Community Care for the Frail Elderly: A Theory of Empowerment

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I. INTRODUCTION

As a result of a great deal of political pressure, including a well-publicized Institute of Medicine report, a reluctant Reagan Administration enacted a comprehensive set of nursing home residents' rights.[1] The rights granted are extensive; consuming almost six columns of the Congressional Record[2], they appear to cover virtually every aspect of patient concerns—rights to free choice, to full participation in care and treatment plans, to freedom from restraints (except for treatment purposes), to privacy and confidentiality, to voice grievances without penalty, to advance notice of changes, to organize, to have visits from family and written statements of legal rights. There are restrictions on transfer and discharge, treatment using drugs, and the regulation of personal funds. The list goes on.

One might applaud this effort. At least there is a statement in the law that this highly dependent, vulnerable group is entitled to autonomy, dignity, respect, and legal rights. However, while a few residents might find some benefit, in general the new code of residents' rights is only symbolic. It will fail to give the vast majority of residents any protection at all, especially those who need it the most, and to the extent it leads citizens and policymakers into thinking that they have accomplished something, the new laws are actually harmful.

In this Article, I will discuss why the legal rights perspective will not protect the frail elderly, and then argue for a different approach. Part I.A. describes the legal rights perspective on protection of the frail elderly and Part I.B. details its failure to provide this protection. Part II discusses the theory of empowerment and the reasons why empowerment provides greater control for the frail elderly than the legal rights regime. Part III considers the frail elderly as a wider community than the nursing home population. This redefinition of the population allows examination of the theory of empowerment, which emphasizes structural reform in the delivery of services, through the use of an empirical example from current home care projects for the frail, elderly poor in Part IV. As detailed in the discussion of the example in Part V, very dependent clients seem to gain some measure of empowerment. Part VI discusses the potential application of these structural changes and techniques when the frail elderly enter nursing homes.

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1. Omnibus Budget Reconciliation Act of 1987, Pub. L. No. 100-203, § 4201 (c), 101 Stat. 1330, 1330-165-69, *reprinted in* U.S.C.A. STATUTORY SUPPLEMENT (West 1988). The Institute of Medicine Report is COMMITTEE ON NURSING HOME REGULATION, THE INSTITUTE OF MEDICINE, IMPROVING THE QUALITY OF CARE IN NURSING HOMES (1986) [hereinafter INSTITUTE OF MEDICINE].

2. 133 CONG. REC. H12,157-59 (daily ed. Dec. 21, 1987 part III).

A. *The Legal Rights Perspective*

The difficulties that dependent people have in exercising legal rights is well-documented. In order for rights to be effective, people must be aware of injury, blame someone, know they have a remedy, know how to use that remedy, have the resources to pursue the remedy, and calculate that the benefits of relief outweigh the costs of trying to obtain relief. Dependent people have difficulty in negotiating these conditions, and if there is a failure in *any* one, then the legal right will fail.[3] The system is not proactive. What is particularly relevant is the cost-benefit analysis. People in continuing relationships have to calculate the costs to that relationship if they choose to pursue legal rights. Those who are dependent on social services—clients, patients, students (and parents), juvenile delinquents, and prostitutes—worry about retaliation from social service providers—health care workers, aides, social workers, welfare officials, teachers, administrators, and the police. Because they fear retaliation, dependent people often fail to exercise their legal rights. This generalization is not always true; on occasion, the powerless will use rights effectively, and if they are aggressive enough, even intimidate officials. But in the main, this is rare; in the more usual situation, power easily corrupts procedure.

At one level, the manifestation of power over the social service client is obvious. The client has to pay a price to receive the goods that the provider controls—usually a behavioral change in return for income or services. The client has a grievance, but lacks the ability to contest the decision. Power is also exercised in more subtle ways.[4] In many instances, the powerless are excluded altogether from decisionmaking arenas; there are barriers to even expressing grievances. In welfare, for example, certain key decisions are decided legislatively and are not subject to individual adjudication. In nursing home regulation, the new law is designed to give residents a voice in decisions from which they have previously been excluded—for example, transfers and discharges.

There is yet another dimension of power—where grievances do not even become conscious. Consensus is manipulated—*A* exercises power over *B* by influencing, shaping, and determining *B*'s very wants. The manifestation of power here looks to the social and historical contexts of the participants, as well as to the subjective effects of politics in shaping demands and expectations.[5] Quiescence comes about not only through the control of information and socialization processes, but also through the psychological adaptations of the powerless—fatalism, self-deprecation, apathy, and the internalization of dominant values and beliefs.

In the social service relationship, power is exercised in all of its manifestations. Social service workers have multiple sources of power. They control the resources and services of the agency; they have expertise, persuasion, interpersonal skills, and

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3. *See, e.g.*, J. HANDLER, THE CONDITIONS OF DISCRETION: AUTONOMY, COMMUNITY, BUREAUCRACY 19–42 (1986); Felstiner, Abel, & Sarat, *The Emergence and Transformation of Disputes: Naming, Blaming, Claiming . . .*, 15 LAW & SOC'Y REV. 631 (1980–81).

4. *See, e.g.*, S. LUKES, POWER: A RADICAL VIEW (1974).

5. *See, e.g.*, M. EDELMAN, POLITICS AS SYMBOLIC ACTION (1971); J. GAVENTA, POWER AND POWERLESSNESS: QUIESCENCE AND REBELLION IN AN APPALACHIAN VALLEY (1980).

legitimacy; they control information and the range of available alternatives; they invoke the rules.[6] If clients want the resources, they must yield at least some control over their lives. Power is not unrestrained; there are rules, regulations, and professional norms. Nevertheless, with vulnerable people, the relationship is largely involuntary since agencies are usually in a monopoly position.

The worker and the client bring to the social service exchange their respective social systems—who they are, what they represent, what they do—their characters, self-conceptions, and identities—which have been formed not only by their immediate lives but also by their past social relationships. The structures of their everyday lives affect the language, beliefs, and symbols which shape their identities and direct their behavior. Ideologies, beliefs, and the social construction of reality have particular importance to the social service relationship. Social service agencies are designed to change people; hence, they are *moral* systems. As clients are recruited, processed, and evaluated, they are invested with moral and cultural qualities by social service workers. Workers select those clients who serve their own interests either by confirming their ideologies or conforming to the demands of their working conditions. By screening incompatible information, the workers' moral evaluations are confirmed through self-fulfilling prophecies.[7] There is a large literature which describes dependent people internalizing the values and beliefs of the powerful or becoming apathetic.[8] It is no wonder that dependent clients, and especially the frail, elderly poor, fail to either pursue or even conceptualize their grievances; they develop a "culture of silence."[9]

B. *Failure of the Legal Rights Regime*

The legal rights regime fails to address these issues on two counts. While formally granting substantive rights and procedural protection, it does not disturb the maldistributions of power in the respective social systems; hence, the powerless either lack the resources with which to pursue their grievances or fail to even conceptualize their grievances. Since the system requires a complaining client, it is not activated. But the legal rights regime is also conceptually deficient. It is an adversarial procedure designed for zero-sum solutions; it looks at past events and decides who wins and loses. Consequently, it works poorly in relationships that continue, *e.g.*, family members, neighbors, and businesses that want to continue interacting with each other. Here, process should look to the future and try to repair relationships. Many social service relationships are continuing. Invoking legal rights not only impairs the relationship, but also raises the threat of retaliation. In one study, nursing home residents were afraid to complain to the ombudsman even where

6. *See, e.g.*, Hasenfeld, *Power in Social Work Practice*, 61 SOC. SERV. REV., at 469 (1987).

7. *Id.* at 472–75.

8. *See, e.g.*, Bumiller, *Victims in the Shadow of the Law: A Critique of the Model of Legal Protection*, 12 SIGNS, at 421 (1987); Felstiner, Abel, & Sarat, *supra* note 3.

9. P. FRIERE, PEDAGOGY OF THE OPPRESSED (1985).

organized groups of friends and relatives performed monitoring and consciousness-raising functions.[10]

The powerlessness of nursing home residents has significant effects on regulation. While there are many reasons for the development of strict, legalistic, command-and-control regulation,[11] an important one is that nursing home regulatory agencies have the full burden of generating all of the information on quality of care issues. Because of the nature and complexity of the institutions and the long-term care task, and the characteristics of the residents, the regulatory task is exceedingly difficult. Other than the occasional disgruntled worker or family member, or visible scandal, there is no other information on how patients are, in fact, personally treated. Residents are too dependent, too vulnerable to complain. Under the best of circumstances, it is hard to know whether dependent people are exercising free choice, are aware of alternatives, are participating in decisions, and are receiving proper care. The regulatory agency has to conduct frequent, burdensome inspections, and if necessary, impose legal sanctions. Along with the failure of legal rights, the failure of nursing home regulation is also well-documented.[12]

This is the context in which the new code of residents' rights has been enacted. For the vast majority of old, sick, and alone residents, it is a cruel hoax.

II. A Theory of Empowerment

How would a theory of empowerment address the two problems of the legal rights regime: asymmetrical power and the continuing relationship? If social work practice is viewed as the exchange of resources, then power relationships are altered by increasing client resources. Empowerment means the ability to control one's environment; thus, clients must have sufficient resources (including alternatives) to be able to make choices and to negotiate more favorable outcomes.[13] Client-worker practice has to shift from its individual orientation to a more structural approach to help people connect with needed resources. Professor Yeheskel Hasenfeld argues that empowerment must occur at all levels in the organization—between the worker and the client, and at the organizational and policy levels. Strategies include increasing client information, improving personal skills, increasing collective strength, and improving links to alternatives. There must be empowerment-based practice technologies and accountability measures that stress empowerment rather than social control. There must be an increase in client control over resources (*e.g.*, vouchers) and the availability of alternative services. The workers must change the definitions of their professional norms and tasks.[14]

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10. Doty & Sullivan, *Community Involvement in Combatting Abuse, Neglect, and Mistreatment in Nursing Homes*, 16 Milbank Memorial Fund Q. Health and Soc'y 222 (1983); *see also* Institute of Medicine, *supra* note 1 (review of ombudsman projects).

11. E. Bardach & R. Kagan, Going by the Book: The Problem of Regulatory Unreasonableness 34–39 (1982).

12. *See, e.g.*, Institute of Medicine, *supra* note 1; B. Vladeck, Unloving Care: The Nursing Home Tragedy (1980).

13. *See, e.g.*, Hasenfeld, *supra* note 6, at 478–81.

14. *Id.*

While these empowerment strategies are primarily addressed to situations where clients perceive grievances or conflicts and lack the resources to complain and negotiate, they may have deeper possibilities. The structural changes that Hasenfeld advocates may affect the cultural contexts of the participants. The destabilization of power relationships, structures, and roles will produce changes in ideologies and beliefs. The participants will view themselves and their relationships differently.[15]

In addition, empowerment strategies, in the social work context, must be based on *trust*. In order for the worker to share responsibility with the client, the worker has to believe that the client understands, agrees, and is willing to cooperate; the worker must respect the capabilities, autonomy, and responsibility of the client. The client, in turn, will not give this kind of response unless the client has confidence in the worker's competence and professionalism, and believes that they share a common belief in the client's best interests. For the dependent client, empowerment requires more than passive quiescence; it requires active, understanding participation, and this requires trust.

People cooperate for a variety of reasons which may or may not involve trust; moreover, trust is used in different contexts. We trust family members, stock brokers, mechanics, babysitters—in short, whenever there is a principal-agent relationship.[16] We trust strangers as well as intimates. There is a distinction between trust and reliance on the dependable habits of others—the former relies on good will.[17] We trust our agents to act in our best interests. Trusting, then, creates vulnerability; we do this because we need help in maintaining what we value—health, children, property, even our lives. But trust does not necessarily have to rely on good will. Trust is rational. Cooperation can be based on a calculation of costs and benefits[18] or even the threat of sanctions. Annette Baier calls the latter a "morally rotten" trust.[19]

Baier proposes a test of expressibility: Can the trust relationship survive the knowledge the parties are relying on as the basis for continuing the relationship?[20] A trust relationship based on suspicion and fear would probably be weakened, if not destroyed, if the real reasons for continuing the relationship were disclosed, whereas knowledge of one's love, respect, concern for some common good, or professional pride would strengthen the trust.

A morally decent trust alters power relationships. Clients become equal moral agents. They share decisionmaking responsibility. Hasenfeld claims that in traditional social services, the clients are invested with moral characteristics which serve the interests of the workers.[21] Empowered clients are invested with moral characteristics,

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15. *See, e.g.*, Merry, *Everyday Understanding of the Law in Working Class America*, 13 AM. ETHNOLOGIST 253 (1986).

16. *See generally* B. BARBER, THE LOGIC AND LIMITS OF TRUST (1983); Shapiro, *The Social Control of Impersonal Trust*, 93 AM. J. SOC. 623 (1987).

17. Baier, *Trust and Antitrust*, 96 ETHICS 231 (1986).

18. K. HAWKINS, ENVIRONMENT AND ENFORCEMENT: REGULATION AND THE SOCIAL DEFINITION OF POLLUTION (1984); Handler, *Dependent People, The State, and the Modern/Postmodern Search for the Dialogical Community*, 35 UCLA L. REV. 999 (1988).

19. Baier, *supra* note 17.

20. *Id.*

21. Hasenfeld, *supra* note 6, at 475-76.

but the interests of the workers participating in empowerment programs differ from those of workers in traditional social work practice. The professional task as redefined by the empowerment philosophy puts trust at the center of the relationship—not blind trust (quiescence) or trust based on sanctions (those kinds of trust will not work for empowerment)—but morally decent trust, where client confidence in themselves and the case managers, and mutual understanding are crucial. The ascribed moral characteristics are empowering rather than subordinating. The clients are changed not only in terms of their relationships with the case managers but also in terms of their self-conceptions. Changes in practice—here, the ability to take more control over one's life—necessarily mean changes in one's ideology. Ideology defines experiences and constructs reality; events become socially meaningful only when they are interpreted.[22] Client participation on the basis of a morally decent trust is both transformative and constitutive.

III. Redefining the Population

For historical reasons, we have defined long-term care for the frail elderly in medical terms and have confined residents in hospital-like facilities. Instead of starting with the most difficult situation—old, sick, alone people confined in a total institution, in an industry under siege—why not transcend the institution? Perhaps we can untie this Gordian knot by redefining the population.

The health and disability characteristics of people inside and outside of nursing homes, controlling for age, are not much different; that is, both groups need varying amounts of care, mostly of a custodial nature (*e.g.*, assistance with transportation, nutrition, toileting, bathing, and chores). What are different are their *social* characteristics; the vast majority of those outside of nursing homes have someone to help them, usually a spouse or an adult daughter.[23]

The elderly should be viewed in terms of a continuum. There are many who are fully capable of functioning in regular activities, there are some with varying degrees of disability who are able to get along with varying amounts of assistance, there are some who are disabled but have no help, and there are some who are very sick. Accordingly, various commentators have called for a continuum of services rather than our present sharp institutional demarcation dictated by public funding mechanisms.[24]

Once it was demonstrated that the reason why large numbers of frail elderly were in nursing homes was that they had no one to help them in their activities of daily living, the idea was born that better care could be provided at a lower cost through community-based services. If community-based services were available, the frail elderly would not have to go into nursing homes in the first place, and further, many

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22. Merry, *supra* note 15, at 254.

23. *See, e.g.*, E. Abel, Love is not Enough: Family Care of the Frail Elderly 3–8 (1987).

24. *See, e.g.*, *id.* at 52–53; B. Vladeck, *supra* note 12, at 210–42. There are examples of where institutions have been combined, *e.g.*, short-stays in nursing homes as respite care. *See* Berman, Delaney, Gallagher, Atkins & Graeber, *Respite Care: A Partnership Between a Veterans Administration Nursing Home and Families to Care for Frail Elders at Home*, 27 Gerontologist 581 (1987).

of those now in nursing homes could be discharged back into the community. As a result, there have been several community-based or alternative care demonstration projects and a growing home care industry designed to supplement or provide custodial and health care so that the frail elderly can remain in their communities; that is, they can live and function like the large number of disabled elderly who have informal support.

So far, government has been reluctant to take this path. The regulatory problems are daunting. The population is very vulnerable and frequently fall prey to commercial victimization. Policymakers see the prospect of hordes of private entrepreneurs hawking home help, transportation, therapy, health, respite, nutrition, and who knows what other services. The case managers themselves are the gate-keepers. The sites are dispersed throughout the community, making it difficult to evaluate these services: how can one tell whether the therapist was rough or gentle, the driver courteous or abrupt, or the home help pleasant or lazy or nasty? These are not trivial matters when dealing with the dependent elderly. Those who have worked with them know how difficult it is to get them to use services or to complain. They are often afraid, or confused, or have a counterproductive sense of independence.[25]

Nevertheless, despite the problems in home care, it would seem that if progress is to be made on the issue of residents' rights, then this is the place to start rather than the total institution. Various demonstration projects and other kinds of activities indicate possibilities.

IV. Community-Based Care for the Frail, Elderly Poor: An Empirical Example

The theory of empowerment and its strategies can be illustrated by an empirical example dealing with community-based care of the frail, elderly poor. Research was conducted on three voluntary agencies and five for-profit agencies in Los Angeles during 1986-87.[26] First, I will report on the voluntary agencies.

A. *Voluntary Agencies*

1. *Agency Organization*

While the three voluntary agencies carried on a variety of activities, I will discuss primarily the Multipurpose Senior Services Program (MSSP), which was designed to test the efficiency of case management. Typically, a team composed of a social worker (at the Master of Social Work level) and a nurse (usually public health), assisted by case aides, is responsible for case management. There is

25. *See, e.g.*, E. Abel, *supra* note 23, at 28–51; R. Kane & R. Kane, *The Extent and Nature of Public Responsibility for Long-Term Care* in Policy Options in Long-Term Care 78 (J. Meltzer, F. Farrow & H. Richman eds. 1981); Hedrick & Inui, *The Effectiveness and Cost of Home Care: An Information Synthesis*, 20 Health Serv. Res. 851 (1986); Lave, *Cost Containment Policies in Long-Term Care*, Inquiry, Spring 1985, at 7; Weissert, *Seven Reasons Why It Is So Difficult to Make Community-Based Long-Term Care Cost-Effective*, 20 Health Serv. Res. 442 (1985).

26. Open-ended interviews were conducted with supervisors, line staff, and clients.

multidisciplinary assessment, planning, coordination, monitoring, and follow-up, with a wide variety of "waivered" services.

The following three agencies were studied. First, Senior Care Network (SCN), which was organized by the Huntington Memorial Hospital in Pasadena. SCN has a membership program free to all area residents fifty-five years or older; at the time of the study, there were 11,000 members. Second, Senior Care Action Network (SCAN), which serves the elderly community in the Long Beach area. From its beginning about ten years ago, elderly citizens, government, health, and human service agencies have participated in the planning and development of SCAN. Seniors continue to play an active role as both consumers and board members—in fact, the bylaws require that at least one- third of the members be consumers. Last, Jewish Family Service (JFS) has served its community since 1851. It has a center located in the older Jewish section as well as various storefronts in the Los Angeles area. JFS offers counseling, discussion groups, social activities, classes, and a health care clinic. It has strong community connections. The JFS center has a board and a Project Advisory Council. The Council includes consumers; some of the board members are volunteer case aides. The extensive use of volunteer case aides under the supervision of social workers is part of JFS's nonexpert-oriented philosophy of care.

The MSSP programs are restricted to seniors who are Medicaid-eligible and are sufficiently disabled to qualify for admission to a skilled or intermediate care nursing facility. Operationally, this means that MSSP clients have difficulty in performing a number of activities of daily living (*e.g.*, bathing, toileting, cleaning, nutrition, transportation) or health maintenance tasks. The total cost for providing services to these clients, including the cost of administration and case management, cannot exceed, on average, ninety-five percent of the Medicaid nursing home rate. At first blush, it may seem that the ninety-five percent cap is generous. In fact, the cap is a tight constraint since the nursing home reimbursement rates have been held down while the prices of other services, including administration and case management, have risen. As it turns out, the programs in these three agencies have been averaging around eighty percent of the nursing home rate.

Most of the services that MSSP provides are contracted. The actual delivered services are provided by existing public and private agencies under an MSSP-coordinated care plan. Services include personal care and housekeeping, adult protective services, meals on wheels, transportation, and care by visiting nurses. Purchased services include supplemental housekeeping and one-time-only services (*e.g.*, beautician services). The most popular service is the homemaker. For this service, MSSP is required to first go to the County Department of Social Services, which makes its own assessment of client needs. Since the county assessments and hourly rates are usually lower than the MSSP determination, MSSP will either supplement the county services or purchase homemaker services privately.

Clients of the three agencies are usually obtained from hospitals, home health agencies, and other agencies dealing with the elderly, plus referrals from friends and neighbors. All of the agencies conducted outreach programs. At the time of the study,

the MSSP clientele ranged from 200 in the SCN program to 500 in the JFS program. JFS not only had the largest program, but also the oldest clientele; the average age was eighty-five as compared to SCN's average age of seventy-five.

The three agencies use combinations of nurses and social workers to staff the program, often working as teams. While there is task concentration (*e.g.*, the nurses concentrating on the health assessments and the social workers on the psychosocial assessments), both nurses and social workers perform case management duties.

2. *Assessment Methods*

The agencies vary somewhat in their screening and referral methods but none of them reports much difficulty in applying the eligibility requirements. Usually, the screening takes place in the client's home, and if the client appears to be eligible, there will be a follow-up visit by the nurse-social worker team, which will make the initial assessments and the final eligibility determinations. Screening interviews take about an hour. If possible, the family is usually involved. The family can provide valuable information and also help in communication, particularly if the client is ill or confused.

The health assessment covers standard health care information, including a careful review of medications. The psychosocial assessment includes information concerning the living situation, family and social networks, and ability to handle daily activities. A variety of skills are used to elicit the necessary information. The home visit allows for direct observation. The case managers will usually focus on specific, concrete tasks, for example, how the person bathes or eats. However, the case managers try to get a picture of the client's functioning as a whole rather than as someone who has difficulty with certain tasks. Clients, naturally, vary in their abilities to give information. Many know about the agency and the program and will provide all of the necessary information. Some clients are very dependent and extremely grateful for help. Others are wary and concerned about loss of independence. And others deny their needs, or are confused or frightened. Sometimes the presence of a family member inhibits the client. Not infrequently, case managers will wait for subsequent meetings to acquire complete information.

The case managers will explain the program including its limitations. Sometimes bargaining takes place, although urgent needs are usually handled promptly—for example, the installation of a "life-line" service. But the normal process of developing the case plan takes about a week or two. The care plan defines both the specific services and the providers which will meet the client's needs. The proposed care plans are presented at agency meetings at which additional staff are present.

As stated, the most popular service is the homemaker, followed by personal care. Providers are selected on the basis of past performance and reputation. In part, information about the providers comes from the clients themselves, a matter which will be discussed shortly. Clients must consent to the care plan, but since the services have already been discussed in the prior meetings, there are usually no objections. During the informal meetings, client input is actively sought, and clients are advised that they must approve of any services that are ordered.

3. *The Client-Agency Relationship*

In order for the MSSP program to work, the client-agency relationship must be based on trust. This is clearly evident with clients who will not disclose their needs. These clients may be confused or mistrustful. They may not want to admit their dependence or they may fear disappointment. With these clients, the case managers have to overcome the barriers to communication but at the same time respect client sensitivities. Various approaches are used. Workers try to be flexible and patient, and not force issues. The agency's satisfaction of certain client needs (*e.g.*, taxi coupons) will be used to explore other needs (*e.g.*, help in shopping). Sometimes clients will be willing to accept smaller amounts of services and wait for trust to develop before admitting larger needs (*e.g.*, a request for a grab bar rather than a bathing assistant). As trust grows, clients are more willing to accept or demand additional services. In one instance, as a result of using housekeeping services, a client felt confident enough to accept the case manager's suggestion to go to a senior center. Sometimes the presence of informals (family or friends) helps in communication; at other times, it hinders communication—the client will feel reluctant to discuss certain issues in the presence of a family member or friend. Sometimes a client will be willing to discuss certain issues with the nurse but not the social worker. The process works in reverse as well. Not infrequently, clients will teach staff members how to go slow, to be less intrusive, to listen, and to be more attuned to client sensitivities.

Client confidence and self-esteem are important. The case managers will encourage clients to build up their informal support systems—for example, going to a senior center, joining a club, or meeting with a volunteer friendly visitor. Case managers try to help re-establish or improve family relationships; often respite care is a big help because it demonstrates to a reluctant family member that the agency can help.

There are other reasons for trust. A basic underlying principle of the three agencies is that the family and the client should be encouraged to do as much as they can—to participate in the content of the care plan as well as the details of its administration. The clients, if possible, are to decide how the services are to be delivered—for example, the distribution of homemaker hours. The staff encourages the clients to state their preferences, if any, for particular agencies or special characteristics of workers.[27] The agency will help in providing lists and appointments of service providers, and present alternatives, but the clients have to make the ultimate selections; they have to interview and select the homemakers, and make other service choices. The staff wants to get the client to take control; sometimes this must be done one step at a time in order for the client to develop the necessary confidence in herself and trust in the case manager. Finally, the clients have to monitor the service and report to the agency. They are the ones who must complain if they are dissatisfied.

With the client's permission, the agencies try as much as possible to utilize the

27. This can cause problems when racial prejudice is involved.

informal care of family, friends, and neighbors. Not infrequently, family members will provide additional help when they see that the agency is supplying needed services. On the other hand, case managers are sensitive to the needs of the informals, and will provide respite care if needed. A common example is the weekend homemaker to relieve spouses or other informal caregivers. Sometimes bargaining takes place between the agency and the family, and in time, partnership arrangements emerge—a sharing of services and costs, coordinated by the care plan. Again, there are combinations of incentives.

Bringing the informals into the care plan provides better care for the client, and often helps the informals in their relationships with each other and the clients. One very useful example is support groups composed of informal caregivers (usually adult daughters). The participants not only share common concerns and feelings, but they also increase their knowledge about the needs of their parents, available services, and the work of the agency itself.[28] Participating staff members find these sessions of great value. At the same time, increasing the participation of informals allows the agency to provide services and stay within the cost constraints. In this way, informal care helps pay the costs of the program, which, of course, is true for informal care in general—it accounts for a large part of the society's long-term care bill.[29]

In addition to participating in the provision of services, clients and the informals also perform a valuable monitoring service. The agency and the case managers have the responsibility to assure quality of care. The rules require that clients be contacted at least once a month, visited at least once every three months, and completely reassessed every six months. In practice, there is much more contact, often initiated by the clients and their families, which is encouraged by the case managers; this helps provide access and build trust, especially with the more vulnerable and needy clients. But most importantly, the contacts provide a fundamental monitoring function; the clients and their families are encouraged to call when they are dissatisfied.

Case managers will investigate complaints, talk directly with the providers, arrange conferences for particular problems, and, if necessary, act as advocates for the client. Sometimes, systemic problems will be uncovered—for example, the need to provide a more effective backup service for a particular provider over weekends. The case manager's opinions about the quality of the agencies are dependent, to a large degree, upon the complaints and feedback of the clients. In the words of one case manager, client comments are the "only way of really knowing what's going on." Some clients, of course, are afraid to complain; here, case managers work patiently, encouraging them, asking them whether the worker is on time and courteous, and whether the client is satisfied. The case managers will schedule home visits to get a better evaluation of the service. At the same time, there are chronic complainers, and the case manager will have to investigate the client as well as the complaint. Racial prejudice can be a problem. The agency position generally is to try

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28. *See* E. ABEL, *supra* note 23, at 33–43; Law, *Equality: The Power and Limits of the Law*, 95 YALE L.J. 1769 (1986).

29. *See, e.g.*, E. ABEL, *supra* note 23, at 9–13.

to talk to the client, but it may also inform her that the next worker will most likely be a minority.

The case managers try to encourage the clients to deal with service problems. Legally the client, not the agency, employs the provider. Case managers try to get clients to take the initiative, with the agency as backup. The agency will encourage the client to manage the problem, including firing the workers if necessary. The objective is to have the client gain sufficient self-esteem so that the client can "assume ownership of the care plan." Success in getting clients involved in these decisions sometimes has spill-over effects, helping clients with psychological problems and encouraging them to take on new activities.

The MSSP relationship ends if the client goes into a nursing home on a permanent basis. If the decision is planned, then the case manager will work with the client and the family. And even though the client is terminated from MSSP, case managers report that they stay in touch with family members. There is some suggestion that the skills that the client and the family developed during the MSSP experience help them better deal with the nursing home.[30]

4. *Fee-for-Service Programs*

Before concluding this description of the agencies' programs, brief mention should be made of the experience of two agencies which provide fee-for-service programs. One (SCN Community Options) provides case management services and performs much of the same functions as MSSP. However, because it is a fee-for-service program, there are no physical or financial eligibility requirements. Nevertheless, about half of the clients are subsidized (either publicly or privately) and the services are costly; therefore, the Community Options case managers are under similar kinds of constraints as those employed by MSSP. They work with clients and informals in much the same manner. Contracts are signed between the agency and the clients.

Community Options case managers say that because the clients pay for the service, they have a much stronger incentive to complain than the MSSP clients. Not surprisingly, complaints rise with the payment process. This increased willingness to complain applies equally to the clients who are subsidized. As with the MSSP, the Community Options case managers need and welcome this feedback; it provides valuable monitoring information and, in the opinion of the case managers, empowers the clients. The case managers also say that the contracts help stimulate complaints. Prior to the use of contracts, there were problems with both client satisfaction and complaints. A clear statement and an agreement seemed to have helped with both issues.

The other program, also a fee-for-service program, is SCAN's combined health and social service demonstration project. Here too, it is reported that because clients pay a premium, co-pay for certain services, and have the ability to disenroll,

30. There was one case in which a client managed to get herself transferred from one nursing home to another. The case manager thought that MSSP experience helped her to initiate the action.

complaints and feedback are very high. The case managers say that the bills create an incentive for the clients to monitor the services carefully.

B. *The For-Profit Agencies*

In the three voluntary agencies, the norms of participation were reinforced by complementary concrete incentives. What would the incentives be in for-profit agencies? If the program has the same professional ideology as the voluntary agencies and has a similar structure, then the client-agency relationship should be approximately the same. If the program pays per unit of service, then providers would stay as long as possible and do as much as possible but the clients would remain passive. If the program is tightly limited per unit of service (*e.g.*, Medicare home help), then the clients will be involved, but in a passive, instrumental manner rather than in a joint decisionmaking capacity. In other words, consistent with existing research, it is not the form of ownership that matters as much as the structure of the program.

1. *Agency Organization*

For-profit agencies are reimbursed either through Medicare or private payments (out-of-pocket or insurance). Medicare covers short-term, intermittent care in the home—nursing, physical therapy, occupational therapy, speech therapy, and services of home health aides. It does not cover homemakers. The home health aide is limited to hourly visits and can only be in the home if another primary discipline is also there providing services (*e.g.*, nursing, physical therapy). Medicare services are highly regulated and strictly limited; they provide only what is necessary to take care of the medical problem. Private payment services provide whatever services are contracted for. In the agencies studied, the services ranged from homemaker to live-in care; some of the live-in caregivers have stayed as long as five years.

In all, five agencies were researched.[31] One of the agencies, part of a national chain which administered a privately-financed program, took an "hours and sales" approach: lengthy care was viewed as a benefit to the agency, so client education and independence were not encouraged. The client was the "patient"; the customer, who paid the bill (usually the family) was afforded a larger role in decisionmaking. But this agency was at one end of the spectrum.

2. *The Role of Empowerment*

All of the agencies, whether private pay or Medicare, develop care plans. The service coordinator screens the client and makes initial determinations. A nurse makes the home visit for the initial assessment. Clinical supervisors (registered nurses) make periodic visits for quality assurance. In most of the agencies, there was some form of case management; in three, staff advocated on behalf of clients with

31. As with the voluntary agencies, these agencies were purposively selected to illustrate types of programs. They are *not* representative.

insurance companies. The staff coordinator or case manager monitored the service providers.

Except for the agency which took the "hours and sales" approach, all of the agencies adopted and practiced, in varying degrees, client empowerment standards. They considered clients as part of the decisionmaking process and valued client independence. Family involvement was encouraged. As with the voluntary agencies, the success of family involvement varied. Several involved the family in the initial planning sessions. The Medicare agencies strongly encouraged family involvement; because of the strict program limits the client and the family had to take over the care when the client's Medicare eligibility expired. Shared decisionmaking varied with the program. In programs funded by Medicare, strict regulations and paperwork requirements limited sharing, although clients did participate in the scheduling of services. On the other hand, Medicare encouraged client education. In private payment programs, there was more direct client supervision of the providers. With the one exception, all of the agencies emphasized the importance of trust and empowerment: they stressed independence, shared decisionmaking, and dignity as important therapeutically and for their own merits. One example involved a client who was homebound because of incontinence. Home health services was able to provide an aide to insert a catheter three times a week, but the agency preferred to train the client (or the family) to maintain the client's independence. Other education programs included diet and medication. Naturally, commitment to empowerment, strategies, and results varied among staff and clients.

3. *Century City Hospital Geriatric Program*

A private, for-profit hospital runs a program that is similar to the MSSP programs in the use of multidisciplinary case management. The hospital program offers a similar range of services, but is broader in that it also includes a more extensive package of health care services. In addition to social workers, the teams include geriatrically-trained internists and psychiatrists. It is modelled after the British day hospital.

The process in the Century City Hospital Geriatric Program is quite similar to that in the voluntary agencies-multidisciplinary, holistic assessments; joint participation in the development and administration of the care plan; and extensive reliance on client information, supervision, and complaints. Family involvement is emphasized. The dominating professional norm is "functional independence" rather than the "invalid role," despite the fact that this program is run out of a hospital.

Why is the Century City program (apparently) successful? The program is successful for structural reasons: its structural patterns are similar to those of the voluntary agencies. Professional norms have been changed from the medical model; geriatrically-trained physicians therapeutically favor the holistic, empowering approach. As with the MSSP programs, the technology encouraged client (and family) involvement, including involvement in the all-important information and monitoring functions. There were also strong economic reasons for the program's success. The

geriatric program operates at a loss, but it is supported by the hospital as a method of recruiting geriatric patients. As with all of the programs discussed, there is complementarity between professional norms, technology, and economics.

V. Discussion of the Empirical Example

A. *Incentives for Client Participation*

The clients, in varying degrees, participated in important decisions affecting their lives. They made choices, monitored, and complained, and they appeared to be listened to. These are examples in which a highly vulnerable dependent group showed some measure of empowerment.

From the perspective of both the staff and the agency, there were three complementary structural reasons or incentives for client participation. First, the leadership and the staff believed in client empowerment; they felt that these frail, elderly, poor people could take more control over their lives and they would be better off by doing so. With varying amounts of support, clients did not have to be so vulnerable, and they had a good chance of avoiding institutionalization. Second, there were technology processes—the clients (and the informals) shared the work *and* provided essential information; this, in turn, lessened the regulatory burden of monitoring quality of care. The agencies relied extensively on client information. There was the financial constraint. The agencies could not do the necessary, time-consuming, detailed work and still remain within the financial cap. As is true of informal care generally, clients and informals were cost-sharing partners. In Hasenfeld's terms, the clients had valuable resources that the agencies needed.

Third, in addition to sharing the work and supplying information, in other programs (*e.g.*, SCN's Community Options and SCAN's health plan), the clients had other resources as well. When they paid a fee and when there was competition to enroll them, the case managers reported higher levels of feedback and complaints. There was probably a fourth structural variable as well—at least two of the agencies had strong, community-based, consumer sources of support and legitimacy. Jewish Family Services was deeply rooted in an old community; over the years, and across many different programs and activities, family, friends, and neighbors served as staff, board members, clients, and participants. SCAN was a new organization; but consumers played an active role in its organization and governance, including its important grievance committee.[32] Encouraging client feedback and participation was consistent with these organizational characteristics.

B. *Client-Agency Trust*

In order for the relationship described in these three agencies to work, there had to be a high degree of trust. The clients had to trust the case managers to accept the services, to participate in the decisions, to share the work, and to report accurately

32. This was especially true of the health plan, where there was no means test.

and honestly. This did not come easily. There were numerous stories of case managers working slowly, patiently, with frequent back-tracking, to gain the trust of the clients. Those who know the frail, elderly poor are familiar with this process. The case managers, in turn, had to trust the clients. The clients had large responsibilities under this program. The case managers had to believe that the clients understood the tasks, were capable of performing them, and were willing to perform them. Unless there was understanding and capability, cooperation would be unreliable. Thus, the professional task was redefined in two ways: reciprocal, concrete incentives flowed back and forth between the professional and the client—there was a partnership—*and* the relationship was founded on trust.

These are examples of morally decent trust. The case managers had confidence in and respect for the capabilities, autonomy, and responsibility of the clients. The clients, in turn, came to believe that the case managers were competent, had professional pride, and shared a common good. This knowledge strengthened the relationship; it transcended the instrumentalism of formal care and the affective reciprocity of informal care.[33]

C. *How Much Empowerment Was There?*

How much empowerment was there? These findings are based on stories told by staff and some clients and their families. Aside from the fact that these agencies were purposively selected, it is difficult to arrive at a theoretical definition of empowerment, especially in this context. The clients are sick, old, weak, alone, and poor; they are very dependent. And the case managers and other staff are middle-class professionals employed by powerful agencies. The clients in these programs are "success" cases in that they have access to services via the program as well as good relations with the staff; they minimize (if not forget) past problems and focus on the present. The staff is attuned to the current professional rhetoric. Thus, we might wonder, how much of what is told is ideological construction? How much change has occurred?

Consider the contrast between the MSSP clients and the Medicare clients in the for-profit agencies. The former were involved in the full range of decisions from the very beginning. The latter were excluded from most of the important decisions: doctors diagnosed, treated, and prescribed for the medical problem, the home health aide under the close supervision of health care professionals *instructed* the client (patient) on how to administer the health care during the tightly controlled time that the home service was provided. We would be tempted to say that there was much more empowerment with the MSSP client; the Medicare patient, after all, was only instrumentally trained to perform a mechanical task. But do we know this? It may be that the ability to self-administer an injection is an enormously empowering act for a frail, elderly person. In view of the subtleties of the manifestations of power, we need similar kinds of conceptualizations and operational definitions of empowerment. In

33. *See* Hoch & Hemmens, *Linking Informal and Formal Help: Conflict Along the Continuum of Care*, 61 SOC. SERV. REV., at 432 (1987) (disjunctures between formal and informal care).

these selected case studies, we seem to see empowering activities, but there are serious theoretical and empirical pitfalls.

We must not exaggerate the changes that have been described—that dependent people seemed to be listened to, that they took some control over some part of their lives, that there was a sharing of power, and that there was equal moral agency based on trust. These changes are a matter of degree. One would hope that the skills and self-perceptions learned here would apply to other areas of their lives, but this is unknown. One would hope that the moral responsiveness of the staff would also be applied to dependent people in other relationships; this, too, is unknown. These may be only small enclaves.

Moreover, the relationships described here may also be transitory. Clients change in terms of health, disability, and social relationships, all of which can affect their beliefs and attitudes. Even in the relationships that have been described, the case managers often had to work constantly to maintain active, understanding participation. This should not be surprising; relationships are dynamic and the population is very dependent.

VI. Empowerment and the Legal Rights Regime

It would seem that empowerment based on professional norms, regulatory and fiscal incentives, and morally decent trust is designed to encourage the recognition and expression of grievances. Here, clients have resources because the agency is dependent on their contribution. It may also be that when there is a morally decent trust and active, understanding participation, communication begins to cross the separate cultures that the respective participants bring to the relationship. While the case managers and the clients still come from different social locations, it may be that with different structural roles clients and case managers begin to see themselves and the other in different perspectives.

The empowerment described here fits comfortably with much of what is contained in the residents' rights sections of the nursing home legislation. Clients are made aware of what is available, are given choices, participate, complain, and are listened to. But they have been empowered by the agencies, through professional norms and administrative practices, rather than the rule of law. Empowerment occurs here because the professional task has been redefined through a combination of professional norms, agency leadership, and externally imposed financial constraints. What this means, then, is that client empowerment is itself dependent on the structure of the program and the characteristics of the agency. This is hard to accept for those raised in the culture of legal rights. But the opposite is no longer even speculative—granting codes of legal rights and protections to the powerless, without more, is fruitless. People need power to use the legal system. What these examples show is that by restructuring the programs and redefining professional norms and tasks, some measure of empowerment is possible.

A. *Current Developments in Community-Based Care*

Home care for the frail elderly is expanding rapidly. It was estimated that between 572 million and 1.2 billion dollars were spent last year, and this is expected to reach 2.3 billion dollars in 1990—fueled in part by hospital cost containment and the dramatic advances in technology.[34] Public health commentators such as Bruce Vladeck say, "in a relatively short period of time we have transformed our system of care from one dominated by nursing homes to one in which a growing majority of services are provided to people in their own homes."[35] Despite the fact that the funding comes primarily (over eighty percent) from Medicaid and the service is popularly known as home health care, the largest single cost is for home attendants.[36]

There seems to be no end in sight. Significant proportions of all adults—not just the elderly—have some functional limitations, and with older groups, the proportions increase. There are widely varying estimates of need, but all of them are large. Policymakers fear that use will increase as more public funds are made available. At the present time, the cost of informal care is profound—relatives provide eighty percent of informal care; two-fifths of those who care for an elderly person in their own home do the equivalent of a full-time job—and typically provide this care over a long period of time.[37] It is estimated that the opportunity, or replacement, costs of this care are worth between 7.2 and 16.6 billion dollars, in addition to the nonquantifiable costs—the physical and emotional stress and the loss of control over one's life.[38] In the programs so far, targeting has proven difficult—consumers are *substituting* publicly-funded formal care for informal care rather than using publicly-funded formal care as an *alternative* to institutionalization.

Legislation was proposed that would have paid for a range of services, including home nursing care, rehabilitation therapies, and social services. To be eligible, people would have to be unable to perform two of the following acts: toileting, eating, bathing, moving about, and dressing. Services would be provided by certified home health agencies; reimbursement would be based on reasonable cost. Local health agencies would monitor the program under the supervision of the Department of Health and Human Services. This time around the bill was defeated. It was controversial, if for no other reason than its cost—the Congressional Budget Office estimated costs of 4.5 billion dollars in fiscal year 1989, increasing to 7.6 billion dollars by 1992.[39] There is the fear of opening the floodgates; already major investors are in the home-care market, and governments are trying to restrict benefits to only those in imminent danger of institutionalization,[40] although these fears may be exaggerated.[41]

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34. *Quoted in* Freudenheim, *The Boom in Home Health Care*, N.Y. Times, May 2, 1988, at D1, col. 3.

35. Sullivan, *NY Shifts Care for the Elderly to Their Homes*, N.Y. Times, May 4, 1987, at A1, col. 1.

36. *Id.*

37. Abel, *Adult Daughters and Care for the Elderly*, 12 FEMINIST STUD. 479, 481 (1986).

38. E. ABEL, *supra* note 23, at 25; L. PARINGER, THE FORGOTTEN COSTS OF INFORMAL LONG-TERM CARE 1466 (1983).

39. Tolchin, *2 Powerful Chairmen at Odds As Vote Nears on Home Care*, N.Y. Times, May 23, 1988, at A16, col.1.

40. E. ABEL, *supra* note 23, at 23–27.

41. *See, e.g.*, A. RIVLIN & J. WEINER, CARING FOR THE DISABLED ELDERLY: WHO WILL PAY? (1988).

There seems to be little doubt that we are at the start of a major expansion of a new social service. With the proper structuring of cost constraints, other financial incentives (*e.g.*, vouchers), and monitoring requirements, incentives would be in place to stimulate the encouragement of client participation which, at the same time, would complement public policy concerns about costs and quality. Regulation could do more, such as the encouragement of support and community groups as is being proposed for nursing regulation, discussed below. Client empowerment takes more, but this would be a beginning.

B. *The Nursing Home Resident Today*

We started our analysis by transcending the nursing home category; it is now time to return. What implications does client empowerment in community-based care have for the nursing home resident? The new legislation and regulations emphasize access and organization by family, friends, and organizations. This reflects the strong view of the Institute of Medicine as well as other commentators that the presence of outsiders is crucial to the key goal of improving the relationship between the aide and the resident so that residents are treated in a pleasant, interesting, respectful, and autonomous manner, one that is helpful, dignified, and caring.[42] Studies have shown that residents benefit and the quality of the home is likely to be higher when there is community involvement. The frequent presence of visitors encourages staff attention to both residents and their roommates. Community groups provide outside contact; they mediate disputes and monitor care. Support groups exchange information and discuss strategies, including advocacy.[43] Vladeck argues that regulation can strengthen community ties through mandated boards of visitors and/or required volunteer programs; several states have such programs.[44] The literature also discusses examples of homes and staffs which have benefitted from community involvement.[45] Family, friends, and volunteers can supplement care. It is recognized that there will be tensions and conflicts;[46] there are examples where these have been worked out, where the family is viewed as the "client."[47]

What is hoped for is that the skills and techniques learned through a process of empowerment in community-based care will carry over when the clients enter a nursing home. Clients, and their informal support (if available), will have learned how to deal with the case manager—to call, report, and complain—as well as with other agencies. They do the interviewing, the hiring, supervising, and firing, if necessary. They will be in a better position to negotiate with the nursing home staff

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42. *See, e.g.*, INSTITUTE OF MEDICINE, *supra* note 1, at 25–44; B. VLADECK, *supra* note 12, at 210–42.

43. E. ABEL, *supra* note 23, at 43–48; Butler, *A Long-Term Care Strategy for Legal Services*, 14 CLEARINGHOUSE REV. 613 (1980) (special issue).

44. B. VLADECK, *supra* note 12, at 210–42; *see also* Butler, *supra* note 43, at 619–22.

45. *See, e.g.*, Butler, *supra* note 43, at 619–22; Doty & Sullivan, *supra* note 10, at 226–35.

46. R. Dobrof, Community Involvement: An Approach to Enhancement of Quality of Life in Nursing Homes (paper prepared for the Institute of Medicine Committee on Nursing Home Regulation, Fredricksburg, Virginia, Dec. 10–12, 1984; copy on file with author); *but see* Hoch & Hemmens, *supra* note 33 (conflicts with home care).

47. Montgomery, *Staff-Family Relations and Institutional Care Policies*, 6 J. GERONTOLOGICAL SOC. WORK 25 (1983).

and to relate to whatever community support groups or presence there is in the nursing home. They will be able to contact their former case managers. Frail, elderly people, whether in nursing homes or the community, need strong structural and professional support if they are to become "rights-bearing" citizens.