Empowering Frail Elderly People: Opportunities and Impediments in Housing, Health, and Support Service Delivery

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The concept of active, successful aging for the well elderly has gained widespread support within academia and the larger society over the past three decades. The notion of positive aging, however, is not very often applied to the frail elderly who are not, at least from the biomedical perspective, aging successfully. The two books reviewed here, make a compelling case for extending the active, engaged, empowered perspective on aging to those elderly who do not fit the medical model criteria of successful aging, including independence and full self-sufficiency. According to Boldy, McCall, and Heumann, the medical model:

...sees disability and frailty as deviations from the norm, so care is designed to reduce the gap between the norm and the pathology. This often means providing a secure and comfortable environment and providing prescribed types and levels of care based on the degree and type of disability or frailty. At its worst, it is a total inhibitor of empowerment of the individual to define the environment of care and support that will maximize personal functional independence and allow a lifestyle that yields the greatest satisfaction and dignity.

The domination of the medical model contributes substantially to an institutional care bias that shapes long-term care policy and practice for the frail elderly at every level—from the formulation of budget priorities (80% of all long-term care public dollars go for nursing home care) to the design and use of hospital discharge and client assessment instruments and care planning and management practices, which tend to focus more on the disabilities than the strengths of long-term care consumers to preclude opportunities for empowerment.

Empowering Frail Elderly People contains 15 separately authored chapters divided into five sections which address issues related to using information and training resources by service providers to enhance consumer empowerment, making conventional housing more supportive of autonomy among the frail elderly, and creating opportunities for consumer empowerment in long-term care, including nursing home care, as well as a concluding overview section which identifies and assesses societal level barriers to empowerment of the frail elderly.

This book represents a valuable contribution to long efforts over decades by some scholars and advocates to create a more balanced view of the aging experience than is provided by the medical model's focus on decline and dependency.

Several of the chapters offer detailed descriptions of how this narrow, disempowering view of aging can be resisted through the development and use of specific policies and practices. For example, many frail elderly who could benefit from consumer-directed care and other forms of community-based, long-term care do not live in physical environments that support this kind of care. Heumann notes that:

If seniors want to maximize environmental support and independent living when faced with advancing frailty, they almost seem to be encouraged to look for a purpose-built retirement or assisted-living solution. There don't seem to be many program options for modifying a conventional home and staying put. Those that do exist seem to be...
very crude and not coordinated under a single care management model. This can only be seen as a limitation in support choices and flexibility, which limits empowerment of frail elderly people who want to retain maximum control of their support system. ...This can ultimately affect one’s desire and ability to remain in what was once and could still be an independent environment. Thus, both the material and psychological costs can cause the ultimate loss of power—a premature move to a totally dependent environment.

The chapter by Boldy, McCally and Heumann addresses the fact that many frail elderly may not be very interested in maintaining control of the care (services) they receive and are ready to have case managers and other professionals handle their care in whatever way they think best. The authors note that:

...after years of acquiescence to professional authority, many frail and disabled persons and their families are afraid of empowerment. Therefore, the proactive professionals must see their roles as becoming advocates and teachers, educating and training elderly and disabled people and the general public to this new way of thinking and acting. ...The most important client-based impediment to empowerment is the loss of confidence and self-esteem that comes with a loss of independence from living in a supportive environment that does not encourage people to continue to seek independence to the margin of their ability. ...any program or strategy that society develops to empower frail elderly people must also recognize that some older people will consciously choose dependence. We are clearly for programs and practices that are sensitive to this choice and have the flexibility to accommodate it as equally as providing full empowerment. From our perspective, however, it is the empowerment model that our societies are having real trouble fully addressing, not dependence by choice.

Germain Harvey, in her chapter on resident empowerment in nursing homes, shows how a Montreal nursing home has implemented policies and practices and constructed a physical environment designed to encourage and cultivate empowerment.

The program is designed to create a resident-oriented balance between freedom and safety by allowing the resident to make decisions and take actions that involve degrees of acknowledged risks that may be inherent in the resident’s efforts to achieve an acceptable quality of life. The program is based on a charter of resident rights and freedoms which has been used to make qualitative changes in the organizational/management structure and day-to-day culture of the facility. These major rights include: 1) the right to be informed and freedom of expression, reversing the traditional balance of power between the residents and staff; 2) the right to privacy, just as the resident would have in her own home; 3) the right to respect and dignity, obliging staff to treat residents with deference and shunning familiarity, infantilism, and personal prejudices; 4) the right to continuity, requiring that each resident is seen and assisted by the same staff; and, 5) the right to responsibility and participation in the organization and administration of the nursing home.

These rights constitute the framework for creating a balance between freedom and safety for residents and a far more comprehensive vision of the needs of residents than is allowed under the conventional medical model. By reducing our concern for the frail elderly to a focus on their physical needs and limiting the concept of quality to staffing standards, pressure sore care, and other criteria contained in our current regulatory regime, adherence to the medical model of nursing home care leaves out most of what makes life worth living for most people—dignity, autonomy, emotional connection, individual identity, and equality in relationships. It is precisely these values and the capacity to achieve them that this program is designed to put back into the lives of residents.

This program is a resident empowerment strategy usually associated with assisted living rather than nursing home care in the U.S. where the focus has been on regulatory requirements related to the quality of medical care. Some progress has been made by the Nursing Home Pioneers and advocates for the Eden Alternative and the Green House Project. All of these groups are committed to changing the culture and ecology of nursing homes and making them more livable environments with greater opportunities for the residents to exercise autonomy. In order for these changes to occur on a broad scale, however, policymakers, regulators, and providers will have to overcome the exclusive commitment to a medical model of care and regulation along with the constant threat of litigation that is endemic to a model that provides so little room for resident autonomy and the availability of opportunities to make choices that may entail some degree of risk.

Ageist assumptions about the elderly, especially those with substantial impairments, stand in the way of consumer empowerment in...
long-term care. These assumptions include the stereotypical perceptions that: 1) functional impairment in old age automatically leads to dependency and a rapid decline in the values of autonomy and control, and 2) younger disabled persons are deeply committed to maintaining as much independence as possible, but older disabled persons are not. The success of the California (IHSS) program and similar consumer-directed care programs in other states and in Europe, including programs for the cognitively impaired, should put to rest the notion that many impaired older persons are not interested in controlling (at least partially) their own care. Boldly et al. state:

Society must get over its fears of aging and its remaining stereotypes about the aged. This means that our goal is not docile, happy and secure people with disabilities. Our goal is to meet the wishes for support and values for independence through empowerment, providing flexible choices and training and explaining the options and risks associated with different choices. Beyond this, there are no institutional norms, no prescribed categorical solutions. Risks, problems and failures on the part of disabled people should not be eliminated, avoided or “solved” for disabled people. Nor should the allowance of risk or problems to exist in individual care planning be seen as unprofessional or project failures. These are essential parts of life being lived to its fullest. We need to define, measure and reward professional caregiving in ways that encourage empowerment in flexible, humanistic and creative ways. If we can’t find these types of solutions, there will never be any real empowerment of frail and disabled people.

Possibly the most promising approach to empowering consumers in long-term care is consumer-directed care (CDC), which has become the primary mode of long-term care in Germany and Austria and is a very substantial part of the long-term care system in California. Ethics, Law and Aging Review, Volume 6, edited by Marshall Kapp, contains papers on various dimensions of consumer direction, including a comprehensive first chapter by Kapp on the philosophical and legal justification for consumer-directed care.

The ethical rationale for CDC is based on recognition of the value of human autonomy and the moral obligation to nurture the autonomy of impaired persons, including the frail elderly, by providing long-term care in the least restrictive manner compatible with the needs and resources of the individual. Personal autonomy is arguably the core value of American culture and the basis of identity in Western societies. Any public policy or program practice that qualitatively restricts the capacity of individuals to exercise autonomy because of impairment bears a heavy burden of justification. The implicit assumption of most long-term care programs for the frail elderly is that they must sacrifice their autonomy—their ability to exercise sufficient choice—as a condition of receiving care. The largely unquestioned rationale for this assumption is that long-term care professionals (those assessing needs, drawing up service plans, and providing services in a heavily regulated command and control long-term care system) should make the decisions about care because they have the training and experience necessary to know what is best for the consumer. This is a model of professional control operating in the name of beneficiaries. Kapp (1999) notes that:

Unless there exists decisional incapacity on the older or disabled consumer’s part, it should be the obligation of both the public and private sectors to empower the consumer to overcome any informational and/or intellectual shortcomings to the greatest extent possible, rather than to permit proponents of extensive regulation to latch onto those consumer limitations as a convenient excuse or pretext to foreclose consumers’ options in the name of beneficence.

Even beneficence, however, as a governing principle in long-term care is severely restricted by the fact that providers operate in a pervasive environment of legal regulation that gives priority to following rules and uniform procedures rather than responding to the unique needs and preferences of the individual consumer. Kapp goes on to argue that:

... displacing command and control regulation [and service delivery] with enhanced consumer control may help address a prevalent, vexing problem with the regulatory model that I have addressed comprehensively elsewhere. That is the phenomenon that a pervasive environment of legal regulation (or a perception that such an environment exists) generally instills in service providers, case managers, decision makers and surrogates for incapacitated patients, and patient advocates powerful anxieties and apprehensions about exposure to potential legal consequences that inspires forms of defensive (or at least intended to be defensive) practices that work at cross purposes to the ideals both of autonomy and beneficence. Choices may be foreclosed to the patient/consumer because those
choices are thought to expose the provider, case manager, surrogate, or advocate to unacceptable legal risk, for instance, even when those choices might have actually benefited the well-being of the patient/consumer.

This is not a system of care designed to achieve either consumer autonomy or beneficence. Autonomy has never been adequately recognized as a value to be achieved in the development of long-term care policy and practice. Respect for the need and desire of the frail elderly to remain as autonomous as their impairments allow by providing supportive, nurturing environments and services has been, more often than not, compromised by the needs of policymakers and providers to achieve short-term bureaucratic or fiscal goals with the implicit notion that autonomy is not an appropriate or achievable goal for the dependent elderly. Kapp’s paper goes a long way toward demolishing this uninformed, misguided notion on philosophical and empirical grounds.

Winsor Schmidt criticizes Kapp’s market-oriented approach for consumer direction by pointing out that the American health care system is dominated by for-profit corporations (insurers and HMOs) who have increasingly reduced the range of choice available to consumers over the last 20 years. I think Schmidt is right to address Kapp’s market rationale in the larger context of corporate domination of the health care market. From Kapp’s perspective, however, consumer direction has the potential to create a more level playing field by giving long-term care consumers far more power over resources than they have now, which is necessary, if not sufficient, condition for the creation of a truly competitive marketplace. A more likely outcome of consumer direction, however, is the withdrawal of resources from the formal market and from proprietary providers and their redistribution within the informal care system as consumers pay friends and relatives for the provision of care. This appears to be precisely the outcome in the German and California cash and counseling programs.

Kathleen Wilber makes the useful point that consumer direction cannot function effectively in a fully deregulated market where fraud and misleading marketing would make a mockery of consumer control, as occurred with the unregulated Medi-gap insurance market and could yet occur with the Medicare plus choice program.

The downside risks of a deregulated market approach to long-term care are also explained by Iris Freeman:

The goal of the marketplace model, on the sunny side, is a more knowledgeable, empowered consumer, with services that aim to please. From the vantage point of consumer advocates, however, one cannot help seeing the shift from a regulatory to a marketplace model as a shift from an entitlement safety net to an “afford it if you want it” reality, a darker, social Darwinistic approach to long-term care policy at the state level.

Lori Simon-Rusinowitz and her associates report the results of a survey they conducted of 20 policy experts in the areas of services for the elderly and younger disabled persons. They found considerable evidence of an emerging consensus of support for consumer direction for both groups. They also provide an overview of the major implementation issues identified by their respondents. These issues, which most respondents consider surmountable, include the need to contain fraud and abuse, to protect the interests of consumer-directed workers, and to address traditional provider resistance and the relationship between consumer direction and managed care.

In a long and detailed chapter describing and analyzing an experimental consumer direction program in New York City for the cognitively impaired elderly, Elias S. Cohen, who has long been an advocate for consumer-directed care for both the elderly and developmentally disabled, and his co-authors identify a number of issues that must be addressed in the development of programs for this population. This paper is mandatory reading for academics, policymakers, and administrators interested in the potential strengths and weaknesses of consumer direction and how to build the former and avoid the latter.

These two books add substantially to the emerging literature on consumer empowerment and self-direction in long-term care and should be of value to anyone interested in qualitatively changing our current, largely appalling long-term care system.