MEMORANDUM IN OPPOSITION

Gov. Hochul 30-Day Amendments to FY 2025 Budget – HMH New Part H

Proposed Restrictions on Eligibility for CDPAP (rev. 2/27/24)

The New York Legal Assistance Group (NYLAG) opposes 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. Our free legal services include representation of older persons and children and adults with serious illness or disabilities in retaining Medicaid eligibility and accessing Medicaid home care in order to live safely in their homes and avoid institutionalization.

NYLAG strongly opposes the proposal added in the 30-day Amendments that would harshly restrict access to the Consumer-Directed Personal Assistance Program (CDPAP).

I. Ban on Allowing a Designated Representative (DR) To Direct CDPAP

It is a myth that requiring consumers to be self-directing would return the program to its original intent. The original state law establishing CDPAP in 1995 allowed for designated representatives. Soc. Serv. L. 365-f, 1995, added L. 1995, c. 81, § 77. That 1995 law, building on the 1992 amendments to the Nurse Practice Act, was the culmination of over a decade of hard work by the disability community, which started a small NYC-only CDPAP project around 1980. They fought for the 1995 law that included those who "had a designated relative or other adult who is able and willing to assist in making informed choices."

1. **With the severe home care workforce shortage, especially upstate, MLTC plans push members into CDPAP** because they simply cannot staff the cases with traditional personal care. It is nearly impossible to staff 24-hour live-in care – and low hour cases as well -- without using CDPAP, even in rural Westchester and Putnam counties, let alone farther upstate. If family cannot serve as Designated Representative (DR) for a person with dementia or other disabilities, these consumers will be left with *no care*. Many will be forced into nursing homes.

2. **CDPAP aides may perform skilled tasks, avoiding use of costly Private Duty Nursing and Nursing Homes.** Since 1992, when the disability community scored a victory in amending the Nurse Practice Act, CDPAP aides have been able to perform tasks that otherwise only a nurse can be paid to do. NY Education Law § 6908, subd. 1(a)(iii). Thousands of consumers young and old have been able to remain safe at home, with CDPAP aides providing skilled care like NYLAG's clients who need a trusted person to serve as their Designated Representative (DR):

- Sam, age 31, has Lennox-Gastaut syndrome, a severe form of epilepsy, with chronic obstructive pulmonary disease and other impairments. He is nonverbal and non-ambulatory, but can be fed pureed foods, which he enjoys. He lives with his aging parents who oversee his care. His mother is his 17A guardian and DR. He receives 24 hours/day care split between private duty nursing and CDPAP, performing many skilled tasks round-the clock - suctioning, frequent seizure interventions, administration of medications, nebulizer treatments, oxygen, enemas, chest physical therapy, and pulse readings. They also assist with activities of daily

living (ADL) -- incontinence care, dressing, transfers, feeding, and mobility in a wheelchair. Without CDPAP, his MLTC plan must approve a second 12-hour shift of private duty nursing – which is expensive and difficult to staff with the nursing shortage. He would lose trusted longtime CDPAP aides who know how to assist with his complex conditions – or be forced into a nursing home without the loving support of his parents.

- Olga has advanced dementia and depends on a CDPAP aide 12 hours/day while her daughter, who cares for her at night and is her DR, is at work. In addition to assisting with ADLs all day, the aide administers medications, which a traditional personal care aide may not do. Despite her dementia, Olga expresses feeling comfortable and safe in her own home and knows and trusts her daughter and longtime aides.
- Under NYS rules, private duty nurses may not help with Instrumental ADLs (IADL) like shopping, meal preparation, laundry, cleaning. Policy Manual §16.2. The plan or State, if fee for service, would have to pay a personal care aide AND a nurse at the same time for those who live alone without family to help. CDPAP aides do it all – saving even more money.

3. Children with severe disabilities depend on CDPAP with their parents serving as unpaid Designated Representatives.

- Anastasia Somoza, with her sister was one of the first children to enroll in CDPAP at age 12. Once she turned 18 she no longer needed a DR, but under the proposed rules she would have been denied CDPAP, making it impossible for her to finish high school. Anastasia went on to college and a successful career - gave a primetime Keynote speech during the 2016 Democratic National Convention, was liaison to the Disability Community for the NYC Council and now is a consultant (https://www.tasspeaks.com/).
- Alex, 9 months old, has hydrocephalus, cancer of the optic nerve, and survived COVID-19. Because both of Alex's parents work and care for Alex's sister, after a series of appeals NYLAG filed, Alex was approved for CDPAP services upon showing that the medical services requested were far beyond "normal parental duties." If his parent cannot serve as his DR, his CDPAP would be cut off, and he would require a private duty nurse since he needs medication administration, care of a shunt and port in his chest, and other tasks beyond the personal care scope. One or both of his parents could be forced to quit their jobs.

4. Denying participation in CDPAP for individuals who lack the mental capacity to "direct" their own care is illegal. As a service provided under NYS's State Medicaid plan, CDPAP must be offered statewide to any Medicaid recipient who meets the eligibility criteria. Under the Americans with Disabilities Act, eligibility criteria may not be used that screen out people based on their disability. 28 C. F. R. 35.130(b)(3)(i). Prohibiting an individual with dementia or an Intellectual/Developmental Disability (IDD) from having a DR would deny them CDPAP based on their disability. Allowing a DR is required as a "reasonable accommodation" of their disability.

5. Limiting access to CDPAP would jeopardize enhanced federal funding of $500 million/year under the Community First Choice Option (CFCO). NYS relies on CDPAP, along with personal care as its primary CFCO services since CMS approved NYS's CFCO proposal in 2015. Since then, NYS has drawn down **$3 billion** in the enhanced Six Percent federal match. CFCO services must include supervision, and/or cueing with ADLs, IADLs, and health-related tasks, and must be

available to Medicaid recipients who needs a nursing home level of care without regard to the type, nature or severity of disability. 42 U.S.C. 1396n(k)(3)(B). Since anyone who needs supervision and cueing with ADLs likely needs a DR, banning DR's would illegally deny CFCO services based on the nature of disability. Banning DR's also violates CFCO requirements for Person-Centered planning, which must include a representative of the individual's choosing. 42 C.F.R § 441.540.

6. The MLTC Capitation Model Caused the Growth of CDPAP and Should be Repealed

NYLAG supports the Home Care Savings and Reinvestment Act (S7800/A8470) that would end the perverse incentives that are to blame for rising costs in MLTC. NYS has lacked transparency about data that show the growth in CDPAP as well as MLTC generally is in low-hour cases; MLTC plans reward both personal care agencies (LHCSA) and CDPAP Fiscal Intermediaries (FI) with better rates as a reward for recruiting members who need low hours of home care. The MLTC plans profit from those cases – more than 90% of all MLTC cases – because they receive the same monthly premium from the State for each member. Removing the incentive caused by this "capitation model" would likely reduce growth in CDPAP. The State would save money because it would only pay the cost of the few hours of CDPAP care provided in most cases, instead of the high premium.

II. Consumer Protections Must be Enacted if Designated Representatives are Banned

While NYLAG believes that limiting CDPAP to those who can direct their own care would be illegal, if the ban on DR's is enacted, consumer protections are vital. The proposed effective date of the ban on DR's is Oct. 1, 2024 (§§ 14 and 18 of part HH). This date is unrealistic, as the law should require DOH to develop and implement, with stakeholder input, procedures to minimize disruption of care, which would take longer. *Emergency regulations with no public input should NOT be allowed* (§7 of part HH). Procedures must include but are not limited to:

- **Every consumer must be assessed by the plan or local district to determine if the CDPAP aide is performing skilled tasks** beyond the scope of a personal care aide. If so, the plan must authorize private duty nursing services for the same schedule provided in CDPAP. If the plan determines that the aide is not performing any skilled tasks and that services could be provided by a personal care aide, or that a nurse could perform the skilled tasks in a shorter shift, the plan must give **advance written notice of the discontinuance of CDPAP** and the change to personal care and/or private duty nursing. The consumer must have the opportunity to appeal and receive continued CDPAP as "aid continuing" in the meantime.
- **Local districts do not authorize private duty nursing, so DOH must establish a procedure for districts to transfer all CDPAP cases where the aide is providing skilled tasks to the DOH Office that authorizes private duty nursing** to authorize services. The local district must continue CDPAP services until the DOH office has either authorized nursing services or, if DOH decides personal care services would be adequate, then the local district must send advance written notice of discontinuance of CDPAP services to be replaced by personal care services, with the opportunity to appeal with Aid Continuing.
- **CDPAP should not be terminated until the plan or local district have secured adequate staffing of the required personal care or private duty nurses – and until the aides have had time and opportunity to do required training.** Even where a shift from CDPAP to private duty nursing or personal care is not disputed, written notice must be provided to the consumer and

the DR of the proposed home care or nursing agency confirming adequate staffing is available, with appeal rights if the consumer cannot verify staffing.

- **Continuity of care when FI's close** -- whether FI's close because of the new contracting requirements or under the proposal to limit the number of FIs in a plan or a county (§2) -- protections are needed to ensure continuity of care. Current law only requires the closing FI to give 45 day advance to the consumer with a list of other FI's. SSL §365-f (a)(4-d)(i). It cannot be left up to the consumer to shop around for an FI – they should be given the opportunity to choose one but, if they do not choose by a deadline, they should be assigned. Also, adequate time must be given for aides to go through the paperwork required in the new FI.

III. NYLAG Opposes Mandated Training and Maximum Limits on Hours Worked

NYLAG opposes state-mandated training for CDPAP aides (§7). A hallmark of CDPAP has always been that the consumer or their DR - not an agency or the state - is responsible for recruiting, hiring, training, supervising, and terminating their own staff. This has worked for over 40 years and was the impetus for reforming the Nurse Practice Act in 1992. The DR's ability to train the aides is reviewed by the local Medicaid office or plan as a condition of approving CDPAP. The bill would prevent an aide from working until they have completed a state-mandated training course, removing a core pillar of consumer responsibility and likely to cause a delay in services. Many CDPAP aides perform skilled nursing tasks (see example of Sam on page 1), for which no aide training program exists.

NYLAG opposes setting maximum daily and weekly limits on the hours PAs can work (§ 7, 13). The federal and state overtime limits already impose a practical limit on hours, as many FI's do not allow overtime. Some consumers want or need aides to work overtime, and if the CDPAP FI approves it this should be left to the consumer and the FI. The proposal would authorize DOH to issue emergency regulations – with no public comment – to limit how many hours the aide can work each day and each week, taking more control away from the consumer – and threatening an even more dire workforce shortage.

NYLAG questions the ban on agencies offering home care and CDPAP (§8, 11). Some consumers want or need to combine CDPAP and traditional personal care because of the staffing shortage. This is easier to manage when these two services are managed within the same agency.

NYLAG SUPPORTS the ban on insurance companies operating CDPAP and home care agencies (§3-a). This is a clear conflict of interest and eliminating the practice is a good idea.

For more information:

Valerie J. Bogart, Of Counsel
Rebecca Wallach, Director
Evelyn Frank Legal Resources Program -- New York Legal Assistance Group
100 Pearl Street, 19th Floor New York, NY 10004
tel 212.613.5047 fax 212.714.7450
vbogart@nylag.org rwallach@nylag.org