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November 15, 2010

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RE: Joint Comments on Notice of Proposed Rulemaking – Consumer Directed Personal Assistance Program [CDPAP], 10 NYCRR 505.28

Dear Sir or Madam,

The undersigned organizations and individuals submit these comments in response to the Notice of Proposed Rulemaking dated September 29, 2010. Our comments address the following issues:

1. Support of expansion of family members who may be CDPAP attendants
2. The Eligibility Requirement that a CDPAP Consumer Must Have a Stable Medical Condition Violates the Objectives of the CDPAP Statute and is Bad Policy.
3. Determination of Whether CDPAP Can Reasonably be Expected to Maintain Health & Safety Must Take into Account Other Available Service
4. Task Based Assessment Must be Prohibited for Consumers Determined to Have 24-Hour Needs
5. Continuous 24-hour Assistance should not be limited to people who need "total assistance"
6. Maintain Consumer's Flexibility over Scheduling Authorized Hours
7. Mandate Timely Processing of CDPAP Applications
8. More Due Process Protections Needed in Reauthorization Process
9. Incorporate Past Guidance Permitting CDPAP Attendants to Drive CDPAP Consumers
10. Mandate Notice of Availability of CDPAP

1. SUPPORT OF EXPANSION OF FAMILY MEMBERS

We support the expansion of the persons who may be hired as the consumer directed personal assistant [hereinafter "CDPAP assistant"] to include any adult relative of the consumer other than the spouse, parent, or person acting as the consumer's designated representative, who does not reside with the consumer or who resides with the consumer because the amount of care the consumer requires makes such relative's presence necessary. This expansion is consistent with the federal regulation that permits State Medicaid programs to expand the range of family members beyond those currently permitted by New York in the personal care program.[1] We applaud this expansion as critical to expanding access to this program, particularly in areas of the state in which there is a critical shortage of potential aides.

2. The Eligibility Requirement that a CDPAP Consumer Must Have a Stable Medical Condition Violates the Objectives of the CDPAP Statute and is Bad Policy.

Section (c) of the proposed regulation includes as an eligibility requirement that the participant must "have a stable medical condition," which, if adopted, would be defined, in section (b)(12) as "…a condition that is not expected to exhibit sudden deterioration or improvement and does not require frequent medical or nursing intervention to determine changes in the consumer's plan of care." This proposed eligibility criterion is not a requirement specified in the state statute, is not "necessary to effectively implement the objectives of…" the statute, contravenes the objectives of state law,[2] and past policy of the Commissioner and is therefore beyond the authority of the Commissioner to promulgate. Soc. Serv. L.§ 365-f, subd. 2(d). .

The proposed requirement of a "stable medical condition" and its definition are imported from the regulation on personal care services under section 18 NYCRR § 505.14(a)(4)(i). Medical stability is undisputedly a condition of the personal care program. However, CDPAP is available not only to a person eligible for the personal care program but also to a person who:

> "…is eligible for long term care and services provided by a certified home health agency, long term home health care program or AIDS home care . . ***or*** is eligible for personal care services… " and has been determined to be "…in need of home care services or private duty nursing…:

Soc. Serv. L. 365-f, subd. 2(a) and 2(c)(emphasis added). The fact that CDPAP is available to people eligible for a broad array of Medicaid home care services other than personal care makes it improper to impose on CDPAP the eligibility criterion of medical stability, which applies to personal care but not to services provided by a certified home health agency [CHHA], long term home health care program, AIDS home care program, or private duty nursing service.

The traditional personal care program requires applicants to have a stable medical condition because (1) the aides have a more limited scope of tasks than home health aides or nurses,[3] and (2) the structure of the personal care program does not subject the consumer and the aides to the

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[1] 42 CFR § 440.167

[2] The proposed restriction undercuts the objectives of both Soc. Serv. L. 365-f and N.Y. Education Law § 6908(1)(a), which authorize CDPAP aides to perform tasks that other home care aides are not permitted to perform.

[3] *Compare* NYS Dept. of Social Services, *Level I and Level II Personal Care Functions and Tasks Scope of Practice*, amended Dec. 1, 1994 (posted at http://wnylc.com/health/afile/7/46/) with NYS Dep't. of Health, *Home Health Aide Scope of Tasks*, April 2006

frequent direct supervision and oversight of nurses required by CHHAs. In the personal care program, a nurse is required to visit as little as once every six months for self-directing clients with no changes expected in their services, or every 90 days for everyone else, with rare exceptions 18 NYCRR 505.14(f)(3)(vi). Federal rules require a CHHA nurse, in contrast, to make an in-home visit to supervise the home health aides at least every two weeks if the consumer is receiving any skilled nursing services, or every 60 days if no skilled nursing is being provided. 42 CFR § 484.36(d). For that reason, CHHA services, unlike personal care, do not have as an eligibility requirement that the recipient have a "stable" medical condition. The same is true for the AIDS home care program and various long term home health care programs. Imposing a "medical stability" requirement violates the explicit eligibility criteria under 365-f, subd. (2)(a), by essentially limiting the pool of eligible individuals to those who are eligible for the personal care program.

By proposing that a "stable medical condition" be a requirement for CDPAP, DOH is unjustifiably retracting well-reasoned past official guidance. DOH has repeatedly affirmed the unique aspects of the CDPAP program that vest in the consumer, or in his or her "self-directing" other, the responsibility for training CDPAP aides to perform skilled tasks otherwise not performable by personal care or home health aides, and for supervising the aides. In a 2008 directive, DOH firmly rejected a policy that would have required a CDPAP assistant to perform skilled tasks only in the physical presence of a supervising nurse or of the "self-directing other/surrogate" who directs care for a non-self-directing consumer.[4] This guidance reinforced the policy that in CDPAP, the consumer, or, if s/he is not self-directing, her self-directing other, is responsible for training and supervising the aide. It is the duty of the local district to determine, in the assessment process, the ability of the consumer or her self-directing "other" to do this training and supervision. Once that assessment has been made, the premise of consumer direction is that the consumer or her self-directing other is responsible for making decisions about her health care, including decisions arising from changes in an unstable medical condition.

Significantly, the 2008 guidance was issued as part of a federal court settlement.[5] The language of GIS 08-OLTC-005 was agreed to *verbatim* and included as an Exhibit as part of that settlement. In its discussion of the type of supervision provided by a self-directing other for a consumer who is not self-directing, the GIS implicitly acknowledges that CDPAP assistants may render services for consumers with unstable medical conditions, and that consumers with unstable medical conditions may receive CDPAP services. The GIS laudably recognized, "The method [of supervision and direction] that is appropriate depends upon the *circumstances of each individual case* and is determined by the assessor through discussion with the self directing other during the assessment process." Id. The guidance continues, "Factors that should be considered include the following:

- whether, based on the consumer's diagnoses, the complexity of the consumer's medical condition, and the specific personal care aide, home health aide or nursing tasks included on the care plan, **it is reasonably anticipated that frequent medical or nursing judgment or intervention may be needed to preserve the consumer's health and safety;**

[4] GIS 08-OLTC-005, "Consumer Directed Personal Assistance Program: Clarification of 06 OMM/LCM-1, "Questions and Answers Related to Administration of the CDPAP"

[5] *Leon v. Daines*, Civ. No. CV-07-1784 (E.D.N.Y.)(Stipulation of Settlement, dated June 12, 2008)

- whether, and the extent to which, the consumer, due to age, or physical or mental capacity, is able to communicate his or her needs to the personal assistant;

- whether the "self-directing other" or surrogate who has trained the personal assistant may be able to adequately supervise and direct the assistant from a remote site by telephone or other electronic means; and?

Id. at p. 4 (emphasis added). Significantly, the highlighted language that requires assessment of whether "…it is reasonably anticipated that frequent medical or nursing judgment or intervention may be needed to preserve the consumer's health and safety;" essentially incorporates the proposed definition of "unstable medical condition," the same definition imported from the personal care program.

The GIS also implicitly acknowledges that a CDPAP consumer's medical condition may be unstable where it states that the supervision may range from on-site supervision to

> …supervision and direction of the personal assistant from a remote site via telephone or other electronic means; or development of an appropriate emergency protocol for the personal assistant to follow *should an unexpected change occur in the consumer's medical, mental or environmental condition*.

GIS 08-OLTC-005 p. 4. Thus DOH recognized that establishment of a protocol for the CDPAP assistant to follow to respond to changes in medical condition is an appropriate part of the self-direction by the consumer or her self-directing other. For example, an individuals who have brittle diabetes can be and are safely served by CDPAP. Their glucose levels fluctuate frequently, and a protocol can be developed for the CDPAP assistant to measure the levels and adjust the insulin levels appropriately.

Another prior DOH policy directive implicitly recognizes that CDPAP consumers may have unstable medical conditions. In 06 OMM/LCM-22, *Second Round of Questions and Answers Related to the Administration of the CDPAP*, Nov. 2, 2006, at p. 3, Question 6 poses the following Question and Answer:

> Q. May a consumer with an uncontrollable seizure disorder, but no other medical needs, receive CDPAP in case the consumer has a seizure, so the personal assistant could take care of the consumer's baby?
>
> A. No. The CDPAP may not be authorized so that a CDPAP personal assistant may care for the consumer's child or other family member. The CDPAP authorization and plan of care are solely for the benefit of the CDPAP participant, not for the benefit of other family members, including children. Services to such family members may be provided through another family member, other informal support or through Title XX.

The consumer with an "uncontrollable seizure disorder" clearly has an unstable medical condition. The Q & A only clarifies that a CDPAP assistant may not assist a consumer's child in the event of a seizure. It is implicit that the CDPAP assistant may assist the consumer -- again, if, following the procedures in GIS 08-OLTC-005, the consumer or her self-directing other have been properly assessed for their ability to train and supervise the CDPAP assistant.

The enabling CDPAP statute does authorize the Commissioner to establish other eligibility criteria "…which are necessary to effectively implement the objectives of this section." Soc. Serv. L. § 365-f, subd. 2(d). Other than the two criteria listed above -- that the individual be eligible for one of a list of home care service programs, that the individual be in need of home care or private duty nursing, the only other eligibility criteria in the state statute are that the individual be eligible for Medicaid and "…be able and willing to make informed choices, or . . .has designated another adult to assist in making informed choices." *Id*. The criterion of medical stability is clearly not required by the statute, is not necessary to effectively implement the objectives of the statute, and conflicts with the language and intent of the CDPAP statute, the settlement in *Leon v. Daines*, and the Education Act exemption allowing CDPAP aides to perform tasks otherwise limited to licensed nurses.

If the goal behind including a medical stability requirement is to protect the consumers' health and safety, it is a misguided means of implementing that goal. Consumers and family members are highly motivated to protect the health of the consumer. Accordingly, they are vigilant in their training and monitoring of the care provided by the CDPAP aides. Many consumers would have to apply for costly private duty nursing services, an outcome not in the State's fiscal interests.

The regulation should incorporate the case-by-case evaluation of the factors enumerated in GIS 08-OLTC-005 as part of the assessment required by the local district, rather than articulate a black and white rule that a consumer must be medically stable in order to be eligible.

3. Determination of Whether CDPAP Can Reasonably be Expected to Maintain Health & Safety Must Take into Account Other Available Services

The proposed regulation states,

> The district must not authorize consumer directed personal assistance unless it reasonably expects that such assistance can maintain the individual's health and safety in the home or other setting in which consumer directed personal assistance may be provided.

18 NYCRR 505.28(e)(1). We support most aspects of this provision, except to add a phrase as shown in the underlined language that follows:

> The district must not authorize consumer directed personal assistance unless it reasonably expects that such assistance<u>, alone or in combination with other services that may be available through the medical assistance program or other sources,</u> can maintain the individual's health and safety in the home or other setting in which consumer directed personal assistance may be provided.

The reason for this added language is to be consistent with section (e)(6) of the proposed regulation that clarifies:

> (e)(6) Nothing in this subdivision precludes the provision of the consumer directed personal assistance program in combination with other services when a combination of services can appropriately and adequately meet the consumer's needs; provided, however, that no duplication of Medicaid-funded services would result.

This provision codifies earlier DOH policy stating that "It is possible to receive services from both a CHHA and through CDPAP." DOH 06 OMM/LCM-02, *Second Round of Questions and Answers Related to the Administration of the CDPAP,* Nov. 2, 2006, at p. 2, Question 3.

Without adding the proposed phrase to (e)(1), this provision is potentially inconsistent with (e)(6), and could be interpreted to permit a district to deny CDPAP services if the CDPAP alone could not be reasonably expected to maintain the individual's health and safety, even if CDPAP in combination with other available services could reasonably maintain health and safety.

4. Task Based Assessment Must be Prohibited for Consumers Determined to Have 24-Hour Needs

New York City and other districts use task-based assessment to assess the need for CDPAP as well as for personal care services. The proposed regulation describes the nursing assessment for CDPAP as one that includes assessment of the consumer's ability to perform various tasks. Section (d)(e)(ii). The Commissioner should include the same language that has been codified into the personal care regulation, which prohibits local districts from using task-based assessment when the consumer has been determined by the local district or by the State to be in need of 24-hour care or the equivalent by informal caregivers. 18 NYCRR 505.14(b)(5)(v)(d). The personal care regulation further requires that the determination of the need for 24-hour care shall be made without regard to the availability of formal or informal caregivers to assist in the provision of such care. Id.

Past guidance of the Commissioner has stated that these rules about 24-hour needs apply to CDPAP. DOH 06 OMM/LCM-01, *Questions and Answers Related to the Administration of CDPAP,* June 30, 2006, Question No. 2. This rule, which originally stems from settlement in *Mayer v. Wing,* should be incorporated into the CDPAP regulation.

5. Continuous 24-hour Assistance should not be limited to people who need "total assistance"

The proposed regulations import from the personal care regulations an antiquated policy that limits continuous 24-hour CDPAP assistance to persons who need continuous, uninterrupted "total assistance" with the basic activities of toileting, walking, transferring or feeding. Proposed section (b)(4). "Total assistance" is defined to mean that a task "… is performed or completed for the consumer," as opposed to "some assistance, in which the task "…is performed or completed by the consumer with help from another individual."

The determinative factor should be whether the consumer can perform the task alone, without any help. If not, whether the type of help is verbal guidance through cueing and prompting, like that needed by a person with a dementia, or hands-on assistance, the determinative factor is that the person needs assistance. The amount of assistance depends on factors such as the frequency needed and availability of other care providers.

The federal Medicaid agency, CMS, in its State Medicaid Manual, which mandates federal policy for all Medicaid programs, provides,

> Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cuing so that the person performs the task by him/her self. Such

> assistance most often relates to performance of ADLs and IADLs. ADLs include eating, bathing, dressing, toileting, transferring, and maintaining continence. IADLs capture more complex life activities and include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.

Center for Medicare & Medicaid Services, *State Medicaid Manual*, Pub. No. 45, Chapter 4, Section 4480 (C) Scope of Services.

Protocols for ADL assessment used for purposes of rehabilitation needs acknowledge that the need for "some" assistance with an ADL must be considered. For example, one widely used tool, the *Barthel Index of Activities of Daily Living*, states in its definition section:

- The main aim is to establish degree of independence from any help, whatever reason.
- The need for supervision renders the patient not independent.

Barthel Index of Activities of Daily Living, University of Iowa, posted at <http://www.healthcare.uiowa.edu/igec/tools/function/barthelADLs.pdf>.

The proposed definition would preclude 24-hour care for a consumer who needs contact guarding, in which the assistant gives standby assistance to help the consumer stand up, walk, transfer, etc., for guidance and safety to prevent falling. This would conflict with DOH's own policy directive which instructs local districts that they must authorize personal care assistance for:

> …appropriate monitoring of the patient while providing assistance with the performance of a Level II personal care services task, such as transferring, toileting, or walking, to assure the task is being safely completed.

NYS Dept. of Health, NYS DOH GIS 03 MA/003, Jan. 24, 2003.

6. Maintain Consumer's Flexibility over Scheduling Authorized Hours

Section (e)(2) of the proposed regulation provides, "The district may authorize only the hours or frequency of services that the consumer actually requires to maintain his or her health and safety in the home." While the district must determine the number of hours to authorize per week, and may take into account the frequency of need for assistance in making this determination, the consumer should determine the frequency of assistance within any week. This policy would be consistent with past guidance that gives the consumer "…some discretion in scheduling the provision of care within that weekly authorization…." DOH 06 OMM/LCM-02, *Second Round of Questions and Answers Related to the Administration of the CDPAP*, supra, at p. 2, Question 4.

7. Mandate Timely Processing of CDPAP Applications

The proposed regulation provides that the time for the district to conduct the social and nursing assessment should "generally not … exceed 30 calendar days after receiving a completed and signed physician's order," and then that the "…final determination must be made with reasonable promptness, generally not to exceed five business days after receipt of the …

completed social and nursing assessments, except in unusual circumstances." Section (d)(4) and (d)(5). While a total of 30 days may not be unreasonable, this should be a firm requirement and not merely a guideline. The language should be strengthened to require compliance with these deadlines.

Additionally, the regulation should clarify that the local district must initiate the CDPAP assessment process once the Medical Assistance application is filed, and not wait until after it is processed. In earlier guidance, the Commissioner stated that districts may complete an assessment for home care after a Medical Assistance application is filed, even though no services would be authorized until Medical Assistance is approved. DOH 06 OMM/LCM-01, *Questions and Answers Related to the Administration of CDPAP,* June 30, 2006, Question No. 6. Advocates have observed long delays that hurt consumers when local districts wait until after the Medicaid application is approved to initiate the assessment for CDPAP. At a minimum, the regulations should clarify that if the district does not begin the assessment until after the Medical Assistance application is approved, the district may not require the consumer to submit a new physician's order -- as long as it was timely, i.e. that it complied with the 30-day requirement in section (d)(1) when first submitted.

The regulation does not address time limits for processing the CDPAP application itself - such as New York City's HCSP Form M13d. Even if all the assessment forms are completed within the 35 days provided by section (d)(4) and (d)(5), districts then take more time to assess the ability to manage the CDPAP assistants, using equivalents of Form M13d. There are two contexts for delay that should be addressed. First, on an initial application for someone who is not in receipt of personal care, the consumer should be given the option of receiving personal care services as an interim measure, while the district is completing review of the Form M13d or its equivalent, and a time limit for this review must be provided. Second, many consumers who are in receipt of traditional personal care services later develop a skilled need, such as someone with multiple sclerosis or ALS, who now needs a tracheostomy or intermittent catheterization. In New York City, consumers have endured delays of as long as three months while HRA reviews the Form M13d and determines eligibility for CDPAP. During that time, the skilled needs must be provided either by costly CHHA visiting nurses or by family members form whom it is a strain to provide them, given work and family demands. A time limit must be firmly set.

8. More Due Process Protections Needed in Reauthorization Process

Sections (f) of the proposed regulation provides that when, as the result of the reassessment process,

> … the district determines that the consumer is no longer eligible to continue to participate in the consumer directed personal assistance program, the district must send the consumer, and such consumer's designated representative, if any, a timely and adequate notice of the district's intent to discontinue consumer directed personal assistance on forms required by the department.

The regulation is overbroad by allowing outright discontinuance, without distinguishing different situations in which the district should determine eligibility for other services before discontinuing CDPAP services. The procedure will depend in part on the reason that the district finds the consumer no longer eligible to participate in CDPAP.

If the district finds the consumer is no longer able to instruct, supervise and direct the CDPAP assistant to the extent required by the regulation, and has no self-directing other, then the district should be required to determine whether the consumer is eligible for personal care services under section 505.14 of the regulations, since the level of direction required for that service is less extensive than that required for CDPAP. In that event, the district must authorize personal care services, and use the *Mayer* criteria in section 18 NYCRR 505.14(b)(5)(v), before reducing hours from those authorized in CDPAP. The CDPAP services should continue until the personal care services are put into place. The form notice provided by DOH, as described in section (h)(5), should include both a finding that the district has found the consumer no longer eligible for CDPAP because of lack of ability to direct care, or lack of a self-directing other, and whether the district has found the consumer eligible for personal care, and if not, the reason, and if so, the number of hours authorized, with the findings required by *Mayer* if the hours are reduced.

If the district finds that the consumer is not eligible for personal care services because the aide must perform skilled tasks not within the personal care scope of tasks, then CDPAP services should continue while the district makes appropriate direct referrals and until those determinations are made. The services should not terminate simply with an open referral to the consumer to find their own services. For example, the local district should submit the case record to DOH to assess eligibility for private duty nursing services. Alternately, referrals should be made for appropriate home-and-community-based waiver services. The regulations should mandate that CDPAP services continue unchanged until a determination is made for eligibility for these alternate services. A procedure requiring continuation of services until a determination is made on eligibility for other services is required by the principles applied in a long line of case law.[6]

If the reassessment determines that a reduction in CDPAP hours is warranted, then both sections (f) and (h) must ensure compliance with *Mayer v. Wing* and incorporate the same language as in 18 NYCRR 505.14(b)(5)(v), requiring findings of medical improvement or other justification for the reduction.

9. Incorporate Past Guidance Permitting CDPAP Attendants to Drive CDPAP Consumers

The regulation should incorporate the guidance issued as GIS 08 OLTC/007, *Non Medical Transportation in the Consumer Directed Personal Assistance Program*, Dec. 24, 2008. The policy permitting aides to drive consumers could be incorporated into the definition of "personal care services" in section (a)(8) of the regulation, or elsewhere.

This GIS notified all local districts that CDPAP recipients may continue relying on their CDPAP aides for transportation to non-medical destinations, if the personal assistant will be performing tasks included in the consumer's Plan of Care at the destination, the consumer has no family members or friends available and willing to provide the transportation, and the aide and the consumer agree to be fully responsible for any potential liability. (Aide-provided transportation remains prohibited as to those consumer's whose physicians have issued orders or opinions stating that, for health or safety reasons, the aide should not drive in order for the aide to be

[6] *See, e.g. Stenson v Blum*, 476 F. Supp. 1331 (S.D.N.Y. 1979), *affd*. 628 F.2d 1345 (2d Cir. 1980), *cert denied sub nom. Blum v Stenson*, 449 U.S. 885, 101 S.Ct. 239, 66 L.Ed.2d 111 (1980); R*osenberg v The City of New York*, 80 Civ. 6198, Partial Final Judgment and Stipulation of Consent to Partial Final Judgment (S.D.N.Y. December 10, 1981).

immediately available while the consumer is in transport.) Since the inception of CDPAP in New York, consumers participating in the program have routinely relied on their personal assistants for both their medical and non-medical transportation needs. It was widely understood that transportation was among the essential tasks personal assistants were to provide their significantly disabled clients under the statute and regulations governing the program.

The GIS was issued in response to opposition by consumers to a change in local and state policy, no longer allowing personal assistants to provide transportation anywhere. Many severely disabled consumers were suddenly left without any reliable and accessible means of getting to work, school, programs, social activities, shopping and other essential errands, and, in some instances, medical appointments. The policy change extremely disrupted life in one Suffolk County family in which 10 disabled adopted children, all young adults living with their mother, were effectively stranded once their aides could no longer bring them to their outside activities. In order to prevent this disruption from occurring again, this guidance should be codified in the formal regulation.

10. Mandate Notice of Availability of CDPAP

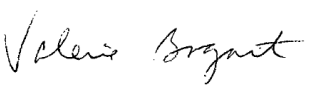
The CDPAP statute mandates,

> All eligible individuals receiving home care shall be provided notice of the availability of the program, and no less frequently than annually thereafter, and shall have the opportunity to apply for participation in the program

Soc. Serv. L. § 365-f, subd. 2. Proposed paragraph (h) of the regulation, states that social services districts have the responsibility of "annually notifying recipients of" the various home care programs "…as appropriate, of the availability of the consumer directed personal assistance program and affording them the opportunity to apply for the program…." The phrase "as appropriate" seems to leave it to the complete discretion of the district whether and how to provide the mandated annual notice. In order to carry out the plain language of the statute, notice of availability of the program and information on how to apply must be mandated on an annual basis, with forms required by the department, to be modified by the district in order to include local information.

Thank you for the opportunity to submit these comments.

Very truly yours,



Valerie J. Bogart
Director, Evelyn Frank Legal Resources Program
Selfhelp Community Services, Inc.

On behalf of Organizations and Individuals Listed On Following Page:

The following organizations and individuals sign on in support of these comments:

Cardozo Bet Tzedek Legal Services
Center for Independence of the Disabled of New York (CIDNY)
Disability Advocates
Empire Justice Center
Independence Care Systems
JASA/Queens Legal Services for the Elderly
Legal Aid Society
Legal Services of Central New York, Inc.
Medicaid Matters NY
New York Association on Independent Living
New York Lawyers for the Public Interest
New York Legal Assistance Group
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