

**MEMORANDUM IN SUPPORT
A5367 (Gottfried)/ S5028-A (Rivera)**

A bill to remove certain restrictions on eligibility for personal and consumer-directed personal care services under Medicaid, which were enacted in the FY 2020-21 budget

The New York Legal Assistance Group (NYLAG) supports this legislation.

NYLAG uses the power of the law to help New Yorkers in need combat social and economic injustice. We address emerging and urgent legal needs with comprehensive, free civil legal services, impact litigation, policy advocacy, and community education. Among the array of free legal services we provide is representation of older persons and people with serious illness or disabilities in retaining Medicaid eligibility and accessing Medicaid home care services in order to live safely in their homes and avoid institutionalization.

**Repeal of Illegal Restrictions on Medicaid Home Care Eligibility Enacted in
FY 20-21 Budget is Necessary to Avoid Violating Federal Law
and Unnecessary Institutionalization**

NYLAG supports repeal of the restrictions on Medicaid home care eligibility enacted last year that arbitrarily and illegally limit eligibility for Medicaid personal care and consumer-directed personal assistance (CDPAP) services, and that covertly shuts down entirely the small but crucial preventative “housekeeping” home care program. Since these restrictions are not yet implemented, repeal will preserve the *status quo* for home care eligibility, saving the cost of implementation of this massive change.

1. The Minimum ADL Limit Unlawfully Denies Services Based on Diagnosis, Violating Medicaid Regulations and Jeopardizes State Funding Under the Community First Choice Option (CFCO)

The recently amended law, Soc. Serv. Law §§ 365-a(2)(e)(v) and 365-f, subd. 2(c) sets new minimum requirements for eligibility for PCS and CDPAP services and for enrollment in a Managed Long Term Care (MLTC) plan. An applicant for PCS or CDPAP services, or an individual seeking to enroll in an MLTC plan, must need assistance with *physical maneuvering* for more than two Activities of Daily Living (ADL’s). The sole exception is for those with dementia or Alzheimer’s disease, who must need *supervision* with more than one ADL. These new limits violate requirements of the Community First Choice Option (CFCO), jeopardizing New York’s receipt of millions of dollars of enhanced Federal Financial Participation for Medicaid home care services.

Because of the nature of vision impairments, traumatic brain injury (TBI), developmental disabilities (DD), and other cognitive, neurological or psychiatric impairments, consumers often need *supervision* but *not physical maneuvering* with ADLs. Denying them PCS or CDPAP solely because they are not diagnosed with dementia or Alzheimer’s disease – even though they have the same need for assistance -- violates the “comparability” requirement of federal Medicaid law that requires state plan services to be available equally in amount, duration, and scope for all individuals within the eligibility group. 42 U.S.C. § 1396a(a)(10)(B); 42 C.F.R. § 440.240(b). The denial of services because an

individual has a different diagnosis -- but the same needs as -- someone with dementia violates the comparability rule,¹ as well as federal Medicaid regulations. See 42 C.F.R. §440.230(c). (“The Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service under §§ 440.210 and 440.220 to an otherwise eligible beneficiary solely because of the diagnosis, type of illness, or condition”).

The State Department of Health wrongly claims that denying PCS or CDPAP to people with TBI’s or Developmental Disabilities does not hurt them because they may access services through the TBI or OPWDD waivers. PCS and CDPAP services, however, are services under the State Medicaid plan. In fact, TBI and OPWDD waiver participants do rely on “State Plan” services such as personal care and CDPAP for their core daily needs. Under federal law, State Plan services must be available to every Medicaid recipient, including those who are in a waiver. The waivers supplement those State plan services with special waiver services like Respite, Residential Habilitation, Day Habilitation, and Community Habilitation. However, these waiver services do not substitute for the essential daily care needs met by PCS or CDPAP.²

EXAMPLE: Sam, age 22, is autistic and has an intellectual disability. He lives with his parents and a sibling who also has a developmental disability. Sam is enrolled in the OPWDD waiver through which he receives some supplemental waiver services. However, his main daily care is provided through 84 hours/week of CDPAP services. Since most of the assistance with ADLs he needs is “supervisory,” he could be denied CDPAP services altogether under the new restrictions. He could be forced into an institution without these services.

Even though Sam is “grandfathered in” as a current recipient, there is a new “Sam” who applies for these vital services every day, whether because of a developmental disability, a vision impairment, or many other diagnoses – they are all at risk of being denied care and being forced into institutions.

We urge full repeal of the ADL limits rather than the approach taken in A.10486 S.8403. That bill extends the “dementia exception” – which requires only supervision with two ADLs rather than “physical maneuvering” assistance with three ADLs – to other diagnoses such as vision impairments, DD, TBI and other cognitive impairments. While this is helpful, it is impossible to list every diagnosis for which the individual would need supervisory rather than physical assistance with an ADL. For example, consumers at early stages of Parkinson’s disease or multiple sclerosis may need supervisory rather than “physical maneuvering” assistance with ADLs. Only repeal of the ADL minimum

¹ See, e.g. *Oster v. Lightbourne*, 2012 WL 691833 (N.D. Cal. Mar. 2, 2012) (finding likely violation where use of functional ranks to determine eligibility for in-home services particularly disadvantaged people with cognitive disorders), earlier injunction sub nom. *V.L. v. Wagner*, 669 F. Supp. 2d 1106 (N.D. Cal. 2009) (cuts to in home support services likely violate comparability requirement); *Parry v. Crawford*, 990 F. Supp. 1250 (D. Nev. 1998) (holding that comparability requirement prohibits the state from conditioning service on a particular diagnosis, if individuals have the same functional need).

² Participants in the OPWDD or TBI waivers have options for how they access State Plan services like PCS and CDPAP. They may enroll in mainstream Medicaid managed care plans, or access PCS or CDPAP through their local district, such as HRA in New York City. Either way, the discriminatory minimum ADL criteria would be applied to deny them PCS or CDPAP services. Presently they are excluded from enrolling in MLTC plans.

thresholds can prevent discrimination against people with an endless list of diagnoses avoid jeopardizing New York’s receipt of the important CFCO funding, discussed below.

Additionally, New York’s enhanced federal match for Community First Choice Option (CFCO) services -- over \$287 million in FY 2016 alone³ -- is jeopardized because the CFCO regulations also prohibit discrimination based on diagnosis. “States must provide Community First Choice to individuals ...[i]n a manner that provides such services and supports ... *without regard to the individual's age, type or nature of disability*, severity of disability, or the form of home and community-based attendant services and supports that the individual requires to lead an independent life.” 42 C.F.R. § 441.515 (emph. added). Also, CFCO requires states to provide assistance with ADLs and Instrumental ADLs (“IAD”) to a CFCO-eligible individual not only through hands-on assistance **but also through supervision and cueing.**⁴ Many applicants who have TBI or DD diagnoses qualify for CFCO because without home care services, they would require an institutional “level of care” – whether in a nursing home, psychiatric hospital, or Intermediate Care Facility for Developmental Disabilities (ICF-DD).⁵

2. Repeal would Restore the “Housekeeping” Program – a Cost-Effective Preventive Service that People Safe in Their Homes

Though the longstanding program that provides vital personal care services of up to eight hours per week for “individuals whose needs are limited to nutritional and environmental support functions” remains in the statute, SSL § 365-a, subd. 2(e)(iv), the FY 20-21 Budget indirectly abolished it. Also known as “Level 1” personal care or “housekeeping” services, the program provides crucial assistance for seniors and people with disabilities who can dress and bathe themselves, but who, because of chronic impairments, cannot do laundry, shop, prepare meals, or clean their homes. Because these household tasks are “Instrumental ADLs” (IADLs) and not ADLs, they do not count toward the new minimum of 2 or 3 ADLs needed to qualify for personal care services. Therefore, these individuals would be denied Medicaid home care services entirely, putting them at risk of falls or other accidents that could totally disable them. By investing in just 8 hours per week of this preventative service, Medicaid prevents accidents, hospital stays and nursing home placement, or costly 24/7 home care– at much higher cost to the State.

³ See Report of U.S. HHS Office of the Inspector General, Feb. 6, 2020, available at <https://oig.hhs.gov/oas/reports/region2/21701015.asp>

⁴ If an individual meets the CFCO level of care criteria, “...the State must provide ...[a]ssistance with ADLs, IADLs, and health-related tasks through hands-on assistance, supervision, and/or cueing.” 42 C.F.R. § 441.520(a). “IADLs” are tasks such as cleaning, shopping, meal preparation, formerly referenced in New York as nutritional and environmental support functions,” SSL § 365-a, subd. 2(e)(iv). These are commonly known in New York as “housekeeping” tasks and are referred to as “Level 1” personal care tasks in the state regulation. 18 N.Y.C.R.R. 505.14(a)(5).

⁵ In the CFCO Technical Guide, CMS clarified, “CMS reminds states that all three ways of delivering assistance with ADLs, IADLs and health related tasks must be made available. States may not limit the scope of this benefit to offer less than all three.” CMS, Community First Choice State Plan Option Technical Guide, available at https://www.medicaid.gov/sites/default/files/2019-12/cfc-technical-guide_0.pdf.

The program is not costly for the State. In November 2020, only 601 New York City residents were receiving these services.⁶ Though the current users would be “grandfathered” in and may keep their services, new people apply for these services every month – a rising need with the increasing aging population. The long wait-lists for the state-funded EISEP program are notorious, and the EISEP program would only be more burdened with elimination of this Medicaid program.

The FY 2020-21 budget law eliminated this vital program surreptitiously; the legislature was likely not aware that the new minimum ADL requirements would eliminate this service, especially since the provision authorizing this service remains in the statute. Such clandestine maneuvering is no way to eliminate a program that has maintained the health and safety of elders and people with disabilities in their homes for decades. Repeal of the FY 20-21 changes would ensure continuation of this important preventative service.

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⁶ See HRA Facts, December 2020, at page 2, available at <https://www1.nyc.gov/site/hra/about/facts.page#caseloads>, with direct link at https://www1.nyc.gov/assets/hra/downloads/pdf/facts/hra_facts/2020/hra_facts_2020_12.pdf.