

**MEMORANDUM IN SUPPORT  
S328 (Rivera)/A6346 (Paulin)**

*A bill to remove certain restrictions on eligibility for personal care and consumer-directed personal care services under Medicaid, which were enacted in the SFY 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 economic, racial, and social injustice. We address emerging and urgent legal needs with comprehensive, free civil legal services, impact litigation, policy advocacy, and community education. We aim to disrupt systemic racism by serving clients, whose legal and financial crises are often rooted in racial inequality. 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 Illegal MRT-II Provisions Enacted in FY 20-21 Budget That Will Require  
Three “Activities of Daily Living” to Qualify for Medicaid Home Care –  
Violating Federal Law  
and Causing Unnecessary Institutionalization**

NYLAG urges adoption of S328/ A6346 to repeal the restrictions on Medicaid home care eligibility enacted in 2020 that have not yet been implemented because of the Maintenance of Effort requirements of federal COVID funding laws. 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 later in 2023 or 2024. The new restrictions would arbitrarily and illegally limit eligibility for Medicaid personal care (PCS) and consumer-directed personal assistance (CDPAP) services, which could force more people into nursing homes, violating *Olmstead*. Also, the restrictions would covertly shut down entirely the crucial “Housekeeping” program, which provides an aide up to 8 hours/week for those who, because of disability, need help with shopping, laundry and other chores but who can independently do personal tasks such as bathing and dressing.

**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 2020 amendments<sup>1</sup> set two new restrictive minimum eligibility requirements for personal care and CDPAP. First, an applicant for these services or enrollment in a Managed Long Term Care (MLTC) plan must need assistance with *three* instead of only *one* Activities of Daily Living (ADL’s).<sup>2</sup> Second, the *type* of assistance needed must be

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<sup>1</sup> Soc. Serv. Law §§ 365-a(2)(e)(v) and 365-f, subd. 2(c)

<sup>2</sup> ADLs include personal functions like bathing, dressing, hygiene, toileting/ incontinence care, ambulation, and transfer (getting up and down). Needing help with Instrumental ADLs [“IADL”] -- housekeeping tasks like shopping, meal preparation, laundry or cleaning -- does not qualify a consumer for PCS, CDPAP or MLTC, except for the limited housekeeping program which has a cap of 8 hours/week. See more below about how the ADL limits would ELIMINATE this program.

for *physical maneuvering* with ADLs – rather than cueing and supervision with ADLs. The sole exception is for those with dementia or Alzheimer’s disease, who qualify if they need *supervision* with two ADLs. See chart of ADL scoring system below. These new limits blatantly discriminate based on diagnosis, and 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.

Current criteria

New criteria

**ADL SCORING SYTEM - NYS<sup>3</sup> (from lowest to highest need)**

1. Independent – No physical assistance, setup, or supervision in any episode.
2. Independent, setup help only – Article or device provided or placed within reach, no physical assistance or supervision in any episode.
3. **Supervision – Oversight/cuing.**
4. **Limited assistance – Guided maneuvering of limbs, physical guidance without taking weight.**
5. Extensive assistance – Weight-bearing support (including lifting limbs) by one helper where person still performs 50% or more of subtasks.
6. Maximal assistance – Weight-bearing support (including lifting limbs) by two or more helpers; or, weight-bearing support for more than 50% of subtasks.
7. Total dependence – Full performance by others during all episodes.

Qualify if need any assistance with 1 ADL at level 3 or above

May only qualify with this level of need if have Dementia and need help with 2 ADLs

Everyone who does not have dementia must have 3 ADLs at this level of need or higher

The requirement that a consumer must need *physical maneuvering* with ADLs discriminates against people with vision impairments, traumatic brain injury (TBI), intellectual and developmental disabilities (IDD), and other cognitive, neurological or psychiatric impairments. They would be denied PCS, CDPAP and MLTC enrollment solely because they are not diagnosed with dementia or Alzheimer’s disease – even though they have the *same need* for supervisory assistance with ADLs because of a diagnosis other than dementia. This arbitrary rule would violate the:

- (1) “Comparability” requirement of federal Medicaid law that requires 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),<sup>4</sup>
- (2) Community First Choice Option (CFCO) – jeopardizing **New York’s enhanced federal match for CFCO services -- over \$342 million** in FY 2021 alone.<sup>5</sup> “States

<sup>3</sup> NYS DOH, UAS-NY Community Health Assessment Reference Manual (August 2022 edition), p. 32, on file with NYLAG.

<sup>4</sup> “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.” §440.230(c); 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).

<sup>5</sup> Data extrapolated from CMS data posted at <https://www.medicaid.gov/medicaid/financial-management/downloads/financial-management-report-fy2021.zip>; See also Report of U.S. HHS Office of the Inspector General, Feb. 6, 2020, available at <https://oig.hhs.gov/oas/reports/region2/21701015.asp>

must provide Community First Choice to individuals ... *without regard to the ...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). Assistance with ADLs and Instrumental ADLs (“IADL”) must be provided to a CFCO-eligible individual not only “...through hands-on assistance, supervision, and/or cueing.” 42 C.F.R. § 441.520(a).<sup>6</sup> 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).<sup>7</sup> Yet they often need cueing and supervisory assistance with ADLs rather than physical maneuvering assistance.

In an extraordinary criticism by one State agency of another’s policy, the NYS Office of Mental Health (OMH) filed comments to the proposed DOH regulations implementing the ADL thresholds enacted in 2020. As summarized by DOH, “OMH indicated that those with serious functional impairments due to their [Serious Mental Illness](SMI) may not present with any physical function needs at all, yet **due to their SMI if sufficiently serious, could be unable to perform ADLs such that they would be placed at risk of institutionalization.**”<sup>8</sup> DOH so much as admitted that denying home care to people with SMI who did not have two ADLs would be illegal – and pledged to “... issue implementing guidance establishing a process whereby services [may] be determined medically necessary for those individuals identified as having SMI when they demonstrate a need for assistance with at least supervision and cueing with...” two ADLs.

DOH’s promise to OMH to protect people with SMI fails on four counts. First, the promised procedure was not incorporated in the final regulations – it was only promised in vague guidance. Second, it imposes a burden on someone with a SERIOUS MENTAL ILLNESS to request a reasonable accommodation to the ADL thresholds, which is unjustifiable and inherently unreasonable. Third, DOH refused to establish a similar exception process for those with TBI’s, IDD, blindness or other disabilities. It justifies this refusal by dismissing comments from NYLAG and other organizations urging protections for these groups solely because these comments were not filed by other government agencies or so-called “experts” in these disabilities. Id. n. 8. Finally, DOH wrongly claims that denying PCS or CDPAP to people with TBI’s or IDD does not hurt them because they may access services through the TBI or OPWDD waivers. PCS and

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<sup>6</sup> See n. 1 for definition IADLs, formally referenced in New York as “nutritional and environmental support functions” and commonly known as “housekeeping” tasks. SSL § 365-a, subd. 2(e)(iv). These are referred to as “Level 1” personal care tasks in the state regulation. 18 N.Y.C.R.R. 505.14(a)(5).

<sup>7</sup> 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](https://www.medicaid.gov/sites/default/files/2019-12/cfc-technical-guide_0.pdf).

<sup>8</sup> See final regulations posted Nov. 8, 2021, available at [https://regs.health.ny.gov/sites/default/files/pdf/recently\\_adopted\\_regulations/Personal%20Care%20Services%20and%20Consumer%20Directed%20Personal%20Assistance%20Program.pdf](https://regs.health.ny.gov/sites/default/files/pdf/recently_adopted_regulations/Personal%20Care%20Services%20and%20Consumer%20Directed%20Personal%20Assistance%20Program.pdf) at p. 186.

CDPAP services, however, are services under the State Medicaid plan, which, under federal law, must be available to *every Medicaid recipient*, including those who are in a waiver. TBI and OPWDD waiver participants do rely on PCS and CDPAP for core daily needs, supplemented by waiver services like Respite, Residential Habilitation, Day Habilitation, and Community Habilitation.<sup>9</sup>

**EXAMPLE:** Sam, age 22, is autistic. He lives with his parents and receives supplemental waiver services in the OPWDD waiver. However, his main daily care is provided through 84 hours/week of CDPAP services. Since he needs “supervisory” assistance with ADLs, he would be denied CDPAP services under the new restrictions. He could be forced into an institution without these services.

Similarly, the State’s online example of a “Level of Care” report shows a hypothetical consumer who, though eligible for long-term care based on a high Nursing Facility Level of Care (NFLOC) score,<sup>10</sup> would be *denied* PCS or CDPAP because she needs physical assistance only with two ADLs – dressing and eating -- and “only” supervision with all other ADLs. Like Sam, she is at risk of being forced into an institution without home care.

## **2. The 2020 Amendment Would END the “Housekeeping” Program – a Cost-Effective Preventive Service that Keep People Safe in Their Homes**

The ADL thresholds enacted in 2020 will, once implemented, eliminate the NYS “Housekeeping” program that has for decades helped consumers who can dress and bathe themselves, but who, because of disability, cannot do laundry, shop, prepare meals, or clean their homes. Also known as “Level 1” personal care, this program is limited to eight hours per week for “individuals whose needs are limited to nutritional and environmental support functions.” SSL § 365-a, subd. 2(e)(iv). Because these household tasks are “Instrumental ADLs” (IADLs) and not ADLs, they do not count toward the new minimum of TWO or THREE ADLs needed to qualify for PCS or CDPAP. Those individuals denied MLTC enrollment will be denied even this minimal service of 8 hours/week, putting them at risk of falls or other accidents that could totally disable them.

The small Housekeeping program is a cost-effective preventive service. In December 2022, only 470 New York City residents were receiving these services – less than 2% of the number enrolled in MLTC plans in NYC.<sup>11</sup> The long wait-lists for the state-funded EISEP program will grow with elimination of this Medicaid program. By investing in just 8 hours per week of this service, Medicaid prevents accidents, hospital stays and nursing home placement, or costly 24/7 home care that costs much more.

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<sup>9</sup> 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 (HRA in New York City). Either way, the discriminatory minimum ADL criteria would deny them PCS or CDPAP services. Presently they are excluded from enrolling in MLTC plans

<sup>10</sup> Level of Care score available on the UAS-NY Reporting webpage [https://www.health.ny.gov/health\\_care/medicaid/redesign/uniform\\_assessment\\_system/docs/level\\_of\\_care.pdf](https://www.health.ny.gov/health_care/medicaid/redesign/uniform_assessment_system/docs/level_of_care.pdf), on [https://www.health.ny.gov/health\\_care/medicaid/redesign/uniform\\_assessment\\_system/archives/uasny\\_reporting02.htm](https://www.health.ny.gov/health_care/medicaid/redesign/uniform_assessment_system/archives/uasny_reporting02.htm).

<sup>11</sup> See HRA Facts, January 2023, at page 2, available at [https://www1.nyc.gov/assets/hra/downloads/pdf/facts/hra\\_facts/2023/hra\\_facts\\_2023\\_01.pdf](https://www1.nyc.gov/assets/hra/downloads/pdf/facts/hra_facts/2023/hra_facts_2023_01.pdf); see other months at <https://www1.nyc.gov/site/hra/about/facts.page#caseloads>.

Moreover, the New York Independent Assessor (NYIA), another Medicaid Redesign Team II change enacted in 2020 and was rolled out starting May 2022 has increased the need for stand-alone Housekeeping services. NYLAG and other advocates observe that NYIA is denying MLTC enrollment and PCS services at a higher rate than before, increasing the need for stand-alone Housekeeping services.

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 the entire Housekeeping program. Repeal of the FY 20-21 ADL thresholds changes would ensure continuation of this important preventative service.

**FOR MORE INFORMATION CONTACT**

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