

# Expanding the Home Care Concept: Blurring Distinctions among Home Care, Institutional Care, and Other Long-Term-Care Services

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**T**HE DEFINITION OF HOME CARE APPEARS OBVIOUS; indeed, it seems to be contained in the very term. At a minimum, home care refers to care given in their homes to people with disabilities or diseases. In the United States, home care also refers to a series of programs that are licensed and reimbursed in specific ways and that have been contrasted to nursing-home care as a way of serving people with chronic illnesses and functional impairments.

This article identifies several trends that, if allowed to continue, blur the definitions of home care and institutional care, change the cast of characters providing both types of care, and even challenge the definition of home. Taken to logical conclusions, this redefinition of home care could result in a sharply different conceptualization of both home care and nursing homes. I begin with a discussion of trends for some home care providers to deliver personal assistance services (PAS) in the community to people who are *not* home bound, and also to provide home care services to people whose “homes” are apartment units in assisted living complexes. Next, I discuss features associated with a “home-care model” for long-term care (LTC), and I then turn to factors that facilitate or impede these trends. I conclude with a summary of the chal-

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lenges to policy makers that stem from the blurring of boundaries between home care and other LTC services.

Home care and residential care providers may decide either to welcome this boundary blurring or to fight to maintain programmatic distinctions. Arguably, widespread confusion about the definition of home and home care could be a positive development, bringing new possibilities to home care providers, reconceptualizing the work done by staff of residential settings, and, most important, bringing new options to disabled people of all ages. The trends toward clouding distinctions between home care and institutional care particularly promise to improve the lives of elderly disabled people—the largest population in need of care and the people whose care presently is most formula driven, owing to the regulatory and reimbursement provisions in Medicare and in state Medicaid policies.

Thematically interwoven are arguments for the policy of developing and financing a flexible array of home care services that achieve the following:

- Eliminate arbitrary distinctions between home health care and other in-home service.
- Move toward a PAS model of home care, which provides service to persons with functional impairments in the places where they live and at the community locations where they wish to go for vocational, business, or recreational reasons.
- Move toward a PAS model of group residential care where people who have relocated into the setting because of functional impairments receive their care in, at a minimum, small, self-contained apartments with full baths and kitchenettes, and where they can experience the privacy, individualization, dignity, and normal lifestyles that are absent from the dominant nursing-home model.
- Change the balance of power for both home care and residential care (now nursing-home care) so that the clients or their agents (usually family members) have more control.
- In group residential LTC settings, separate the mechanisms for financing the housing and hotel-like functions from those for the care functions (the former include housekeeping, laundry, and restaurant services; the latter include personal care, nursing, and other professional services).

## Trends toward Blurring Boundaries

In the past decade, "home care" has assumed a wider meaning than care in self-contained private homes. On the one hand, home care providers are following clients into the community; on the other, home care providers are following people into group living situations. Both these directions were accentuated in the community LTC entitlement proposed by President Clinton in 1993 as part of the Health Security Act. Although the specific proposed health care reforms expired in 1994, the principles enunciated for home and community-based care were derived from experiences at the state level, and states are continuing to develop their LTC programs along those lines (R.L. Kane and R.A. Kane 1994).

### *Home Care Moves Out of the Private Home*

Increasingly, home care workers are assisting home care clients, including some elderly clients, in settings other than their own homes. For example, home care workers may assist clients to travel about the community, participate in the labor force, go shopping, and perform errands. This development has been heralded by some spokespersons for younger disabled people, who advocate for PAS under the direction of the consumer rather than, or as a supplement to, home health care under a medical model. Arguably, PAS maximize overall functioning of people with disabilities (Sabatino and Litvak 1992).

Spokespersons for young disabled people often object to both words of the term "home care." Some prefer to reserve the term "care" for intimate relationships characterized by affection, maintaining that disabled people who need concrete help or assistance should be able to choose whether or not to have that help provided by family members or others in caring relationships with them (Asch 1993). Furthermore, they argue that disabled people need assistance not only when they are in their homes, but also in order to function and flourish at work and at leisure in the larger community. Most certainly this model is incompatible with the requirement that clients must be homebound to receive assistance. Personal care attendants are viewed as enabling clients to go where they wish whenever they wish (Litwak, Zukas, and Heumann 1987).

Most of the public dollars for financing home care for the elderly comes from Medicare, a program that requires the beneficiary of services to be homebound, to have rehabilitation potential, and to have a medically identified need for skilled care on an intermittent basis. Medicaid programs in most states mimic this model, which has become ingrained after almost three decades as practice orthodoxy in the thinking of staffs of thousands of home health agencies. Thus, home care for the elderly in the United States has a dynamic that differs markedly from PAS. On the other hand, by 1991, statewide PAS benefits ordered by physicians were available in 28 state Medicaid programs, which, however, largely serve younger recipients and explicitly exclude from the benefit tasks requiring professional skill (Lewis-Idema, Falik, and Ginsburg 1991). However, the boundaries between the services of a PAS worker and of a home health aide, or even those of a licensed professional under home health funding, are less clear-cut than the program descriptions would suggest.

Recent developments in state-funded and Medicaid-waiver-funded programs, moreover, have allowed an end run around Medicare definitions of home health care for the elderly. For example, most waiver programs emphasize PAS rather than home health care, and they make eligibility for benefits contingent on measurable functional impairment rather than medically endorsed "need" for specific services (e.g., skilled nursing, physical therapy, speech therapy, occupational therapy, medical social work, and home health aide services, as in the Medicare rules).

Thus, care plans under Medicaid waiver and state programs tend to endorse and authorize an amount of help (measured in hours) and enumerate the tasks for which help is required rather than order services from particular professionals. In some jurisdictions, home care personnel assist elderly clients by taking them on walks and accompanying them to the doctor, the grocery store, and other destinations where they have business. Depending on the program, the home care provider may be asked to chauffeur clients in their own or the worker's car and to facilitate clients' participation in activities that might be viewed as social. Well-to-do elderly people with functional impairment have purchased such assistance for centuries; what is new in the United States is the gradual and somewhat grudging recognition that people requiring public subsidy for their care should also have access to this model of service. Of course, when the person is eligible for Medicare coverage, the Medicaid program seeks to utilize the federal dollars, and the Medicare regula-

tions and conventions then apply. The relation between services under the two forms of funding is typically poorly articulated.

The trends toward PAS were reflected in the 1993 Health Security Act, which called for a new community LTC entitlement with the following features:

1. Program eligibility is not based on age.
2. Program eligibility is based on measurable impairments (the measures differing somewhat for different target groups) rather than on medically prescribed services.
3. Personal care is at the heart of the benefit.
4. States are required to make available both client-directed home care (where the client is responsible for selecting, training, supervising, and evaluating the worker) and care purchased from agencies.

### *Home Care Workers Follow Clients into Group Residential Settings*

In some jurisdictions home care agencies and workers provide service to people living in group residential settings such as board and care homes (Hawes, Wildfire, and Lux 1993) and adult foster homes (Kane et al. 1991b). In such cases, a person who receives room and board and housekeeping help from staff of a residential setting also may receive personal care and/or home health care from an outside agency. This clearly stretches the definition of home. Such patterns are familiar in Canada (R.L. Kane and R.A. Kane 1985) and in Europe (Jamieson 1991), but are relatively new in the United States.

Recent trends in the United States have encouraged a group residential model, often called "assisted living" (Mollica et al. 1992; Kane and Wilson 1993). There, people disabled enough to be found in nursing homes live and receive service in self-contained, unfurnished apartments in complexes that offer a full range of personal care, nursing services, housekeeping, and congregate meals. In these settings, the residents (or tenants, as they may be called) are likely to have units with full baths, kitchenettes with stoves and refrigerators, and keys to lock their doors. Attendants bring care and service to the apartments according to individual plans. One could argue that such settings should be construed as

the clients' own homes, analogous to apartments anywhere, rather than as upscale institutions resembling nursing homes. If viewed as constituting homes, the services are a form of home care, whether they are provided by staff in the complex, by home health workers from an outside agency, or by some combination of these.

Currently, state regulation of assisted living settings has resulted in substantial intrastate and interstate variation (Kane and Wilson 1993). Among the standards that may be in place are environmental standards, which refer to the settings themselves; staffing and services standards, which refer to type and ratio of staff; and admission and retention standards, which refer to the characteristics of the clientele who may be admitted to, or retained in, the setting (Kane and Wilson 1993). Some states have forms of assisted living that are literally licensed as types of home care, which means that operators must take out a separate home care license if they provide personal care services to their tenants. In other jurisdictions, operators of assisted living complexes have been precluded from delivering hands-on personal care or nursing services directly; they may, however, help their tenants gain access to services from certified home health agencies or from other home care agencies. Some states require no licensure for assisted living complexes at all if the complexes are composed of individual apartments with cooking facilities. In these states, if no governmental subsidy is requested for the shelter or the service, arrangements can be made for tenants to receive care from staff of the program, staff of outside agencies, or both. The charges and the location of the care coordination role varies in such programs.

In some state jurisdictions, state-funded or Medicaid-waiver-funded clients have been able to receive subsidized care in assisted living programs as authorized by a case manager who controls access to the subsidies. In such schemes, the tenants pay for the housing, housekeeping, and congregate meals from their incomes, and the service component is fully or partly funded by the public program (if these tenant clients meet the pertinent income requirements). If the older person has a very low income, the housing component may also be subsidized by SSI supplements, and public assistance may be used to furnish the apartment unit. In some states, notably Oregon, most of the services are purchased directly from the operator of the licensed assisted living setting, although the case manager or the private-pay client may purchase additional assistance from outside agencies or consultants—using home health agencies or licensed health care personnel as needed.

Again, some federal reform proposals and a few existing state policies recognize and encourage assisted living by making people eligible for the new community care service regardless of where they reside as long as they are not in a licensed nursing home. Credibility for the role blurring in the definition of home is also found in a recent monograph on home care for the elderly, designed to provide an overview of the field:

The concept of “home” also requires comment. In the current context, this includes any residential setting in which formal medical services are not provided as part of the housing component, although supportive services may be. In other words, nursing homes are excluded but board and care homes are included. “Home” may mean a detached home, an apartment in a family member’s home or a large complex, or a unit in a congregate housing arrangement with supportive services. (Benjamin 1992, 13)

For practical purposes, some states have defined a home by the presence of a kitchen with cooking facilities (or at least a microwave and small refrigerator) and a bathroom within the unit rather than off a common corridor. Market analysts assert that older people and their families much prefer this design, even when they are so disabled that their use of the kitchen will be minimal and when they require the three daily meals served in a congregate dining room, which could be viewed as a restaurant.

## Features of a Home Care Model of LTC

A home care model, in this discussion, refers to a model of care that shifts the balance of power from professionals to consumers and views the client’s living space as his or her home, where he or she can expect to exercise control. In this article I argue for such a model, which in turn has minimum requirements. The residential setting must be sufficiently private and self-contained to coincide with a reasonable definition of home; and the providers of service, whether they are home care agency personnel or staff of the residential program, must treat clients as tenants in their homes rather than as residents of an institution.

A hospital or a nursing home is the turf of paid staff, both professional and paraprofessional. A person’s home, according to the proverb, is his or her castle. The very circumstances that render quality assurance

difficult in home care (Kane et al. 1991a) give consumers a chance to make the ultimate decisions about their lives. Elderly and disabled people in their own homes have the opportunity to set their schedules, eat their choice of food, maintain their lifestyles, and reject medical and nursing advice from time to time (Kane et al. 1994). Elderly and disabled people in nursing homes live according to care plans, presumably crafted for their benefit. These care plans shape the clients' daily lives, and exceptions require specific permission from professionals. Nursing-home residents have little opportunity to set their own schedules or to reject professional advice (Kane and Caplan 1990).

Thus, clients receiving home care, in contrast to those with equivalent disability receiving nursing-home care, are more likely to have individualized care, to exercise choice, to maintain privacy, and to experience "normal" lifestyles. Some would argue that values of individualization, dignity, privacy, autonomy, and "normalization" should also apply to nursing-home residents. However, the design of the space, with its double-bedded rooms and lack of privacy, and the conventions of care (driven by regulation, interpretation of regulation, fear of liability, and efforts at efficiency) stand in the way (Kane and Caplan 1990).

Arguably, therefore, settings where elderly or disabled people relocate in order to receive LTC services at affordable prices should be designed to feel like a private home, and the service model should foster a balance of power between client and care provider that more closely resembles home care than nursing-home care. With some conceptual rearrangement, policy makers and regulators could begin to consider complexes that would serve disabled persons as a collection of individual homes, avoiding the sparse and uniform physical settings and the forced sharing of quarters with strangers that belie the concept of home.

Home tenancy (whether ownership or rental) does not carry unbridled license. The mortgage or rent must be paid. The property must be kept in reasonable condition to protect the investment of mortgage holders or owners. The tenant's personal habits must not constitute a public nuisance or health hazard for the others in the building or neighborhood. Short of these kinds of problems, however, public authorities cannot remove people from their own homes against their will just because of a view that they would be safer or better served somewhere else. In contrast, residents may be removed from licensed board-and-care homes, foster homes, or assisted living sites in many states because their disabilities exceed the legal capacity for service licensed for those settings. A



person living in an apartment, however, cannot easily be removed to a “higher” level of institutional care because, for example, he or she cannot transfer in and out of bed, or because a professional has judged that he or she is unsafe in the setting. Such removals are only possible in the wake of draconian legal steps to assert that the person is incompetent and to strip him or her of legal rights. When an entity is construed as a private home, its inhabitants have rights that do not apply in a health-related facility.

To summarize, consumers who experience a home-care model for LTC control its arrangements, the activities that take place there, and the timing and intensity of the health and personal-care services brought to them there. The living space must meet minimum prerequisites for privacy and autonomous living: single occupancy, a full bathroom inside the unit, a kitchenette, and a locking door. The tenant (or the tenant’s agent, in the case of those who are cognitively impaired) bears ordinary responsibility for upkeep of the premises and payment of the rent. The rent and the service arrangements are priced separately, and may be subsidized through either public or private insurance.

## Forces Accelerating and Impeding Boundary Breakdown

Various factors contribute to the blurring of boundaries between home and community-based services and institutional services. These factors largely provide opportunities for expanded home care and for more flexible, normal, dignified approaches to the care of people of all ages with functional impairments. There are forces, however, in the public policy arena at both the state and the federal level that threaten to undermine the best features—tenant autonomy and reasonable pricing—inherent in the assisted living movement.

### *Cost-Effective Alternatives to Nursing Homes*

Starting from the assumption of a dichotomy between home and community-based care, on the one hand, and nursing-home care, on the other, policy makers and researchers have labored for at least two decades to identify the circumstances under which home care can be a cost-effective

alternative (Applebaum, Harrigan, and Kemper 1986; Weissert, Cready, and Pawelak 1988). A series of controlled demonstration projects has shown that, under current pricing structures and service models, home care will be more expensive than nursing-home care for people with substantial disabilities unless they receive the bulk of their care from unpaid family members. The economies of scale attained by caring for people with substantial disability under a single roof, rather than at far-flung individual locations, and the current pricing structures for Medicaid payment in both sectors have foreordained that nursing homes will be more cost effective than community care for identical clientele with severe functional impairments.

Such studies, of course, are done in the context of reimbursement rates established for nursing homes by state Medicaid programs (often artificially low) and rules governing home care frequency and type. Ironically, given the below-subsistence wages typically paid the line paraprofessional home care worker, the cost of home care has often been kept relatively high by the amounts of service deemed necessary, the high costs of the legally required visits by professional nurses either to supervise the workers at established intervals or, sometimes, to render services that only licensed nurses can provide, and the front-end costs of professional (often team) assessment and care planning. Care for very disabled persons in group settings should be cheaper than care at home because of absence of travel costs, joint production functions, and economies of scale.

There is a break-even point below which the cost of home care is the same or less than the cost of nursing-home care, and after which home care will exceed the cost of nursing-home care. Obviously that break-even point is more likely to be reached if the home care client has high levels of disability, has little or no family help, and lives in a home that is inaccessible or difficult to maintain. It is less often recognized that people with substantial disabilities will be likely to receive care at home under the break-even point if nursing-home reimbursement rates are relatively high, if home care rates are relatively low, if plans for home care are relatively parsimonious, and if home care providers can organize their services to achieve economies of scale. Such an eventuality can be achieved by eliminating requirements for minimum hours of service and by assigning workers or teams to particular buildings and geographic areas where many clients reside.

Nursing homes are billed as 24-hour care. In a typical scenario, a doctor explains to a family that the discharge planner will look for a nursing home because their mother needs 24-hour care. In reality, these prescribed settings provide remarkably little nursing care. A recent study of a large sample of nursing homes and nursing-home residents in six states uncovered the following facts: about 39 percent of the sample received no care from a registered nurse (RN) during the 24-hour study period; the average RN time per resident was 7.9 minutes; the average LPN time, 15.5 minutes; and the average nursing assistance time, 76.9 minutes (Friedlob 1993). Yet this modest amount of care cannot be replicated at home for the same price because the nursing home efficiently provides stand-by assistance and can meet unscheduled, quickly arising needs.

The need to reexamine the way housing and ongoing care needs are met is illustrated by the experience of On Lok, a capitated program in San Francisco's Chinatown, where low-income enrollees with nursing-home levels of disability are served by an organization that receives a capitated rate from Medicare and Medicaid and is at financial risk for all the enrollees' acute-care and LTC needs. The program and its replication programs, known as Programs for All-Inclusive Care for the Elderly (PACE), rely on adult day health care to monitor and serve the clientele. They have found that highly disabled clients who need care at night and on weekends, and who have no relatives able to provide this assistance, cannot be cared for cost-effectively or kept out of nursing homes unless their housing and services are rearranged. Thus, On Lok has invested in housing developments that have created communities of elderly apartment dwellers. On Lok has also enabled its enrollees to obtain assistance from live-in personal care attendants. In some arrangements, one such attendant provides service to several On Lok clients who live in the same apartment (R.L. Kane, Illston, and Miller 1992).

Thus, capitated programs like On Lok and PACE (so far feasible only for low-income persons dually eligible for Medicare and Medicaid) had to innovate in order to cut through the barriers between home care and nursing-home care and to provide practical assistance to people in settings they could consider as home. This same principle applies to services that are pieced together by, and on behalf of, functionally impaired elderly people whose incomes exceed Medicaid eligibility and who can afford to pay for much of their care. At present, rigid licensing definitions for group residential settings, for home care agencies, and even for home

care workers may prohibit their purchase of the kind of help consumers want at prices they can afford. Developments in assisted living can cut through those barriers.

Some state officials still think in strict dichotomies between nursing homes and their "alternatives." Indeed, such distinctions are embedded in the home- and community-based Medicaid waiver program, in which those served must have a medical "need" for nursing-home care according to some operational definition. Unfortunately, several states acknowledge a catch-22 attached to the use of waivers for assisted living. Licensure for group residential homes may prohibit admitting or retaining anyone who needs routine nursing service, yet the waiver requires that clients need a nursing home before their care can be reimbursed.

Other states, impelled partly by safety concerns and partly by pressure from the nursing-home industry, are setting new thresholds for nursing-home admission, construing that some "nursing-home-eligible" people can be served in assisted living, which permits them to be financed under the waiver, whereas others are classified as too disabled. A state using case-mix designations for Medicaid nursing-home reimbursement may target assisted living to the lower acuity levels of the nursing-home clientele. Or, a state may determine that some procedures or client disabilities are incompatible with assisted living. Some states, notably Oregon, have made a commitment that Medicaid waiver and state-funded LTC programs will provide true alternatives to nursing homes for people with high levels of disability. They have accordingly created a range of flexible home care options, some linked to housing alternatives. In a review of such programs in Oregon, Washington, and Wisconsin, the U.S. General Accounting Office (1994) substantiated the widely held perception of Oregon's programs as both cost effective and user friendly.

Such steps still vastly expand the home-care-like possibilities in assisted living. However, the policies just described cling to the idea of a continuum that suggests that professionals can determine how different disability levels dictate different care arrangements and that rates the nursing-home model as the most appropriate for some people. Elsewhere, I have criticized the goal of a continuum of care, to the extent that this requires professionals to judge the best "placement" for the client (Kane 1993a). On these grounds, continuing-care retirement communities are vulnerable to criticism. Although designed to offer older people the security of a full spectrum of care from home care to nursing homes, typically the consumer does not retain the right to decide where

in the community to live, and fixed levels of care are linked to residential arrangements along the continuum.

### *Nurse Delegation*

Many nurse practice statutes have been interpreted to mean that only an RN or a licensed practical nurse (LPN) can perform a wide range of tasks (e.g., administer oral or injectable medications, care for wounds, monitor vital signs, change catheters, monitor ostomies, monitor people on respirators). Of course, in practice, family members carry out these tasks for their relatives of all ages. In fact, the home care field has a long literature and tradition of instructing patients in self-care and family members in the care of patients who cannot care for themselves. Although some strict interpretations of nurse practice acts state that even unpaid relatives cannot legally perform functions defined as nursing practice (Kapp 1993), home health nurses themselves have included the transmission of skills to family members in the definition of their functions. It is only when individuals unrelated to the client perform tasks and receive compensation for them that the boundaries are drawn between the responsibilities of a nurse and those of other personnel, and that the conditions under which the latter are carried out receive scrutiny.

In the late 1980s, Oregon modified its nurse practice act explicitly to permit people who are not nurses to perform nursing functions if they have been taught by a nurse on a patient-specific and procedure-specific basis and have been certified as able to do the task. Thus, paraprofessional home care workers, adult foster care staff, and assisted living staff may be instructed in the specific nursing procedure for the particular patient. Records of tenants in assisted living settings in Oregon typically contain documentation for each person who has been delegated as capable of performing a list of nursing functions for each tenant. Assisted living settings in Oregon typically hire a nurse directly if they serve more than 50 tenants, and they typically contract with a nurse for part-time service if they are smaller, but any and all nursing procedures can be delegated to people who are not nurses. Indeed, the nurse on the staff or on contract may spend considerable time preparing others for their delegated duties. Sometimes staff of certified home care agencies provides the delegation instruction to staff of adult foster care homes while delivering Medicare-reimbursed home health service. Oregon case manage-

ment programs also employ or contract with nurses who can provide the delegation training to persons who deliver home care under the client-directed home care program. Some adult foster care homes also have their own contractual arrangements with a nurse who provides this function. Contrast this to rules in some states (e.g., Washington) that require licensed nursing personnel for assisted living, thus driving up the costs and making small programs economically inviable.

Oregon authorities believe that their nurse delegation provisions opened the way for the state's well-known cost-effective community programs (U.S. General Accounting Office 1994) for people who are as disabled as nursing-home residents in other states. Kansas also has nurse delegation provisions in its nurse practice act, although these do not extend to injectable medications. Texas enacted such a provision in 1992, and Colorado also has made changes that permit greater delegation of nursing functions. Some informants suggest that the current nurse practice acts in their states do not really prohibit an Oregon-style delegation, although, in practice, it might not occur. For example, Minnesota's nurse practice act explicitly states that licensed personnel may delegate their tasks. It is left to the nurse, however, to interpret what tasks may be safely delegated and how much ongoing supervision would be expected of the nurse, who is responsible for any untoward events. Conservative interpretations are most likely under these conditions, especially because home health nurses are schooled by Medicare regulations that require frequent supervision of home health aides. Minnesota's home care licensing statute is more restrictive than nurse practice statutes because it exacts requirements that all personnel delivering more than 40 hours of assistance a year to a functionally impaired person in their own homes must receive training and supervision from a licensed agency (Kane, O'Connor, and Baker 1995).

A nursing task ripe for delegation is that of dispensing oral medications. This task is performed by outpatients on their own behalf as part of regular medical practice and by parents on behalf of their outpatient children. Performance is not particularly monitored and is known to vary markedly from the specifications for dosage, timing, and other conditions on the prescriptions. Yet current regulations and practice conventions that allow the patient and the family to assume this responsibility do not allow nonlicensed paid caregivers to dispense medications, even when they have been taught how, and even though one would expect accuracy standards to be at least as good as those observed by the patient

and family. Because medication management is one of the services that assisted living tenants most frequently need, elaborate rules are built around a system that is often a charade: Assisted living staff are allowed to provide assistance with self-administration of medications. In some states (e.g., New York) self-administration of medicines is construed so broadly that it can describe a staff member selecting the medication from a locked cabinet, delivering it to the tenant in unit doses, or opening the bottle, removing the medicine, and placing the pill on the tenant's tongue. This liberal definition of self-administration of medications avoids grappling with the real issue, which is whether a nurse must administer medications or provide frequent surveillance of paraprofessionals who administer medications when clients are incapable of administering the medications themselves. So far, a number of states find it easier to create a fiction that many clients—even those with dementia—are self-administering drugs than to face this issue head-on.

The National Council of State Boards of Nursing (1990) and the American Nurses Association (1992) have addressed the issue of delegation directly. Neither organization is opposed to nurse delegation as long as authority to delegate is at the discretion of the nurse and nurses are not forced to delegate tasks. In general, nursing assessment, diagnosis, and planning require professional judgment and are viewed as inappropriate to delegate to unlicensed personnel. My own review of this topic (Kane, O'Connor, and Baker 1995) suggests that considerable training and support services are needed before nurses generally will be comfortable with exercising delegation.

### *ADA and Fair Housing*

The Americans with Disabilities Act (ADA) is new enough that regulations have not been fully promulgated for housing settings, nor has much case law been developed. It is plausible, however, for the ADA to be evoked to prohibit insistence that people be evicted from assisted living settings where they, in fact, have their home because of increasing disability. In some instances where this has occurred, the argument has been successfully made that persons with dementia need not leave a particular assisted living setting just because the state had approved for the setting only people who could summon help and preserve themselves against danger. The Fair Housing Act (FHA) prohibits discrimination in housing because of disability, and may also be invoked to establish the

right of disabled people to live in homes of their own choosing (Redfoot 1993). Although the terms “eviction” and “transfer to a higher level of care” denote very different acts, their effects may appear identical to the person being moved.

ADA and FHA introduce untraveled roads in law. Clearly, a hospital “discriminates” on the basis of health and disability; such distinctions form the basis for diagnosis and treatment recommendations. Nursing homes make such discriminations, and case-mix reimbursement systems employ fine gradations of payment based on configurations of measurable functional and cognitive disability and prescriptions for measurable service.

Thus, a health care facility is expected to make distinctions based on disability. A hotel or a housing development is not. This leaves open possible legal interpretations regarding assisted living complexes where tenants rent self-contained apartments, however small, and receive hotel-like services from the complex (e.g., meals in a dining room and housekeeping). Some developers and managers of assisted living programs interviewed in a recent study (Kane and Wilson 1993) frankly preferred their product to be construed as a health care setting because they wished to be exempted from ADA and Fair Housing requirements; those who preferred assisted living to be an option replacing nursing homes for many residents, rather than a niche on a continuum, expressed the hope that ADA requirements would undermine the state licensing rules that force discharge of people at specified levels of disability. At present, requirements are murky and sometimes contradictory, as, for instance, when an accommodation in a private apartment with a kitchen does not meet a state standard of fire safety for retention of persons who cannot transfer that is higher than the one applied to hotels or high-rise residential structures, which may be housing people with identical physical limitations. Another contradiction may occur if the state takes no notice of the situations that prevail in the private market (often because the residences themselves are unlicensed), but imposes strict admission, retention, and service-level standards on persons who receive public subsidy for the service. This introduces the inequity that well-to-do people can live in apartments that provide service and can purchase private-duty care to supplement what the complex provides when they have reached a level of disability that would prohibit a home care agency or management of assisted living from billing the state for their care.



*Pressures on State Governments*

It is axiomatic that LTC is a large part of state expenditure, and that states have many pressures influencing their stance about the emerging phenomenon of assisted living. Most states feel impelled to curtail the growth of LTC budgets, and are willing to invest in assisted living only if they believe it really can reduce total fiscal liability for LTC. States are also concerned about quality issues; no state official wants a major board-and-care quality scandal on his or her watch. Officials may fear that the delegation of nursing functions and the increased personal autonomy for tenants associated with some assisted living settings are formulas for disaster, and that the cost of doing it any other way would be the same or more than nursing-home costs.

States also combine an interest in system reform with a need to utilize existing state resources. In many states, the licensed entities providing board and care are sharply bifurcated into relatively luxurious entities for private-pay clientele and lower-amenity settings that accept SSI as payment in full for the room and board function. Clients and workers in the latter "SSI-settings" are already marginalized (Eckert and Lyon 1992). Some states doubt that they can mandate the kind of minimal environmental standards for private occupancy, kitchens, and baths to pertain to programs serving low-income clientele and justify costs. Oregon, in contrast, does require single occupancy, full bath, kitchenettes, and many other features that enhance autonomy and dignity for its licensed assisted-living facilities and expects the requirement to be met regardless of the clientele payment source. Oregon, however, has few staffing standards (largely the requirement that at least one person be on duty and awake at any time) or service standards (three meals must be served congregate style), trusting to internal and external case management and market forces to maintain quality. External case management is provided by the case managers who allocate the service for low-income people and therefore have a presence in the setting. The state also expects providers to have an internal capacity for case management and to have developed specific plans with and for each tenant. Market forces act in the sense that privately paying consumers seem to prefer foster care (Kane et al. 1991b) and assisted living to nursing homes. Finally, nurse delegation and regulatory relief keep costs in bounds.

Most other states have proliferated staffing and service standards that drive up costs and have failed to establish the minimal environmental

standards that would make assisted living fit common definitions of home. (Despite the rhetoric that promotes the view of a nursing home or board and care home as the resident's home, when staff can enter at will, when residents are told not to expect their possessions to be safe, when hospital beds and small amounts of furniture are arranged according to regulation and staff convenience, and when the mathematics of room assignment preclude true choice of roommates or of single rooms for most people, residents and their families are not fooled. They know they are living in an institution.)

In wending their way through the problems created by a genuine wish to improve quality, an urgent need to contain costs, and a desire to get a proactive handle on planning by building on the existing housing stock, state governments are also subject to multiple interest-group pressures. Nursing homes may lobby against rules that allow alternative housing settings to serve any but the least disabled of the LTC clientele—that is, those who do not “need” nursing-home care. Existing board and care homes may lobby against enhanced environmental standards for new payment programs that would eliminate them as vendors. Professional groups like nursing and pharmacy boards may argue that flexibility reduces quality. Ombudsmen and advocates for LTC clients may also argue for increased protections. Sometimes consumer groups convey the double message to state officials that they want increased personal autonomy for their constituency while still holding the state responsible for accidents that occur to clients who are receiving care with public dollars or from publicly licensed programs. Most federal and state home care organizations have not yet formulated policy on the issue of assisted living (Kane and Wilson 1993).

## Policy Challenges

At present, organized home care (especially organized home *health* care) has paid little attention to assisted living or other developments that may change the very shape of home care provision. A key informant study of assisted living (Kane and Wilson 1993) showed that, with some exceptions, state and federal home health or home care organizations had not developed policy on the topic and were not particularly monitoring developments. At some point, however, home care organizations will be jolted into taking a stand on the topics I have discussed here.

Their positions will either move service systems in the direction of more flexible, individualized provision of care to persons with functional disabilities regardless of where they live or reaffirm rigid service categories of home care, board and care, and nursing-home care. Arguably, the way of thinking about the “customer” that has necessarily been reflected by home care agencies, who realize their staff cannot ultimately control the consumer’s behavior, would benefit workers in other locations of care. The agencies and individuals who provide home care could, with reorganization and different ground rules, work in settings that are not exactly private homes, but are their clients’ homes nonetheless. For this to occur, the home care industry needs to consider the following issues.

### *Distinguishing Type of Care from Place of Care*

The place of care should not be confused with the type of care. Public policies are dysfunctional if they insist that people who are “appropriate” for care in a nursing-home setting because of their disability levels therefore must receive care either in a nursing home or not at all (at least under public expense). As an intermediate step, home care providers and case managers for home care programs should reconsider their criteria for determining that a client can no longer be cared for safely in the community.

The interchangeability of various care arrangements for persons needing LTC should be recognized. It is a fallacy to suggest that a single best arrangement can be designed for an individual based on his or her health needs. Personal choice and resources can suggest different ways for services to be mixed and matched.

### *Delegation*

Serious attention must be given to determining what care can be safely delegated to nonprofessionals and under what circumstances. Rather than supporting rules that require certain increments of professional supervision (which are based on professional orthodoxy), the home health industry should support and participate in studies that test the efficacy of arrangements where nurses provide training and backup support rather than ongoing supervision at fixed intervals.

### *Personal Assistant Services (PAS) Models*

Flexible home care and PAS that are under the control of the consumer of care to the extent of that consumer's desire and capability is a goal that disabled people of all ages are likely to support. Policy makers will confront a number of decisions, however, as they move toward this model. One issue requires disentangling the concept of PAS and consumer direction from that of the consumer as employer. For in-home workers to receive adequate protections as employees, it may be impractical to expect each disabled individual to manage the benefits of a small group of employees. Perhaps different kinds of home care agencies can emerge that serve as low-cost finders, screeners, and fiscal intermediaries for such workers. Another issue concerns whether the public mood will tolerate an approach to serving disabled people that emphasizes PAS and facilitates their functioning in the community. Although unit costs of PAS are lower than those of home health care, some critics might view it as frivolous to use public dollars to assist older people to navigate in the community; however, they may be willing to use such money to enable younger people to remain in the workforce. Subsidized services should be linked to clear, and probably stringent, eligibility criteria. Moreover, it will be important to explore ways of ensuring that the technical health care needs of those receiving PAS are met.

### *Assisted Living with Services*

Home care organizations should welcome the opportunity to provide service in group residential settings (here called assisted living). They should also be open to arrangements where assisted living staff become a de facto home care agency that provides most of the service to the clients. The latter is obviously a more efficient model for meeting unscheduled need. Nurses and other professional therapists from outside agencies may have to visit tenants of assisted living whose specialized needs cannot be met internally. They may also be engaged to teach and delegate tasks to unlicensed personnel. The effects and costs of various ways of mingling staff-delivered and externally contracted services in programs of various sizes and in environments with varying service availability should be studied.

In this article, I have argued for a minimum environmental standard that emphasizes privacy, space, and autonomy-enhancing features like

bathrooms and kitchenettes, even for people who are very disabled and may seldom use the kitchens. These features may be criticized as either an expensive indulgence or a dangerous innovation that combine more opportunity for accidents with less opportunity for staff surveillance. Therefore, studies of the costs, risks, and benefits of these interventions are needed. I have also argued that states should not succumb to the pressure to subsidize LTC services provided by the staffs of board and care homes. This view could be criticized on equity grounds. Some question the fairness of denying a care benefit to those living in board and care homes while providing such a benefit to those in assisted living settings? However, it seems fair enough from the perspective of low-income consumers; once they are deemed to need a nursing level of services, they would be able to receive them in an enhanced environment. The main equity issue concerns providers seeking reimbursement. One cannot, however, expect the marketplace to change the paradigm of care if financing is provided in settings that meet neither minimal expectations as homes nor the staffing and health-related requirements of nursing homes. Ethicists might well turn their attention to these issues (Kane 1993b); in the meantime, obligations to consumers seem to trump any obligation to provide a market to providers. Analyses of the kinds of regulations and quality assurance provisions that would enhance the evolution of assisted living for older people with disabilities, such as recent work by Wilson (1995), are much needed.

Some advocates may object to any idea of relocating people with disabilities to assisted living settings rather than leaving them in their own home. Here, however, we must distinguish between a person's own home and a person's original home. Many people experience multiple residential relocations over a lifetime. The value-laden question concerns what actually constitutes a home. A small group setting housing four individuals may be less of a "home" than is a small apartment for one person in an assisted living complex that has 60 such apartments and a staff available to provide help and care in the unit.

### *Charting the Future of the Nursing Home*

What about nursing homes as we know them? There will still be people who cannot benefit at all from the privacy and autonomy inherent in an assisted living model of care. For example, this service system makes no sense for people who are comatose or so severely demented that they are

in vegetative states or do not interact with their environment in the slightest way. The model may not work for some medically unstable people who truly need around-the-clock high tech care.

It is often noted that nursing-home clientele has changed in the past decade. Residents are sicker, and shorter stays, terminating in death or rapid discharge to acute-care facilities, are more common (Kodner 1993). Many proposals have been advanced for more effective nursing-home care in the future, some of which emphasize the need for the nursing home to be better integrated with care networks providing both acute care and LTC (Evashwick 1993). Recently, Burton (1994) has suggested that the nursing home could be at the hub of a service system for people with chronic disability, providing ambulatory care, home care for those living independently, and various types of group residential care for people with different needs. An alternative view (Kane 1993b, 1994) notes the heterogeneity of those now in nursing homes and suggests that the nursing home as we know it (an institution that could never be mistaken for a home) should be reserved for people who cannot interact with their environment, who are so medically unstable that they need hospital-like medical attention, and who perhaps need intensive rehabilitation on an inpatient basis. (The jury is still out on the latter group, however, because physical environment and autonomy are important to the morale and outcomes of rehabilitation patients.)

### *Financing and Payment*

Financing of and reimbursement for home and community-based care is beyond the scope of this article. Undoubtedly, however, both financing and reimbursement policies need rethinking in order to eliminate current barriers (Feder 1991) and to build on the developments I have described. The Health Care Financing Administration has initiated a process for examining the Medicare home health benefit, in part, to see if it could be more flexible and user friendly (Vladeck 1994). It will be important also to try to eliminate the differentials that make Medicare-covered services more expensive than those purchased privately or by other payers. Case managers in state programs will always be enjoined to find a federal payer when possible, and the general public is most concerned with the total public costs rather than which public payer gets the bill. Making flexible in-home and PAS services available to a wide range of users in a variety of settings possibly would work best with a disability

allowance rather than a system of authorizing services, a stance that has its advocates (Batavia, DeJong, and McKnew 1991). Future studies should explore the advantages and disadvantages of various ways to make public dollars available to individuals with needs for service without inducing demand and increasing costs unduly.

Home care and assisted living providers could play pivotal roles in furthering a movement in LTC that would bring a home-care style of service to people who have established new homes in group residential settings so that their LTC needs are met. This will require flexibility and new paradigms for thinking, but the benefits for the lives of clientele are potentially enormous. One hopes that organized home care will be part of imaginative solutions to the care of functionally impaired older people rather than part of the problem that narrows and stultifies their lives.

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