

Consumer Directed Assistance Program Offers Greater Autonomy To Recipients of Home Care

BY VALERIE J. BOGART

For elderly and disabled individuals who are nevertheless able to direct their own care or have someone who can assist them in providing that direction, the state's Consumer Directed Personal Assistance Program (CDPAP) provides an opportunity to obtain government financial assistance while maintaining a level of independence that is not possible when an agency takes the responsibility.

The home care services available from the New York Medicaid program range from skilled private duty nursing services¹ to personal care² or home health aide services³ by paraprofessional aides, to a coordinated plan of combined services through the Long Term Home Health Care Program.⁴ Although these services enable many to avoid placement in a nursing home, in most cases the client and family members have little control over choosing, training or supervising the aides who will assist them – they must accept virtually whomever a contracting home care vendor sends to their home. The CDPAP serves as an alternative, empowering disabled individuals of all ages by allowing them to select their own aides, who may then perform certain skilled tasks that would otherwise require a nurse.

In both CDPAP and the traditional home care programs, once someone has met the financial qualifications for the Medicaid program, the county agency that administers Medicaid assesses the potential client's needs and authorizes the number of hours of care for which Medicaid will pay the salary and benefits of an aide or private duty nurse.

The CDPAP program differs from the other home care programs in two key ways. First, in the traditional home care delivery system, a certified or licensed home care or nursing agency manages the delivery of home care – it hires, trains and schedules the aides. In CDPAP, the consumer or the person directing the individual's care performs these management functions directly – recruiting, hiring, training and scheduling the aide, whose salary is paid by Medicaid. The aides work as independent contractors rather than as employees of a home care vendor agency. A second unique feature of CDPAP

allows aides to perform health care tasks that in the traditional system may be performed only by nurses (either registered nurses or licensed practical nurses) or by certified home health aides.

Background of CDPAP

The consumer-directed movement was born in the late 1970s at the initiative of young people with disabilities who were strongly opposed to home care administrators, nurses and social workers having control of their lives in their homes. Some of these individuals had been institutionalized in facilities for many years before winning the right to live in the community. Although they needed extensive and often sophisticated types of care, such as management of ventilators or suctioning of tracheostomies, they understood their care needs well and wanted to hire and train aides of their choice, instead of having their care controlled by outside nursing agencies.

A core group of these self-directing, disabled people formed an organization called "Concepts of Independence" at a time when the New York City Human Resources Administration (HRA) was changing its service



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delivery system to one based on contracts with non-profit vendor agencies.⁵

In late 1980, after a year of negotiations, Concepts of Independence, Inc. became the first CDPAP program in New York State when it won a contract with HRA to provide consumer-directed home care services for New York City residents who were self-directing and severely disabled. The agency, known as "CONCEPTS," acted as a fiscal conduit for Medicaid payments, and processed payroll and benefits for personal assistants. The consumers were responsible for recruiting, hiring, training and supervising their personal assistants. Initially, the HRA required CONCEPTS to enroll at least 100 consumers by the end of 1980 as a condition of continuation of the contract. By the end of 1980, more than 200 self-directing consumers had enrolled.

Over the next 10 years, CONCEPTS continued to grow in New York City, more than doubling the number of consumers enrolled. Meanwhile, the disability rights movement was advocating for expansion of CDPAP to other parts of the state. In 1991, the New York State Department of Social Services issued a Request for Proposals for what was then called "Patient-Managed Care" demonstration projects. The following year, demonstration projects were started in Utica and Syracuse.

In 1992, with strong advocacy by consumers, a new state law established a Patient-Managed Home Care demonstration program statewide.⁶ In part, that law amended the Nurse Practice Act to allow aides hired through patient-managed care programs to stand in the same shoes as family or household members, friends, or domestic workers, who had long been permitted to perform skilled nursing tasks without being accused of practicing nursing without a license.⁷ Because the 1992 program was not mandatory, however, the goal of expanding CDPAP throughout the state did not happen.

After more extensive lobbying by consumers, in 1995, the Consumer Directed Personal Assistance Program, with its name changed from "patient-managed care," was changed from a demonstration program to a statewide program.⁸ All local districts were mandated to file an implementation plan with the State Department of Health by October 1, 1996, and the department would then provide all persons eligible for the CDPAP program an opportunity to enroll.⁹

Although the 1995 legislation required all counties statewide to create CDPAP programs, not all counties have done so even as of late 2002. More than 30 operating Consumer Directed Personal Assistance agencies cover about 48 of the 62 local districts in the state. New York City's CONCEPTS agency has expanded its consumer enrollment to 1,300 persons, and now serves six counties beyond New York City. In many counties, the local independent living center has won the contract to

provide CDPAP services. A chart listing all CDPAP agencies in New York State, identifying the counties served and providing contact information, appears on page 14. Note that while CDPAP agencies may give information, the consumer does not apply for services with the agency directly; services must first be authorized by the local Medicaid agency.

Regulations have never been promulgated to implement the CDPAP authorizing statute. Between 1992 and 1995, the New York State Department of Social Services issued several Local Commissioner's Memoranda setting forth guidelines for districts developing CDPAP programs.¹⁰ In spring 2002, the Department of Health informally circulated a draft of regulations to be proposed in the future for informal comment.¹¹

Who Is Eligible for CDPAP Services?

An "eligible individual" is defined as a person who:

(a) is eligible for long term care and services provided by a certified home health agency,¹² long term home health care program¹³ or AIDS home care program authorized pursuant to article thirty-six of the public health law,¹⁴ or is eligible for personal care services¹⁵ provided pursuant to this article;

(b) is eligible for medical assistance;

(c) has been determined by the social services district, pursuant to an assessment of the person's appropriateness for the program, conducted with an appropriate long term home health care program, a certified home health agency, or an AIDS home care program or pursuant to the personal care program, as being in need of home care services or private duty nursing¹⁶ and is able and willing or has a legal guardian able and willing to make informed choices, or has designated a relative or other adult who is able and willing to assist in making informed choices, as to the type and quality of services, including but not limited to such services as nursing care, personal care, transportation and respite services; and

(d) meets such other criteria, as may be established by the commissioner, which are necessary to effectively implement the objectives of this section.¹⁷

As shown by this definition, CDPAP enrollment is open to virtually all persons receiving any of the various Medicaid home care services. While the various types of home care services include a continuum of levels of care – from private duty nursing as the most skilled type of care to personal care provided by an unskilled para-professional – CDPAP eliminates the hierarchy of levels of care and any requirement that the aide be certified in any type of home care. A CDPAP aide is permitted to provide the care needed by persons eligible for all of these types of care, from skilled nursing to basic assistance with personal care needs. This change is made possible by the amendment of the Nurse Practice Act

CDPAP Application Process

The steps required to apply for CDPAP services in New York City follow. The procedures vary in other areas of the state, but the pattern is similar.

Where to Apply In New York City, applications for CDPAP services are submitted to the Community Alternative Systems Agency (CASA), which maintains the neighborhood offices of the Home Care Services Program of the New York City Human Resources Administration. The CASA offices administer “personal care” also known as “home attendant” services. Even though CDPAP services are different from traditional personal care services and have some different eligibility criteria, they are authorized by the CASA offices. The CASA addresses and phone numbers are listed at <http://www.nyc.gov/html/hra/html/serv_homecare.html>.

Medicaid Application In New York City, the CASA office can process both the Medicaid application (financial eligibility for Medicaid) and the home care application (functional eligibility for home care services). Thus while potential recipients of assistance must be financially eligible for Medicaid at the time they apply, it is not necessary to have a Medicaid card beforehand. If the client does not already have Medicaid, it will speed up the application process if a completed Medicaid application and documentation are sent to the CASA along with the home care application.

Home Care Application Each local Medicaid district has its own “physician’s order” form on which the client’s treating physician describes the client’s functional and medical impairments and the need for home care services. Filing a completed physician’s order is the first step in applying for personal care services.¹ In New York City, this form is called the “Medical Request for Home Care” or Form M11q, and is filed with the CASA. The Suffolk County form is at <<http://www.co.suffolk.ny.us/Social%20Services/ma241-a.pdf>>.

Because the same form is used for applications for both CDPAP and personal care services, the attorney

should clarify in a cover letter and/or on top of page one of the M11q that the applicant wants CDPAP services, more commonly referred to as “CONCEPTS” in New York City. This is important in cases where the applicant may be ineligible for traditional personal care services because of skilled needs, but is eligible for CDPAP services. For guidance in completing the M11q, see “Q-Tips,” published by the Center for Disability Advocacy Rights at <<http://wnylc.net/web/news/XcNewsPlus.asp?cmd=view&articleid=1323>>.

Approval of Hours After receiving the M11q, the CASA office conducts a series of assessments mandated by state regulation – one by a case manager, one by a nurse and, in some cases, one by a physician. The CASA then determines whether the applicant is eligible for personal care services and, if so, the number of hours per week. If insufficient hours are approved, a fair hearing may be requested. Accepting the hours offered to get services started does not bar the applicant from pursuing more hours at a hearing.

CDPAP Enrollment In New York City, it is only after the CASA authorizes a certain number of hours of services that the Home Care Services Program will determine whether an applicant may enroll in the CDPAP program. The client or the attorney handling the matter asks the CASA worker for a CONCEPTS application, on which the client, or the family member or other person who will direct care, answers questions explaining their plans to recruit, train, schedule and supervise aides in the CDPAP program. They must show the ability to assure aide coverage when the regular aide is on vacation or is sick. Denial of enrollment in CDPAP may be appealed at a fair hearing, but might be resolved informally.

Actual Enrollment Once CDPAP enrollment is approved, HRA notifies the CDPAP contractor CONCEPTS of the number of hours authorized. At that point the client’s chosen aides may go to the CONCEPTS office at 120 Wall St. to process the paperwork necessary for payroll and benefits (including verifying citizenship or legal authorization to work in the United States). CONCEPTS phone: 212-293-9999.

1. 18 N.Y.C.R.R. § 505.14(b)(2)(i).

which allows CDPAP aides to perform tasks that must generally be performed only by licensed nurses.¹⁸ As such, the CDPAP aides are viewed the same as a family member who, although not a nurse, might be trained at a hospital to administer injections or tube feeding for a loved one at home.

The elimination of levels of care in the CDPAP program has the effect of making home care accessible to persons who may otherwise be ineligible. For example, in the traditional personal care program, the client must be able to self-administer medications.¹⁹ Although a personal care aide may assist the client with “self-adminis-

tration” by reminding the patient about the time, identifying the medication and reading the label for the client, bringing the medication and liquids to the patient, opening the container and positioning the patient for administration, the aide may not physically put the pill into the client’s mouth, put eyedrops in the client’s eyes or inject the insulin shot.²⁰ An application for regular personal care services would be denied if the client could not put a pill into her own mouth. The same client, however, would be eligible for CDPAP services provided that she, a guardian, family member or other adult is approved to manage the care.

To be eligible for CDPAP services, individuals in the various specified home care programs must be able and willing to direct and manage their care, or have a legal guardian, relative or other adult able and willing to direct their care. The statute defines this ability to direct as the ability to make “informed choices . . . as to the type and quality of services, including but not limited to such services as nursing care, personal care, transportation and respite services.”²¹ Beyond the ability to make choices, the consumer or his or her guardian or family member must demonstrate to the local Medicaid agency the ability to recruit, select, hire, train and manage the CDPAP aides. For example, the local Medicaid agency such as HRA asks applicants for CDPAP to state, in a questionnaire, how they will ensure continuity of care when the aide is sick, takes a vacation or is unexpectedly absent for any reason. In CDPAP, there is no vendor agency to call in such an emergency, and the consumer must make all such arrangements.

Persons who lack the cognitive ability to manage their own care may have a legal guardian, relative or other adult apply to direct their care.²² This statutory language enables people who have dementia or other psychiatric or cognitive impairments to receive CDPAP services, managed by a family member or other adult. Services are also available to children with disabilities, whose parents or other caretakers are willing and able to assume responsibility to direct their care. When the statute was enacted in 1995, HRA initially did not comply with these provisions, and denied enrollment in CDPAP to persons who had Alzheimer’s disease. Since a fair hearing decision was issued in 1997, reversing a denial of enrollment in one such case where a daughter applied to manage her mother’s care,²³ enrollment has expanded to persons who have dementia or other mental impairments.

Who Can Be Hired as an Aide?

One of the most desirable features of CDPAP is the right to recruit and hire aides of one’s choice, rather than be assigned an aide selected by a home care agency. This feature is highly desirable for persons who have paid

privately for home care and are now switching to the Medicaid home care program, but want to retain the same aides they hired privately.

In addition, people with special language or cultural needs may find aides who speak their language and are familiar with their cultural dietary preferences. Finally, consumers who have skilled needs and are training their aides to perform complex tasks such as the suctioning of tracheostomies or administration of ventilators want the right to select aides they determine are competent to perform these functions, and in whom they have personal confidence.

There are some limitations on who can be hired. First, the aide must either be a U.S. citizen or demonstrate authorization to work legally in the United States. Second, regulations prohibit certain family members from being hired as the aide. There is some conflict between federal and state regulations over which family members are barred. At a minimum, the aide may not be a family member who is “legally responsible” for the consumer.²⁴ This prohibition bars spouses from being paid for caring for one another, and bars parents from being paid to care for their minor-age children. State regulations promulgated prior to the 1997 federal regulations, however, are even more strict. They prohibit *any* member of the client’s immediate family, defined as a spouse, parent, child, son-in-law or daughter-in-law, from being paid as the aide.²⁵

The state regulation allows other relatives to become the aide if they do not reside in the client’s home, or if they must reside in the home only because of the high amount of care needed.²⁶ Thus, under federal regulations, but not state regulations, adult children of elderly consumers and parents of disabled *adult* children could become the paid CDPAP aide. The discrepancy in these regulations has not been litigated.

How Does CDPAP Work?

Because most local Departments of Social Services (LDSS) do not comply with the requirement that they inform every Medicaid-eligible consumer receiving home care services about the availability of CDPAP, consumers and their advocates generally must learn independently about the program and then apply for services through the LDSS.

Although recipients have a right to enroll in CDPAP if eligible, it is important to remember that Medicaid home care services are subject to a prior authorization process. This means that eligibility for services and the number of hours of services to be provided each week must be approved by the LDSS. The CDPAP agency has no authority to increase hours of weekly care beyond what is approved by the LDSS.

New York counties differ on how they approve individuals for the CDPAP program, and how they determine the number of hours of care to authorize. In New York City, the HRA Home Care Services Program administers CDPAP for all consumers through its personal care (or “home attendant”) program. For someone initially applying for services through HRA, and probably in other districts, it is important to note clearly on the application (the “Medical Request for Home Care” or Form M11q),²⁷ that the individual is applying for CDPAP (commonly known as “CONCEPTS” in New York City) services. This is especially important for those persons who may not otherwise qualify for personal care services because they cannot self-administer medication or because they have other skilled nursing needs.²⁸ Without this notation, the application might be rejected.

After the physician’s order is submitted, the local district is required to conduct a series of assessments to evaluate the individual’s eligibility for home care and the amount of hours to authorize. These include a nurse’s assessment, a social assessment and, in some cases, a referral to the local medical director of the local district.²⁹

Counties vary on how they conduct these assessments, both in their general home care and in their CDPAP programs. In some counties, the nurse’s assessment is conducted by nurses who are employed by or are under contract with the LDSS; in others, the nurse is employed by or under contract with the CDPAP program or other home care vendor. The nurse’s employment may influence his or her orientation and recommendation for services. After conducting all these assessments, the LDSS determines whether to approve services and, if so, the number of hours to authorize. Whether the applicant seeks CDPAP services or traditional home care services, that determination can be appealed through a fair hearing.

After an applicant who has requested CDPAP services has been approved for basic home care coverage, a separate determination must be made by the LDSS regarding the person’s ability to assume responsibility for managing his or her own care, or the ability of a family member or other adult to do so. Local districts vary in the way they made this determination. In New York City, the consumers or those directing their care must complete a questionnaire explaining their ability to direct care, and an administrator in the HRA Home Care Services Program evaluates the responses to the questionnaire and approves or denies care. A denial of eligibility for CDPAP services is appealable in a fair hearing.

Once approved for CDPAP, the consumer is referred to the local CDPAP contractor agency. A list of these agencies is in the Appendix at the end of this article. The

CDPAP contractors vary in the extent of guidance and supportive services they provide to consumers in helping them to recruit and train aides and manage their services. Some CDPAP agencies administer payroll and benefits directly; others contract with outside payroll agencies. The CDPAP agency generally requires the consumer and/or person directing care to sign a contract agreeing to perform various duties.³⁰ These include:

- Managing the services of the persons they employ – recruiting, hiring, training, scheduling, assigning tasks, firing.
- Processing and supervising required paperwork including time sheets, annual employee health assessments or medical examinations, and all required employment documents including but not limited to the W-4a and IT-2104 forms, employment/wage agreement, and enrollment eligibility verification (I-9).
- Scheduling and arranging for vacation and holiday coverage.
- Developing an emergency backup system in the event substitute employees are needed to replace permanent employees.
- Distributing paychecks to each worker under the consumer’s employ.
- Informing the program of changes in their personal status that may include but are not limited to hospitalization, changes in phone number and/or address, etc.
- Informing the program of changes in the status of the persons they employ, including changes in schedules, numbers of tax exemptions and terminations.
- Scheduling visits with a registered nurse once every six months for the required nursing assessment.³¹
- Agreeing that the CDPAP agency is not liable for the fulfillment of the responsibilities agreed to be undertaken by the consumer.

In its contract with the consumer, the CDPAP program generally agrees to:

- Process the home care employee payroll.
- Monitor the completion of annual employee medical forms and all required medical documents.
- Act as the employer-of-record for insurance, unemployment and workers’ compensation benefits.
- Coordinate annual leave, health insurance, unemployment and other benefits.
- Monitor the completion of the required nursing assessment forms and the consumer agreement outlining obligations and responsibilities.
- Maintain a personnel record for each CDPA including, at a minimum, copies of the enrollment forms, annual health assessments and the information needed for processing the payroll and administering benefits.

- Engage in ongoing monitoring of activities that include periodic contacts with the consumer, and reviews of the six-month nursing assessment.

- Provide appropriate notification pertaining to any intention to transfer or terminate the consumer from the program.

In the absence of state regulation, some of the local CDPAP providers and local districts have adopted policies and procedures that subvert some of the purposes of consumer-directed assistance. For example, the Columbia County CDPAP program had refused to approve aides selected by the parent directing care of their disabled child, on the ground that the aide had not provided three job references to the CDPAP program. In a fair hearing decision, the state held that once an individual was accepted into the CDPAP program, the CDPAP contractor could not impose restrictions on the consumer's selection of aides.³²

In another case, a county had threatened to terminate CDPAP services because the consumers were receiving visiting nurse services through a certified home health agency (CHHA) in addition to the CDPAP services. The county was interpreting federal Medicaid regulations to prohibit the provision of CHHA nursing services concurrently with CDPAP aide services. The matter was resolved through negotiations among the State Department of Health, the local district and consumer advocates. It was clarified that although a consumer might train a CDPAP aide to perform certain skilled nursing tasks, the consumer might nevertheless have a need for a registered nurse or licensed practical nurse to perform other assessments or tasks, which might require more complex or sophisticated clinical expertise or judgment.

Conclusion

The Consumer Directed Personal Assistance Program is one of the innovations that places New York State in the vanguard for providing consumer-oriented services that enable individuals with disabilities to live at home with independence and autonomy. Advocates for elderly or disabled clients should keep in mind CDPAP as an option for their clients, because it allows them more flexibility and access to vital home care services.

Advocates whose clients live in counties that have not complied with the statutory mandate to establish a CDPAP program are encouraged to join with their local independent living center and advocate with the state and local district to secure access to this vital program.

1. N.Y. Social Services Law § 365-a(2)(a) (SSL).
2. SSL §§ 365-a(2)(e), 367-p, 365-f(2)(e); 18 N.Y.C.R.R. § 505.14.

3. SSL § 365-a(2)(d); 18 N.Y.C.R.R. § 505.23; 10 N.Y.C.R.R. § 763.5.
4. SSL §§ 366(6), 367-c; 18 N.Y.C.R.R. § 505.21.
5. See Web sites of Concepts of Independence, Inc. <<http://www.CONCEPTScdpap.org>> and the Consumer Directed Personal Assistance Association of New York State <<http://www.cdpaanys.org>>.
6. L. 1992 Ch. 795, eff. Dec. 1, 1992.
7. Compare N.Y. Education Law § 6908(1)(a)(iii) (enacted L. 1992 Ch. 795) (Educ. Law), with Educ. Law § 6908(1)(a)(i).
8. SSL §§ 365-f, 367-p(c) (L. 1995 Ch. 81).
9. *Id.*
10. New York State Dep't of Social Services, Local Commissioners' Memorandum No. 93 LCM-113, dated Sept. 1, 1993 reissued and updated as Number 94-LCM-3, dated January 12, 1994 regarding Patient-Managed Home Care 95 LCM 102.
11. Because they were not officially published in the State Register, no citation is available.
12. SSL § 365-a(2)(d); 18 N.Y.C.R.R. § 505.23; 10 N.Y.C.R.R. § 763.5.
13. SSL §§ 366(6), 367-c; 18 N.Y.C.R.R. § 505.21.
14. SSL § 367-e; 18 N.Y.C.R.R. § 505.21(a)(2).
15. SSL §§ 365-a(2), 367-p, 365-f(2)(e); 18 N.Y.C.R.R. § 505.14.
16. SSL § 365-a(2)(l).
17. SSL § 365-f(2)(d).
18. Educ. Law § 6908(1)(a)(i), (iii).
19. 18 N.Y.C.R.R. § 505.14(a)(6)(ii)(9).
20. *Id.*
21. SSL § 365-f(2)(c).
22. *Id.*
23. Fair Hearing No. 2553407R, dated January 28, 1997 (available in fair hearing bank at <wnylc.net>) New York Legal Assistance Group, representative.
24. 42 C.F.R. § 440.167 as amended 62 Fed. Reg. 47896 (Sept. 11, 1997, eff. Nov. 10, 1997).
25. 18 N.Y.C.R.R. § 505.14(h)(2).
26. *Id.*
27. The M11q is the form used by New York City HRA as the treating physician's order, which is the first of several assessments used to determine eligibility for home care and the amount of services authorized. 18 N.Y.C.R.R. § 505.14(b)(2)(i), (3)(i). Each county develops its own physician's order form.
28. See *supra* note 13 and accompanying text.
29. 18 N.Y.C.R.R. § 505.14(b)(2).
30. This list is based on information on the Web site of the Consumer Directed Personal Assistance Association of New York State available at <<http://www.cdpaanys.org>>.
31. 18 N.Y.C.R.R. § 505.14(b).
32. Fair Hearing No. 3027026J, dated October 25, 1999 (Columbia Co.) (appellant represented by Nina Keilin, Legal Services for the Elderly, New York City, and Simeon Goldman, Disability Advocates, Albany).

**THE LIST OF PROGRAMS ORIGINALLY PUBLISHED WITH THIS ARTICLE IS
OUTDATED.**

**FOR AN UPDATED LIST OF
CONSUMER DIRECTED PERSONAL ASSISTANCE PROGRAMS
IN NEW YORK STATE --**

PLEASE SEE

<http://onlineresources.wnyc.com/kbbase/afire/40/43/>

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