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"

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Downstate New York ADAPT is a chapter of the nation's largest disability rights organization. ADAPT fights to end the institutional bias that keeps disabled people in institutions, and promotes a society that fully invests in home and community based programs. To achieve this goal, we support the Fair Wages Campaign to increase home care wages, Bill A226 to repeal the Medicaid Global Cap, and Bill **A5367;S5028 to repeal harmful home care eligibility criteria.** In this letter, we will discuss in depth our support for **A5367;S5028** being enacted immediately in the 2021 budget.

Part MM of last year's Health Budget Law proposed to drastically limit the eligibility criteria for Medicaid Personal Care Services and Consumer Directed Personal Assistance Services ("CDPAS"). **This bill (A5367;S5028) will repeal these changes, and thus, is a matter of critical importance for disabled people and seniors in your District and across the State.**

Typically one is eligible for life-sustaining home care services once receiving Medicaid when diagnosed with a disability that necessitates assistance with at least one "personal care service," defined broadly. This new eligibility criteria dictates that in order to be eligible, one must need help with 'physical maneuvering' for at least 3 activities of daily living ("ADL"), except for those with an Alzheimer's diagnosis, who would instead need 'supervision' with at least 2 ADLs. ADLs are defined not only in a more limited manner than personal care services, but are also determined by a proprietary tool that is not transparent to consumers, the public, or the Legislature. The new eligibility does not take into account other important tasks like medication management, cooking, laundry, housekeeping, and more. **In the following document we outline why such an egregious change would be absolutely detrimental to New York State, especially during a time in which there is so much suffering amidst the COVID-19 pandemic.**

First, 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 CDPAS 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.

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**. It appears that the State may have violated and may continue to violate federal code and guidance for CFCO. This, 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 New York State never had any intention of complying with proper guidelines for the extra 6% FMAP. **We are fully prepared to report the State's noncompliance with these regulations to CMS. It appears that the Budget violated Federal guidelines in the following ways:**

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, "*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 new law would disregard federal guidelines set forth by CFCO, which states that IADLs/Level 1 care must be included. Please refer to pages 3-4 of the State Amendment Plan #13-0035 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 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 proposed 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.

1. To put this in perspective, this eligibility criteria would eliminate IADLs from eligibility criteria (shopping, cooking, housekeeping, making beds, etc.), essentially stating that "physical maneuvering" is the only valid form of caretaking for people with physical

disabilities. The mandate also dictates that we must need support with a certain number of tasks to be eligible. 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 and an increase in injuries. A decrease in the overall well-being of New Yorkers will only increase long-term care costs.

2. This criteria for community-based care is **STRICTER than the eligibility criteria for institutional living.** 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, one of the many drawbacks of purportedly living in an institutional setting is they cost significantly more money.

3. **The extent to which Governor Cuomo disregards 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 has since shown little remorse. We got the message loud and clear from his dismissive response to the AG's report[1] which revealed that the number of nursing home COVID deaths was deliberately underreported by his team. As if that is not appalling enough, he simultaneously proposes a policy that will send more disabled people into institutions while failing to prioritize us for COVID-19 vaccines. **It is your job as a State Official to sound the alarm when harm is done to marginalized groups--and act swiftly to prevent such harm.**

Thirdly, this stricter criteria would allow the Department of Health (DOH) to utilize a proprietary assessment tool to define ADLs. This tool, the Community Health Assessment or the Universal Assessment System (UAS—NY), from the minimal information the public has been allowed to know so far, disregards most personal care services from eligibility determination, including but not limited to cooking, medication management, or washing our hair.

1. An example of not only the impending Olmstead lawsuits, but the sheer irresponsibility of allowing the DOH to use a proprietary tool in these determinations can be seen in what the DOH publicly published on their website as a UAS sample. In this example, the UAS produced a score of 18 for that person's physical needs, which meets "nursing facility level of care." Yet, out of the ADLs listed on this sample of the proprietary tool, they only meet "physical maneuvering" for TWO of them. This Jane Doe, like thousands of others applying for home care AFTER this goes into effect, will be denied and forced into an institution.

2. Equally as jarring, this UAS sample is from 2014. Since it is a proprietary tool, it is subject to change without any notice to the Legislature or the consumers of home care — yet it holds so much power in eligibility determination. "Three ADLs" may sound reasonable to those unfamiliar with this system, but it is NOT — *especially* when the

[1] https://ag.ny.gov/sites/default/files/2021-nursinghomesreport.pdf *(Accessed Feb. 3rd, 2021)*

definition of those ADLs are hidden, arbitrary, and picked by a Maximus nurse from a drop down menu that is determined by a tool from a company with a $9.4 million dollar New York State contract that will probably continue to grow unfettered by public review. Nevertheless, the fact that even the sample case given by the DOH did not meet the new criteria should speak volumes.

We implore the State to create a health budget that centers **the rights of disabled people to live in the community with the guarantee of services that keep us alive, healthy, productive and active**. We will all become disabled 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. Therefore, services for disabled people should not be trivialized, cut, or misconstrued in the ways that they historically have been 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 services will be available should they experience deteriorating health or the onset of disability.

Enacting a policy that will send more people to institutions during a time in which we are dying there at exponential rates during a pandemic (*especially* while our Governor is being investigated by the federal government for his role in nursing home deaths) is not only irresponsible, but active and deliberate violence. **We are asking the State to include Bill A5367;S5028 to repeal the stricter eligibility criteria in the 2021 Budget.**

Ever Upward,
Downstate New York ADAPT