming State budget:**

(1) A5367/S5028 to repeal MRT2's stricter eligibility criteria for home care,

(2) A6329/S5374A Fair Pay for Home Care, and

(3) A226/S5255 to repeal the arbitrary Medicaid Global Cap.

Repealing MRT2's Stricter Eligibility Criteria

As we have already made the Health Committee well aware that DNY ADAPT has been working diligently to repeal the disastrous changes set forth by MRT2. **We demand that bills A5367/S5028 be included in the upcoming Budget.**

MRT2 had one major goal: cut 2.5 billion out of Medicaid spending[1]. We fundamentally disagree with this form of cost-saving. Austerity politics never save money. Decreasing access to public services and healthcare only decreases the health and well-being of the public, which later accrues MORE spending for the State because public health declines. **MRT2 should not have happened, especially with so little consumer input.**

The other two directives of MRT2 was for the proposed initiatives to have "zero impact on beneficiaries and local districts," which the former Governor delineated himself[2]. This claim was obviously made in bad faith because restricting the eligibility criteria for home care **directly impacts our daily lives**.

We constituents consider it a great act of violence to restrict access to home care in ordinary times, but it is especially callous during a pandemic in which thousands have died in institutions. In the following section we outline why such an egregious change to home care eligibility would be absolutely detrimental to New York State:

> **First and foremost, it seems that these changes will violate the federal Community First Choice Option ("CFCO").** New York State receives an additional 6% funding from the Federal Government (FMAP) for complying with CFCO policies. The additional FMAP is supposed to be earmarked for community-integration, as long as these programs continue to meet CFCO standards. New York State has put 90% of the pre-existing CDPAP-- under CFCO to collect the extra 6% FMAP instead of implementing a "CFCO program" and offering **all** CFCO services. According to CMS Expenditure reports, the average amount NYS gathers for CFCO is $282,507,547.23 annually, and $1,130,030,188.92 in total from 2015-2019[3].
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> **Shockingly, while this additional money is supposed to be earmarked for Olmstead-like efforts, there is evidence that NYS may instead be exploiting this e-FMAP toward other expenditures through the State General Fund.** Furthermore, NYS avoids fully implementing all CFCO services, including environmental/vehicle modifications, moving assistance, and assistive technology. On top of these pre-existing CFCO issues, the restrictive eligibility criteria from part MM of last year's budget even further disregards the framework of CFCO. We remain concerned that the State violates federal code and guidance for CFCO and it seems that New York should not have been getting this Federal funding in the first place due to its failure to carry out full implementation of the program. The new eligibility criteria makes it even clearer to the Federal Government that NYS never had any intention of complying with proper guidelines for the extra 6% FMAP. We are fully prepared to report NYS's noncompliance with these regulations to CMS. The 2020 Budget violated Federal guidelines in the following ways:

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[1] **NYS Governor Cuomo Picks Members for Medicaid Redesign Team; No Consumer Representation Some Focus on Workforce and Safety Net Sustainability** *(2020):* https://www.nyaprs.org/e-news-bulletins/2020/2/5/cuomo-picks-members-for-medicaid-redesign-team-ii-without-consumer-representation-some-focus-on-safety-net-sector-sustainability

[2] https://www.wxxinews.org/post/tense-moments-hearing-cuomos-plan-medicaid-cuts

[3] Medicaid.gov, **Expenditure Reports From MBES/CBES:** https://www.medicaid.gov/medicaid/financial-management/state-expenditure-reporting-for-medicaid-chip/expenditure-reports-mbescbes/index.html

1. Creating a more **restrictive** eligibility criteria that differs based on "type of disability" (i.e. physical disabilities versus Alzheimer's, 'physical maneuvering' versus 'supervision') violates CFCO. Pursuant to **42 U.S.C § 1396n(k)**, acceptance of CFCO funding mandates that home and community based services must be given in such a manner that is without regard to an individual's "***type or nature of disability, severity of disability***". Also reiterated on Page 7 of the **CFCO Technical Guide by CMS**[4], "*42 CFR 441.515 requires states to provide CFC to individuals on a statewide basis and in a manner that provides services and supports in the most integrated setting appropriate to the individual's needs and without regard to the individual's age, type or nature of disability, or the form of home and community-based attendant services and supports the individual needs to lead an independent life.*"

2. 42 U.S. Code § 1396n (k)(1)(A) requires that any State receiving CFCO funding "*make available home and community-based attendant services and supports to eligible individuals, as needed, to assist in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing.*" The NYS Budget law that changed New York State's Social Services law disregards federal CFCO guidelines set forth by **CMS**, which states that IADLs/Level 1 care must be included. Please refer to pages 3-4 of the State Plan Amendment #13-35[5] and page 17 of the **CFCO Technical Guide** by the Centers for Medicare and Medicaid Services ("CMS"). You will find that they highlight the mandate of both ADLs and IADLs services be included and that such services "***are a means to maximize independence and integration in the community, preserve functioning and defer or eliminate the likelihood of future institutional placement.***" Second, these eligibility changes will fuel a grave public health crisis, increase healthcare costs long term, and violate the Olmstead mandate that requires States to provide services in the most integrated setting.

Second, to put this in perspective, this eligibility criteria would eliminate from consideration the need for assistance IADLs from eligibility criteria (shopping, cooking, housekeeping, making beds, etc.), essentially stating that "physical maneuvering" of the body is the only <u>valid</u> form of caretaking for people with physical disabilities. This is an incredibly restrictive criteria to meet, and is not a very nuanced or accurate portrayal of disability. Needing help with tasks that are about the ways in which we navigate or interact with our environment (IADLs) are JUST as critical and life-saving as body focused tasks (ADLs).

Third, this criteria for community-based care is STRICTER than the eligibility criteria for institutional living. Therefore, this change will violate the Supreme

[4] **Community First Choice Option (CFCO) Technical Guide, CMS:** https://www.medicaid.gov/sites/default/files/2019-12/cfc-technical-guide_0.pdf

[5] **NYS SPA #13-35**: https://www.health.ny.gov/regulations/state_plans/status/non-inst/approved/docs/app_2015-10-23_spa_13-35.pdf

Court's Olmstead mandate. The Supreme Court's Olmstead[6] decision mandates that services must be made available in the least restrictive setting[7], which sets forth a legal requirement for home care services to be available BEFORE nursing home care[8]. Yet, this new criteria will leave eligibility for home care up to a proprietary assessment tool that indicates this new criteria for home care would be STRICTER than the eligibility criteria for nursing homes.

Fourth, long-term care costs will skyrocket when more disabled people are forced into institutions, as congregate care settings are exponentially more expensive than home care. Not only will the State have an abundance of Olmstead lawsuits in the coming years, but the State will also be forced to spend more money because people will be approved for institutional care more frequently and more readily than they will be for home care. As we know, institutional settings cost significantly more money. Annual costs for these settings range from $130,284 in Central New York to a whopping $166,008 on Long Island[9].

Fifth, congregate care settings are not as safe, as shown during the pandemic. The high costs of nursing homes are not correlated with a high quality of care; instead, congregate settings have been demonstrated to isolate residents and spread infectious disease. In fact, *"Since March, Attorney General James has been investigating nursing homes throughout New York state based on allegations of patient neglect and other concerning conduct that may have jeopardized the health and safety of residents and employees."*[10]

Six, it leaves eligibility determination up to a proprietary assessment tool determined by the commissioner in the Dept. of Health. This tool, the UAS-NY **was never intended to be used in eligibility determination,** as it was created as a quality of life assessment. Therefore, it is not enough of a nuanced or comprehensive tool to be used for this matter. Even more concerning, consumers do not get a copy of their assessment outcome, even though it is common practice in other states. Eligibility would be determined by an algorithm and the score that the UAS produces, instead of it being determined in a more nuanced and inclusive way that accounts for the individual nature of each person's disability.

Seven, creating stricter criteria in order to deny people home care will only leave them in the community without proper services, which will inevitably lead to deteriorated health, an increase in injuries, and greater medical spending long term. A decrease in the overall well-being of New Yorkers will only increase long-term care costs, ER visits, hospitalizations and overall medical spending in the long run.
A disabled person who is denied home care will incur injuries and infections that progress their disability, and if they don't die, it might make them eligible for home care

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[6] **Olmstead v. L.C., 527 U.S. 581. (1999):** https://supreme.justia.com/cases/federal/us/527/581/
[7] https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html
[8] Olmstead Community Integration for Every New Yorker:
https://www.ny.gov/programs/olmstead-community-integration-every-new-yorker
[9] Estimated Average New York State Nursing Home Rates: https://nyspltc.health.ny.gov/rates.htm
[10]NYS Attorney General's Report:
https://ag.ny.gov/press-release/2021/attorney-general-james-releases-report-nursing-homes-response-covid-19

eventually BUT at that point they will require a higher level of care and cost to the State, not to mention the pain and suffering imposed upon the individual. This change in eligibility criteria is the equivalent of not allowing medical care for a basic cold, but instead only providing healthcare for when it develops into pneumonia.

Finally, the extent to which the former Governor Cuomo disregarded the value of disabled lives is abundantly clear. Not only did he deliberately put COVID-19 patients into nursing homes, where the most medically at-risk are incarcerated, but he showed little remorse. We got the message loud and clear from his dismissive response to the AG's report, which revealed that the number of nursing home COVID deaths was deliberately underreported by his team. The Senate and the Assembly now have an opportunity to **do better**, and create a different path for New York.

Therefore, repealing MRT2's stricter eligibility criteria for home care by including Bills A.5367 and S.5028 is a critical first step. The austerity politics that have diminished the care and dignity in disabled lives must stop with the end of the former Governor's reign. We have the opportunity to act swiftly to undo the harm that he left. He stepped down for a glaring reason: the damage that he left is abounding. Luckily for the State, we are handing you an opportunity to address it immediately.

Fair Pay for Home Care

A living wage for our home care workers is long overdue. Low wages are a leading reason for a mass exodus from the field despite an ever-increasing need for community-based personal care services. These workers, even if deeply committed, simply cannot afford to stay in these positions. At present, New York State faces the worst home care worker shortage in the nation, and the consequences are dire.

Disabled people in need are struggling to fill shifts and to retain their existing staff. Many are sleeping in their wheelchairs when adequate help is not available.

In the interest of justice for consumers and their home care staff, we must pass Fair Pay 4 Home Care (A6329/S5374) in the 2022 budget.

This critical bill will raise the salary for home care workers, also called personal care assistants, to 150% of the minimum wage, ensuring that their occupation remains viable.

Wage increases have already occurred in competing industries such as fast food and home care workers deserve similar recognition for their essential contributions. With a home care workforce that is 90% female and more than 80% people of color, Fair Pay 4 Home Care is not just an economic issue, but one of racial and gender justice.

A recent study by the CUNY School of Labor and Urban Studies found that public investment in home care workers would actually save money long-term, and represents a strategy that is both morally and fiscally compelling. Given that the COVID-19 pandemic has laid bare the vital role

of caregivers, now is the time to make lasting change. Furthermore, COVID-19 has been a mass disabling event which suggests that the demand for home care will only grow in the years ahead.

Fair Pay 4 Home Care is a common sense solution with bipartisan support and the endorsement of more than 50 community organizations. Put simply it is a win-win-win: for consumers, for workers, and for the government. New York State was once a leader in compassionate long-term care policy and we can be once more.

Repeal the "Medicaid Global Cap"

New York State's self imposed global cap is an arbitrary, austerity-driven structure designed to limit access to life-saving services. **Therefore, we demand bills A226/S5255 to repeal the global cap be included in the budget.**

Imposing any sort of cap on Medicaid spending implies that growth in the program is a problem that requires austerity tactics to manage. We would like to reiterate that our lives and our care are not should not be budget item issues for the State to negotiate. An increase in access to Medicaid is a good thing because it saves lives, and it should be regarded as such. **Medicaid keeps our community alive. All we are asking for is our survival.**

Additionally, this cap in particular has many critical issues. The cap was not designed to account for program growth, the increase in program or services costs, or the global pandemic. Furthermore, State Medicaid spending includes a federal match. By imposing a limit on state spending, the global cap also halts the amount of federal funding the state can receive for its Medicaid program. This is not logical or beneficial, especially during a health and financial crisis.

Concluding Statement: We are tired of being used as scapegoats

The cost of Medicaid skyrocketed because of managed care's "administrative costs" and profiteering. Profit margins are **built into** the monthly **capitation payments** -- meaning that profit margins for these private business companies are embedded within the calculations for each Medicaid enrollee. Yet, disabled people are **continuously** made **scapegoats** for these rising costs! Our needs, our bodies, and our lives are made to blame. We are called "**burdens"** and **"leeches** on the system" and the austerity rhetoric in Medicaid from the past few years have reinforced this narrative, and perpetuated this myth.

Our need for help getting out of bed in the morning is **demonized** by the public, the media, in political discourse, by our politicians, and MRT executives. Meanwhile, the true culprits responsible for the rising costs of our services remain unscathed.

Even if our needs *did* increase Medicaid spending significantly, we in the disability community find this to be a **non-issue**. When we hear that home care spending has increased, we **cheer.** We say, *"Our brothers and sisters are safe. They are getting the services they need and to which they are entitled!"* What we are asking is for a **paradigm shift** in the way that we think about long term care and the value of disabled lives. An investment in Medicaid, is an investment in our

lives and the greater community. **We are <u>not</u> asking you for a seat at this table. We are reminding you that <u>it is our table</u>. It is <u>our lives</u> that are at stake here.**

We implore the State to create policy that centers the rights of disabled New Yorkers to live in the community with the guarantee of services that keep us alive, healthy, productive and active. We will all acquire impairments and, possibly, disabilities someday, should we live long enough. Disability is a natural part of the human condition and the needs of our community are inextricably intertwined with those of all others.

There is no "Us and Them", there is only "Us". Therefore, services for disabled people should not be trivialized, cut, or misconstrued in the ways they have been, historically, because allocating resources to us will only benefit society as a whole.

All New York citizens/voters/taxpayers deserve to live with dignity and peace of mind knowing that Medicaid services will be available should they experience deteriorating health or the onset of disability.

In summation, **<u>we demand that the following bills be included in the upcoming budget:</u>**

(1) A5367/S5028 to repeal MRT2's stricter eligibility criteria for home care,

(2) A6329/S5374A Fair Pay for Home Care, and

(3) A226/S5255 to repeal the arbitrary Medicaid Global Cap.

<u>This is the bare minimum that the disability community will accept.</u>

Thank you for this opportunity, and for all the work you do every day for New Yorkers.

Respectfully yours,
Downstate New York ADAPT
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