
Building the Home Care Triangle: Clients and Families, Paraprofessionals And Agencies

by Rick Surpin and Frederick Grumm
With the New York City Home Care Work Group

The New York City Home Care Work Group, initiated a research and planning project designed to draw a profile of the home care system of New York City and formulate specific proposals to address system-wide home care service delivery issues. The resultant report focuses on ways to improve the quality of home care services and means of involving government toward that end.

The New York City Home Care Work Group consists of a broad range of representatives from service agencies, client advocacy groups, labor, and universities. About one year ago, the Work Group initiated a research and planning project designed to draw a profile of the various programs, services, clients, and funding streams within the home care system of New York City; describe the critical perspectives of the major actors in the system; and from these findings, formulate specific proposals to address critical system-wide home care service delivery issues.

The focus of the Work Group's report is on how to increase the quality of care at the point of service delivery, in the home. The group's recom-

mendations address fundamental issues in strengthening the home care triangle of clients and families, paraprofessionals, and agencies.

The report calls for rebuilding the partnership with government by moving toward a more integrated and stable home care system and proposes several specific additional steps that will facilitate movement in that direction.

The research for the report was limited to New York City as the Work Group did not have sufficient staff to do a statewide profile of the system and conduct focus groups throughout the different regions of the state. Further, the consensual process that resulted in the recommendations made would have been impossible to conduct simultaneously throughout the state. Despite this limitation the issues raised and the substance of the recommendations made will be relevant to areas outside New York City.

Profile of Home Care System in New York

In the first half of the 1980s, home care in New York City was one of the fastest growing sectors within the human service system. This profile of the New York City home care system is an update of the four major home care programs—HRA Home Care Services: Home Attendant, Housekeeper, and Homemaker programs; Certified Home Health Agencies (CHHA); the Long Term Home Health Care Program (LTHHCP; also called the Nursing Home Without Walls program); and the

Editor's Note: This article is excerpted from the report of the New York City Home Care Work Group, January 1990. Additional information or copies of the report may be obtained by contacting Rick Surpin or Frederick Grumm at Cooperative Home Care Associates, 349 East Street 149th Street, Bronx, New York 10451; 212/933-7104.



Virtually all clients in the home care system start out with the belief that they need help with personal care and household tasks they can no longer do.

Expanded In-Home Services for the Elderly Program (EISEP)—as they developed into the latter half of the 1980s.

This analysis, based on various government reporting services, indicates that overall growth in home care has stabilized. In addition, we have documented a changing pattern of financing for home care services, and profiled home care clients within the different programs. Key findings are described below.

Service Utilization and Volume

Between 1986 and 1988 the total number of clients served on a daily basis stabilized at about 66,000. HRA home care programs represent 66% of these clients; CHHAs represent 26%; the LTHHCP represents 5%; and EISEP represents 3% of the total daily home care client volume.

Within home care programs, the HRA Home Attendant program stabilized at about 34,000 daily clients; CHHAs decreased by 20% to about 17,000; the LTHHCP increased by 10% to about 3,400 daily clients; and EISEP served about 1,800 clients on a daily basis.

In terms of the number of clients receiving services over the course of a year, CHHAs serve the largest number of annual clients—113,000. This is due to the short duration of stay by CHHA clients; the majority receive continuous service for less than three months. In contrast, the average duration of stay for HRA and LTHHCP clients is one year.

Cost and Financing

In 1988, New York City home care program service costs exceeded \$850 million. Medicaid dollars paid for approximately 85% of this total. Between 1985 and 1988, CHHA Medicare revenues decreased from 53 to 38% of total CHHA home care revenues, while Medicaid dollars increased from 28 to 47% of total CHHA home care revenues.

Paraprofessional Services

Paraprofessional care is the dominant service provided to home care clients. In HRA, paraprofessionals represent about 98% of all service hours; in the LTHHCP, paraprofessionals represent about 98% and in CHHAs paraprofessionals represent about 33% of all visits. HRA home care programs represent over 90% of all home care paraprofessional service hours.

Client Profile

A number of formal and informal client surveys over the last four years confirm the basic finding that among home care programs clients are similar in terms of needs and required services. This does not mean that the needs and services of all clients are the same, but that the diverse range of home care clients is distributed similarly throughout the different home care programs.

The similarity of clients and the increase in severely disabled and special care clients across all programs is a system-wide challenge that requires the industry to critically assess and address the quality-of-care issues for clients, paraprofessionals, and agencies.

A View of the System from the Point Of Service Delivery

The Home Care Work Group conducted a series of approximately fifteen focus groups or small, indepth interviews. The focus groups consisted of 6–10 people from one of the following groups of major actors: older and disabled people who receive services; patient advocates; home care workers; union representatives; and provider agency administrative staff. A facilitator from the Work Group guided the discussions based on structured questionnaires.

A summary of the Work Group's findings is provided below. The summary is separated by the three sides of the home care triangle: clients, workers, and agencies.

Clients

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personal care and household tasks that they can no longer do themselves. Many clients also need assistance with such health-related tasks as monitoring their medical condition, self-administering medication, or using prescribed equipment. They are aware that the city provides an "attendant" to deliver these services, no matter what the actual title of the paraprofessional may be. They also have their own conception of how many hours of service they need, usually a minimum of four hours a day, with more preferred.

Most clients are in clear agreement that what is most important for receiving quality care services is having an aide or attendant who displays the following characteristics:

- Compatible
- Reliable
- Capable of properly doing required tasks such as physical transfer or keeping the house clean
- Willing to do what the client would like to have done, within reasonable limits
- Trustworthy
- Capable of speaking a language they understand
- Patient and caring

When a client has an aide or attendant who meets most of these criteria, she or he wants that individual "to stay forever." Having the same person for a long period of time and developing an effective working relationship is the core of the service. The more physically disabled the client is, the more important this relationship becomes. One client described it as, "Almost like a marriage, it is that kind of intimacy." Another client said, "I had a worker once who always could make me feel good when I was down. She was not like a worker, she was like a friend. She really seemed to care about my needs."

By all accounts, when the paraprofessional in that kind of relationship leaves, it is a devastating experience for the client. Moreover, since the client's physical condition has not improved, she or he has to start all over again. Developing new working relationships is both physically and emotionally taxing, especially for those clients who are physically disabled.

Many clients do not have this kind of relationship. Sometimes, they have workers who do not regularly perform some personal care or household tasks or who are not dependable or who take advantage of them by staying out of the home for long periods of time. In the words of a client: "I have a worker who refuses to push the wheelchair. I would like to know how is it that they are not allowed to push the wheelchair, or is it that they just don't want to do it."

In other cases, the client treats the worker as



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"my girl" or "the housekeeper" and is engaged in a constant struggle to get the home care paraprofessional to maintain the household in exactly the same manner she or he once did. One client said, "I have a problem—you see, I can't keep my house clean. The way I clean it, it looks spotless. I feel, if a person is going to come in, they should try to keep it like that. A house isn't clean unless you clean every corner."

Clients and their advocates universally agree that resolving problems once they arise is difficult. As a client advocate explains, "A lot of times what happens is that a consumer will not complain because they're terrified that the service will be taken away from them. Some people are willing to say, 'I know what I have, and I can somehow live with what I have—getting something new might even be worse.'" Further, as another advocate states, "People do not know what their rights are. They do not know what a home attendant is supposed to do, what they've been told to do, what they're permitted to do."

Clients typically interact with the administra-

tive staff of the agency providing the services only when problems arise. When clients do call they expect respect and cooperation; instead, they often feel that "people in the office seem very unconcerned" and "they act like they don't want to hear what you have to say about anything."

The limited interaction between the agency and the client also extends to the case assignment process. When a paraprofessional is assigned to a new case, often the only information available comes from the patient's file. This makes making the right match between client and paraprofessional very difficult.

As a result, both parties may be quite unprepared for their potential relationship. Many agencies do not call the client to notify him or her that a new paraprofessional has been assigned to the case—the worker just arrives at the door. The client may be physically disabled or mentally impaired and the worker may not have the proper training, sensitivity, and, in some cases, physical strength required.

One wheelchair-bound client recounted the following incident reflecting this problem: "A couple of years ago a young lady in her early 20s came. She was totally unprepared for anything she was walking into and, in fact, she didn't walk into it. I opened the door, she saw me, she blessed me, she turned around and left."

In most instances, the worker does not turn around and leave. Often the paraprofessional and the client negotiate with each other, learn from each other, and make adjustments. These adjustments are rarely made known to anybody else out of fear that they violate some regulation or procedure. Most clients feel that the system is designed for a stereotypical client that is not exactly like them, and that there is little flexibility in responding to their particular needs. Clients who are physically disabled name this lack of flexibility as a major problem more consistently and dramatically than elderly clients. Therefore, when the worker-client match is not particularly good, the client's choice is to either negotiate private adjustments or endure a "silent war" for as long as possible.

Workers

Virtually all workers in the home care system start out with the belief that the home care paraprofessional position represents a good opportunity to help other people and get paid for it. Most paraprofessionals are attracted to the idea of working in the health care system; some see the job as the initial step in realizing their dream of becoming a nurse.

They are aware that there are different job titles, such as home attendant, home health aide, or homemaker-home health aide, and different kinds of agencies, such as home attendant agencies that have "city" contracts, or "private" agencies that mostly work for hospitals, a visiting nurse service, or private patients. Generally, they are attracted to work in a particular agency based on a variety of factors: whether they already know someone there; the style or content of their newspaper advertisement; whether the office is located near their house; whether their employment or public assistance office referred them there; and/or whether they like the "feel" of the office once they apply for a position.

Most paraprofessionals are in clear agreement that what is most important to them is having a job that provides important services and has the following attributes:

- Adequate wages
- Good benefits
- Stability
- Adequate training
- Compatible clients and families
- Good working relationships with clients and families
- Safe and clean working conditions
- Recognition and respect from the client and the agency
- Communication and support from the agency
- Opportunity for upgrading

There is no consensus on what constitutes an adequate wage. However, it is generally described as "a starting wage of \$7-8 an hour" with increased pay for "taking special training" or "putting in overtime" for required duties or having "seniority" on the job. The current starting wage, however, is in the range of \$5-6 an hour. There is typically limited monetary reward for anything beyond the starting wage and a one-step increase for one year of service.

Benefits have become increasingly important. Health insurance, preferably for the entire family, and a pension plan are considered the most desirable benefits. Most workers are now covered by health insurance, although the quality of their plan differs markedly by agency. No agencies are known to have a pension plan.

Most paraprofessionals want full-time, year-round work. They prefer a salary to an hourly wage in order to be relatively free from anxiety about fluctuating income levels. Many workers do not have regular shifts, let alone salaries, and have frequent changes in clients or case hours. When their client goes to the hospital, enters a nursing home, or dies, they must wait for a new assignment,

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sometimes for extended time periods. Some workers are employed in two or three different agencies, typically under different job titles, just to get enough work to bring home a sufficient income.

Many workers serve clients with complex problems. Some clients may be chronically depressed, forgetful, or often agitated; some are physically disabled and require help with their equipment; and some have families living with them who expect to be taken care of as well. Paraprofessionals in these situations want more information about their clients' conditions and training and support to handle their work without constant stress and anxiety. They also want premium pay for taking on the most difficult assignments.

Finding a compatible client is a particularly important issue for virtually all home care paraprofessionals. They thrive on developing a special, one-to-one relationship with a client. It enables them to feel helpful, appreciated, and trusted in their job. Their decision to remain on the job and not seek other work is often a decision to stay with a particular patient.

Even with "good" clients, however, there is a constant struggle to avoid being talked about or treated as "my girl" or "the maid." This struggle reflects deep-seated prejudices about poor and working-class women, especially African-American and Latina women. Since most workers choose this field as a health-related position, it is particularly frustrating for them to be perceived as glorified domestic service workers.

There is considerable stress in daily travel to unfamiliar and often unsafe neighborhoods and buildings. Home care paraprofessionals travel and work for long periods in areas where many home care nurses will not go unescorted. They may also work in apartment buildings and individual homes pervaded by drug use and/or sales, as well as in filthy and unsanitary conditions.

Moreover, they have a sense of virtual total responsibility for a client's health, since they are isolated from other paraprofessional and professional staff, and get limited support or supervision from the agency. The case coordinator, who is generally both case manager and scheduler, is the paraprofessional's first-line supervisor and pri-

mary agency contact. If this person is perceived as fair and competent in scheduling, which means consistently giving the worker "good" cases with sufficient hours, and able to communicate well, the worker will typically like the agency. Many experienced workers also consider a "good" case to be an "easy" one since they are not paid a premium for working on difficult cases.

After some time on the job, many workers develop a minimal expectation for obtaining support in problemsolving from their agency. However, this does not diminish their desire for more information and support.

Finally, many home care workers desire opportunities to learn new skills and for upgrading their position over time. They would like to hope that they "could do something a little different," "make some more money," or "become a nurse" based on good job performance. Instead, they quickly realize that they are

"stuck" after the initial training—there is no ladder to go anyplace else.

"The most important thing in home care is the relationship between the consumer, the worker, and the agency. There's the triangle. Once there's a wrinkle there, you run into difficulty."

—Home care client and advocate for the disabled

Agencies

Virtually all home care agencies in the home care system start out with the belief that they are in the "middle." They exist to serve clients and their families, they are regulated and usually paid by state or city government, and they are faced with increasing pressure from workers and their unions to provide better jobs.

Most agency directors are in clear agreement about what clients and their families want or need:

- Timely case coverage
- Consistent service
- Properly trained and competent paraprofessionals
- Compatible workers who are trustworthy and caring
- Administrative staff who are accessible and responsive to problems

Most agency directors also agree that many clients expect a level of service greater than they can or should provide. They expect timely case coverage "to the minute," and "everybody wants service in the morning." They expect a "girl" to "do laundry for everybody" in the household, to "scrub the floors," and "clean the stove." They expect

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totally uninterrupted service, including on weekends, and longer hours than whatever they already have, with the exception of 24-hour live-in cases. In the agency directors' terms, these are not realistic expectations.

Agency directors also think that state and city regulatory agencies have unrealistic expectations and constantly increasing requirements that are too often unrelated to the delivery of quality home care services. No matter which component of the home care system they represent, agency directors are frustrated by the attitudes of the regulatory agencies. In their terms, such agencies are dominated by cost-containment concerns, bureaucratic control, and a preoccupation with their public image. Too often regulations are issued without any input from the agencies responsible for implementing them. Too often, such regulations result in increased "rigidity," "intrusiveness," paperwork, and monitoring of paperwork requirements. In the view of the agencies, this only serves to increase the cost and the workload without increasing the quality of important services.

Agency directors are confronted with a changing environment, which they think no one else sees:

- Clients who are sicker and families who are more "dysfunctional" than ever before and therefore need more services.
- Consistent staff shortages for nurses, physical therapists, and paraprofessionals for certain kinds of cases—e.g., 24-hour live-in, 2-3 hour, weekends.
- A workforce dissatisfied with the level of pay, benefits, the apparent lack of appreciation, and "escalating dangers" in the neighborhoods in which they work.
- A small administrative staff that lacks training, particularly for supervision, and receives relatively low pay for the required work.
- A nursing staff that is largely unprepared for the role of supporting and supervising home care paraprofessionals and mostly prefers to concentrate on direct patient care.

Recommendations

After listening to the perspectives of clients, workers, and agencies and attempting to develop a comprehensive profile of the current home care system in New York City, the Home Care Work Group is convinced that there is considerable common ground concerning fundamental service delivery issues for the further development of the home care system.

Clients want paraprofessionals who are consistent, reliable, properly trained, capable, and will-



There is common ground concerning home care service delivery issues—clients want "good service" and paraprofessionals want "good jobs."

ing to do the work. Paraprofessionals want an adequate income and benefits, job stability, decent working conditions, and opportunities for advancement. In sum, clients want "good service" and paraprofessionals want "good jobs." Both "good service" and "good jobs" are the required foundation for building a high-quality home care service system.

Agencies represent the vehicle for meeting both client and worker needs. They are in business to serve clients and most consider themselves expert in doing so. Providing "decent," if not "good," jobs has become a prerequisite for providing quality service. High levels of worker turnover make continuity of care impossible and increase recruitment and training costs.

However, provider agencies are not able to give sufficient focus to these issues in the current system. The regulatory agencies define quality standards without provider management or practitioner input. These standards impose organizational and process requirements that have little to do with what happens in the home. Combined with extensive monitoring, they are designed to prevent a scandal and have done so to date. They have also, however, created a system with a major contradiction: while the provision of care ultimately depends on agency performance, regulators communicate their distrust to these agencies every day.

We seem to have unintentionally created a system-centered home care system rather than a client-centered one. Paperwork gets more attention than anything else. For regulators, home care is unfamiliar territory; it is geographically dispersed, out of their sight, and controlled by clients more than institutions. It is extremely difficult to know what is actually going on in the home and, therefore, almost impossible to enforce standards regarding the delivery of direct care. A different approach is required.

Home care primarily concerns the individual client and the paraprofessional in a particular home. The only real assurance of quality care is developing each agency's capacity, to the fullest possible extent, to be able to satisfy the client and his or her family and/or advocate within reasonable expectations with the resources available. Accountability must be focused toward those who use and need the service rather than those who administer it.

In this context, the Home Care Work Group is recommending several systemic changes that enjoy a broad base of support and can be implemented immediately. If adopted, these recommendations will accomplish the following goals:

- Simplify the system for both clients and workers.
- Establish uniform standards across the four major programs.
- Increase entry-level training requirement for most paraprofessionals.
- Provide specialized training and increased pay for paraprofessionals working with complex care clients.
- Increase support and supervision in the home through extensive use of a newly created senior home care aide position.
- Allow for a more client-based agency supervisory structure.
- Provide opportunities for advancement for paraprofessionals.
- Provide the basis for service continuity across subsystems.
- Provide for increased flexibility at the point of service delivery.

Together, these actions represent significant and necessary steps toward creating a home health care system that will consistently provide high-quality services for home care clients.

Uniform Home Care Paraprofessional Title

A new uniform home care paraprofessional title, supported by a standard certification training program, should be established. This new title,

called Home Care Aide, would be a generic title that would incorporate the current titles of home attendant, personal care aide, home health aide, and homemaker.

Senior Home Care Aides

A new position called Senior Home Care Aide should be created in all home care agencies providing paraprofessional services. The Senior Home Care Aide will be a salaried, front-line supervisor. She or he will speak with and observe the paraprofessional, client, and family in the home, and identify issues that enable the aide to more adequately perform her or his duties.

Specialized Training

Home care professionals should receive advanced training for specialized work such as complex care or special needs cases. Completion of this training should be rewarded with a promotion to a Home Care Specialist position with increased compensation. Initially, an additional differential of 15% of the specially trained aide's hourly wage should be paid when the worker is serving a complex care or special need client. This is a transitional step to creating a salaried Home Care Specialist position. The number of complex care and difficult-to-serve clients is increasing throughout the system.

Self-Directing Individuals in the Home Care System

Self-directing individuals of any age in the home care system should be given a wide range of options to facilitate their independence. A self-directing individual is defined as one who is capable of making choices about his or her activities of daily living, understands the impact of the choice, and wishes to assume responsibility for these activities. Each individual should be able to choose from a list of specific services to respond to her or his varied needs. A special amendment to the Nursing Practice Act is also required which would allow paraprofessionals to perform health-related personal care tasks such as suctioning of a stable tracheostomy under the direction and training of a self-directing client.

Uniform Client Complain System

A uniform client complaint system should be established that can be easily reached by clients, and that can be relied on to impartially resolve complaints. At present, each program has a separate complaint procedure. The procedures should be simplified and made uniform across programs.

Rebuilding the Partnership with Government

Today, the role of government in the home health care system may best be characterized as "reluctant financier." While government pays for most of the service, it is extremely nervous about how its money is being spent. For the regulators, home care is a largely unseen, uncontrolled service that takes place in tens of thousands of individual homes rather than traditional health institutions. It therefore invests a tremendous amount of its resources in monitoring and auditing.

The government's role in establishing minimum relevant standards and in monitoring their implementation is essential. However, these standards are too often unrelated to the quality of care in the home. Monitoring also tends to be too one-dimensional. By relying on "surveillance" as the primary tool of oversight, government regulators emphasize recordkeeping requirements over joint problemsolving, rigidity over flexibility in the form of service delivery, and centralized management rather than decentralized decisionmaking within broad parameters. The result is an inefficient system whose direct service agencies are constantly preparing to defend themselves from the

regular visits of distrustful "investors."

The recommendations made in this report are designed to focus on quality care from a client perspective; develop a relatively highly trained workforce to respond to diverse and complex client needs; and provide maximum service capability and flexibility at the point of service delivery. In order to fully accomplish these objectives, government must be willing to rebuild its relationship with the home care triangle—clients and families, paraprofessionals, and agencies. Oversight must be combined with a willingness to recognize the validity of the perspectives of the major actors at the level of service delivery. It must be combined with a respect for professional judgment and agency autonomy and with rewards and incentives that value "good practice" as much as "good paperwork."

At the same time, government's role should be to provide a foundation of coherence, stability, and high-quality service to a fairly fragmented and tumultuous system. The rebuilding process represents the next stage of policy and program innovation. It should initially move in the direction of integrating the system and developing a salaried, permanent workforce.

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Investing in and treating the home care system as a needed partner in the larger health care system now will ensure quality health care in the future.

A View to the Future

Several of the recommendations made in the Work Group's report will save money. The costsavings will come in two basic areas: administrative simplification and reduced staff turnover. The current system has a relatively high administrative cost because of the multiplicity of program eligibility criteria, standards, and recordkeeping requirements. There can be substantial costsavings to the extent that services can be integrated and paperwork reduced. High staff turnover is also costly, particularly in terms of recruitment and training. The recommendations that will lead to a more professionalized, permanent workforce will also significantly reduce staff turnover.

Several of the recommendations will also cost money, probably marginally more than the savings. For too long, home care has been "sold" in the public policy "market" as the low-cost alternative to institutional care. It has been priced so cheaply because the paraprofessional workforce has received low pay and minimal benefits and only minimal investments in training, support, and supervision. Since workers have been viewed as transient the minimal investments seemed justified. However, the results of this policy are now clear: continuity of care is impossible without continuity (i.e., retention) of home care aides.

If we invest in and treat the home care system as a needed partner in the larger health care system, home care costs will increasingly approximate nursing home costs. Such a thought strikes fear in the heart of some home care advocates, elected officials, and regulators. It should not.

If we do not make investments (primarily in the area of training), we will pay eventually for our lack of action. A long-time home care observer has often said that the system is "a scandal waiting to happen." If nothing else changes, one day the rubber bands holding things together will break. At that time, people will ask: "How did it happen?" or "How could things have gotten so bad?" A great deal of money will then be required to repair the damage.

We believe that many of the key actors in the home care system today already know the answers to the above questions. We believe, as well, that together these actors are capable of creating a different scenario. □

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