The Science and Ethics of Long-Term Care

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As a researcher and policy analyst in aging, I have been puzzled by the wide and arguably growing gap between, on the one hand, what we know about the long-term-care preferences of the elderly for community-based alternatives to institutional care and about our capacity to provide these alternatives cost effectively and, on the other hand, the kind of care, mostly institutional, we have in fact made available. Even though over the last several years we have learned how to make community-based programs affordable and effective, long-term care remains dominated by nursing homes in the vast majority of states. This failure to use what we know to change long-term care in ways vastly preferred by those at greatest risk of needing care (the frail elderly) reflects less a gap in knowledge than a lapse of moral imagination.

We have not paid sufficient attention to the ethical dimension of the debate over health care policy for the elderly, especially the frail elderly with chronic conditions and impairments requiring long-term care. We have been absorbed with cost-containment, efficiency, and cost-effectiveness issues and have tended to pay little attention to the many ethical and moral assumptions inherently related to these issues, which are most commonly treated as technical matters. I am referring to such assumptions as the notion that autonomy is not important to the impaired elderly and should not be used as a criterion in the development of long-term-care policy. I think this situation is a manifestation of what Taylor (1991) has described as the domination of "instrumental..."
reason"—pure, self-verifying rationality in the conduct of contemporary policy studies and in policy making.

Instrumental reason, as described by Taylor, has dominated our thinking about long-term-care policy and practice. Many of us, I think, have long believed that we were just one or two extensive studies short of having the evidence needed to make a conclusive case for the cost-effectiveness of home- and community-based alternatives to nursing homes and the creation of a consumer-oriented long-term-care system, as if justification of such a model rested singularly on its cost-effectiveness. I am now convinced, however, that we cannot rely on either cumulative learning from multiple research projects or a "big bang" breakthrough (the big study) to achieve a basic change in long-term-care policy. The science of long-term care will not do the work of the moral imagination in the development of a long-term-care system that is fundamentally responsive to what the frail elderly and their caregivers want and deserve.

In fact, we already have a body of research that demonstrates the capacity of community-based programs to serve the seriously impaired in a cost-effective fashion. These studies have found that, by making available certain services to high-risk recipients in increased quantities (e.g., number of nurse visits or hours of homemaking services), community programs may reduce nursing home use. Findings reported in recent articles by Jette, Tennstedt, and Crawford (1995), Greene and colleagues (1995), Weisert (1995), and Weisert and associates (1997) indicate that certain mixes of clients and services have the potential to reduce nursing home use substantially.

While we need to continue to conduct research studies on long-term-care options, we should not expect that the results of research alone will create sufficient conditions for a profound change in the direction of long-term-care policy. Such change will require a collective change of heart that is fundamentally dependent on the creation of a clear moral vision for long-term care. Research can help us identify the most efficient and consumer-responsive methods of achieving policy priorities inherent in a moral vision. Research is not, however, a substitute for the kind of moral reasoning we need to undertake as a community and as an aging society.

As I will discuss later, adult communities of people who are, respectively, developmentally disabled and physically disabled have substantially changed their systems of care over the last 25 years. They have done this through advocacy initiatives to change the way society views the disabled. They have used research to make pragmatic program decisions and to evaluate outcomes. They have not, however, relied on research to shape fundamental policies. For this, they have articulated and acted on a moral vision that maximizes the rights of people with disabilities to define and control their own destinies. The examples from these two communities about the role of moral reasoning in achieving change can serve as a model for revolutionizing long-term care for the elderly.

THE CURRENT SYSTEM

Many states began to develop in-home and community-residential programs in the 1970s in the hope that they would eventually lead to a substantially reduced dependency on nursing homes and a far more balanced system of long-term-care services. However, the percentage of public long-term-care expenditures going to nursing homes (80–90%) is essentially the same now as it was when the first community-based programs were implemented (Kane, Kane, & Ladd, 1998). The very large increase in the Medicare home health care program, which has grown from 1.6 million beneficiaries in 1986 to 3.6 million in 1995, does not seem to have done much to change the economic dominance of nursing homes in long-term care (Ladd, Kane, & Kane, 1999). On the other hand, without the increase in the Medicare home health care program, nursing home dominance might have been even greater in many states, reflecting the stagnation in public funding for nonmedical home- and community-based care.

Some policy analysts and advocates who work on aging issues, including myself, assumed that, with the decline of general-revenue funding for community-based programs, states would shift to Medicaid waiver funding sources. Waivers would replace state general revenue and maintain the momentum in the development of community-based programs that had been generated in the early and mid-1980s. This assumption, however, was largely unwarranted.

Data do not support the notion that Medicaid waiver funds have been used in place of state general revenue funds to continue the expansion of community-based programs for the elderly (Polivka, 1999). Waivers have instead been used in most states to maintain existing community-based programs, while general revenue funds were increasingly shifted to the politically popular areas of education and criminal justice.

Bruce Vladeck, former administrator of the federal Health Care Financing Administration, recently noted that very little has been accomplished over the past fifteen years in the implementation of home- and community-based programs for the elderly, even as the demographic pressures and demand for services have continued to build inexorably.
He acknowledges the trends described above, by pointing out that “almost all the growth in Medicaid and home- and community-based services has been among the non-elderly populations eligible for such care” (Vladeck, 1998).

The absence of substantial progress in the development of community-based long-term care for the elderly over the last several years is made even more egregious by what we know about the nature of life in most nursing homes for many residents. Nursing homes have improved over the last ten to fifteen years and they are the only feasible option for some small percentage of the most impaired elderly, but they were not designed to nurture autonomy or provide a high quality of day-to-day life. Most of us dread the specter of nursing home placement for ourselves and our loved ones, and would prefer to remain at home with supportive nursing and homemaker services, or live in as homelike and noninstitutional an environment as possible.

**PUBLIC POLICY AND DIFFERENT PERCEPTIONS OF DEPENDENT POPULATIONS**

What then accounts for the discrepancy in the kinds of publicly-funded long-term care available to the impaired elderly and that available to persons with physical or developmental disabilities? We usually hear that this discrepancy is largely a function of differences in the kinds of physical or cognitive impairments experienced by these populations, differences in the extent of involvement in their own care, and differences in commitment and the amount of advocacy in which the respective populations are engaged. These are important differences, but the real reason is that the aging research and advocacy community does not have a coherent, compelling moral vision and ethical theory that can compare to the development/normalization model that has guided policy and practice in the disability community since the early 1970s.

The community of persons with developmental disabilities has long benefitted from well-organized, intensive advocacy initiatives at the federal and state levels. These initiatives have historically been guided by a moral vision and ethical framework (a theory of rights and obligations) grounded in the normalization principle, which holds that while individuals with developmental disabilities may be different from others, these differences should not be viewed negatively and should be accommodated by a society prepared to support and nurture them as autonomous individuals.

Advocates in the independent living movement have largely recast disability as an oppressed-minority-group status, which has allowed the disabled to advocate for a more responsive and supportive environment and to generate sources of self-empowerment. By comparing the independent living orientation of nonelderly disabled with the perception of dependency imposed upon and acquiesced to by many disabled elderly, Kennedy and Minkler (1999, p. 94) show how disability is, in substantial part, socially constructed: “We speak of the disabling environment. This concept places the locus of disability not solely within individuals who have impairments but also in the social, economic, and political environment. By this argument, people are impaired but the environment is disabling.”

Kennedy and Minkler contrast this perspective with the currently dominant view of the disabled elderly: “Whereas ‘access’ and ‘full participation’ have become key concepts for the younger disabled population, for disabled elders, the rights of families and professionals, and of the disabled elders themselves, tend to be far more circumscribed.” In this way, “aging professionals, elders, and society in general appear to have traded earlier, limited views of aging for an even more limited view of what it means to be old and disabled” (p. 101).

**TOWARD AN ETHICS OF LONG-TERM CARE**

During the past few years I have often thought about what kind of ethical framework would begin to do the kind of work for the impaired elderly that the developmental model and normalization principle have done for the developmentally disabled for almost 50 years. I have found helpful a complex, interpersonally oriented notion of autonomy and also the efforts of feminist ethicists to develop a theoretical framework for an ethics of care.

The concept of autonomy integral to the conventional ethics of acute care emphasizes the role of informed consent by a competent, uncompromised patient confronting relatively precise decision-making events involving specific medical procedures and short-term treatment strategies.

This conventional notion of autonomy, which is based on the fundamental liberal values of freedom and the integrity and dignity of the self (the bases of identity in Western culture), has played a critical role over the last two centuries in defining what it means to be a person in Western societies. Individual autonomy provides the framework for the legal concepts of competency, consent, and confidentiality. After years of legislation and litigation, these concepts have emerged as hard-won tools for ensuring that individuals have the right to be presumed compe-
tent (rigorous criteria must be met to prove incompetence) and to control what is done to and for them (consent and confidentiality). These rights, if effectively enforced, protect autonomy and help preserve the individual’s sense of self—of who she or he is.

This approach to informed consent and confidentiality, however, is not an effective means of preserving autonomy in long-term care, where the lives of patients are shaped less by discrete decision-making events than by daily routines and styles of caregiving. The effective application of informed consent in long-term care is dependent on continuous, undistorted communication between the impaired person and his/her care providers. This approach has been referred to as a process model of informed consent, as contrasted with the event model of informed consent in acute care (Agich, 1993).

In the absence of continuous, undistorted communication in long-term-care settings, Moody has noted that we have the “colonization of the life-world in old age, where the last stage of life is emptied of any meaning beyond sheer biological survival. . . . This whole development is part of a social and historical process, not all a matter of individual choice. Therefore it is not surprising that the traditional ethics of individual autonomy has been helpless to halt this erosion of freedom. The ethics of patient autonomy may insist on informed consent or encourage advanced directives. But those very instruments are compromised by the institutional structures and the systematically distorted communications in which the elderly receive care” (Moody, 1992, p. 115).

In Autonomy and Long-Term Care, Agich (1993) makes a sophisticated argument for autonomy as the core value governing long-term-care policy and practice. His argument is based on a critique of the concept of autonomy that includes many of the same concerns raised by Moody. The concept of autonomy derived from liberal theory with its heavy emphasis on individual independence, nonintervention, and rational decision-making does not provide a practical framework for an ethics of long-term care. It is too abstract and removed from the complex realities of long-term care. Agich’s view of autonomy is grounded in a situated perspective that focuses on interpersonal relations, institutions, culture, and other contextual factors that shape the development of the self.

Agich’s emphasis on communication and negotiation reflects his intention to identify ways of protecting and expanding opportunities for autonomy in the complex “real world” of long-term care. A person’s evolving sense of self and the need to choose activities and projects consistent with his/her sense of self does not end with frailty and long-term care. Autonomy in long-term care is preserved by listening to and taking seriously the unique life stories of the impaired person and providing the kind of support that helps that person maintain his/her identity despite impairment and illness. This positive interpretation of autonomy is based on the recognition of human interdependence and the limitations inherent in the liberal theory model of complete independence, especially in the context of long-term care.

Long-term care, therefore, must include a broad range of options and alternatives in order to maximize the opportunities for choices and actions that are consistent with the impaired person’s sense of self and the need to create opportunities for the person’s continued development. Even nursing homes, the most limited long-term-care environment, should be designed to maximize opportunities for autonomy, offering supportive substitutes for the activities the impaired person values but may no longer be competent to perform without assistance.

I don’t think the more complex notion of autonomy, as described here and as distinct from notions of autonomy found in biomedical ethics, has ever been adequately recognized as a value to be achieved in the development of long-term-care policy and practice. In my experience, respect for the need and desire of frail elderly people 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 policy makers and providers to achieve short-term bureaucratic or fiscal goals and the implicit notion that autonomy may well not be an appropriate or achievable goal for the dependent elderly.

Autonomy among the dependent elderly cannot be recognized and supported in the absence of the kinds of nurturing relationships mandated by an ethics of care, which prepares us to protect the vulnerable, including dependent older people. Tronto has noted, “Throughout our lives, all of us go through varying degrees of dependence and independence, of autonomy and vulnerability. A political order that presumes only independence and autonomy as the nature of human life thereby misses a great deal of human experience, and must somehow hide this point elsewhere” (1994, p. 135).

Marilyn Friedman has noted that an ethics of care which incorporates mutual recognition of autonomy and vulnerability, fosters a respect for persons which is “. . . not the abstract respect owed to all persons in virtue of their common humanity, but a respect for individual worth, merit, need, or, even, idiosyncrasy. It is a form of respect which involves admiration and cherishing, when the distinctive qualities are valued intrinsically, and which, at the least, involves toleration when the distinctive qualities are not valued intrinsically” (1998, p. 270).

Friedman admits that we cannot respond to everyone in their particularity, including each person’s unique needs and preferences and cases.
ities to act autonomously, and that a comprehensive ethics of care (autonomy and vulnerability) may operate somewhat differently at the levels of society (of public policy formulation) and the individual relationship.

According to this framework, rule-based equal respect for the frail elderly needing long-term-care services would require the equitable allocation of public resources to long-term-care programs. At the level, however, where decisions are made about how to spend and administer the allocated resources, the focus shifts from the general to the particular; from the frail elderly as a group to the frail person who is dependent on day-to-day care and intimate, responsive relationships with others, which are essential to an acceptable quality of life in any long-term-care setting.

The kind of ethical framework for the care of the frail elderly outlined here can be linked to the emergence of the human rights movement over the last half century. I think that efforts to improve care of the elderly can be strengthened by making them part of the evolving human rights agenda which increasingly constitutes the moral criteria we use to judge the behavior of governments toward their own citizens and those of other nations. Respect for the autonomy and dignity of each individual, which are the guiding values of the human rights movement and the ethical framework for the care of the frail elderly that I am recommending, is based on what the social theorist Paul Heelas (1996) calls the ethics of humanity which has emerged in Western culture over the last 200 years. According to the great sociologist Emile Durkheim in his late 19th century work, *Suicide* (as cited in Heelas, Lash, & Morris, 1996):

As societies become greater in volume and density, they increase in complexity, work is divided, individual differences multiply, and the moment approaches when the only remaining bond among members of a single human group will be that they are all men (sic). Under such conditions the body of collective sentiments inevitably attaches itself with all its strength to its single remaining object, communicating to this object an incomparable value by so doing. Since human personality is the only thing that appeals unanimously to all hearts, since its enhancement is the only aim that can be collectively pursued, it inevitably acquires exceptional value in the eyes of all. It thus rises far above all human aims, assuming a religious nature. (p. 211)

It was only after the savagery of World War II, however, and in response to the growing awareness of the evils of racism and murderous nationalism, that the need to recognize and protect individual rights, including autonomy and equal opportunity within a community of humankind, began to emerge as the framework for a universal ethics of humanity. This is expressed in "The Preamble of the Universal Declaration of Human Rights (1948)... Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world..." and Article 1 states, "all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." (Heelas, 1996, p. 208).

Many religious traditions offer spiritual foundations for an ethical framework for the care of the frail elderly. Regardless of one's religious orientation, however, the application of a human rights perspective, based on an ethics of humanity in long-term-care policy and practice, could help generate the moral passion that I think will be necessary to create a just and compassionate long-term-care system.

**APPLYING AN ETHICS OF CARE TO LONG-TERM-CARE POLICY AND PRACTICE**

Our current policies and programs for the frail elderly are not designed to protect their autonomy and the provision of basic care is far from adequate. Most publicly supported long-term care is provided in nursing homes, where patient autonomy is a low priority and the quality of care is shaped by the impersonal bureaucratic routines described by Agich. In short, our treatment of the frail elderly falls far short of our stated respect for autonomy, as defined more narrowly by an ethics of justice or more broadly by an ethics of care. Given the current and growing emphasis on reducing public expenditures and replacing publicly administered programs with privatized alternatives, which are presumably responsive to the efficiency maximizing operations of the market, this gap threatens to widen as members of the huge baby boom generation reach their 70s in the next two-to-three decades.

An ethics of long-term care, based on the work discussed in this chapter, would recognize the need to balance the protection of autonomy with the realities of dependency and interdependency in the provision of long-term care for the frail elderly. A critique of our current long-term-care system from the perspective of an ethics of care, which incorporates Agich's concept of complex autonomy and a commitment to what Hofland calls the "right to flourish," would discover, at a minimum, that the current system does not accommodate a wide range of dependency nor does it maximize autonomy. Such a critique should be designed to draw on the findings of the Retirement Research Founda-
tion’s project on personal autonomy in long-term care (Hofland, 1995, and chapter 2, this volume).

The first of the four major findings from the project was, “Personal autonomy is seriously and unduly restricted in many long-term-care facilities. Most nursing home residents report that they value autonomy highly and want more control over everyday aspects of their lives and care including their personal space, room, and day-to-day lifestyle. Both professional and paraprofessional staff members agree that it is important for residents to exercise control over everyday matters, but staff members sometimes doubt that it is possible in the present regulatory and reimbursement environment” (Hofland, 1995, p. 22).

Rosalie Kane (1995) has described a number of steps that could be taken through the regulatory process to enhance rather than restrict the autonomy of persons in long-term-care facilities. She notes, “Expectations embodied in regulations that require residents or their agents to have the opportunity to participate in their care plans have the potential to enhance autonomy. Such provisions offer residents a chance to provide input and question the care plan. On a systemic level, regulations requiring resident councils, requiring mechanisms for appeal of care decisions, requiring the residents be consulted on room or roommate changes all have the potential effect of increasing residents’ voices and power within the facility” (p. 79).

Other autonomy enhancing regulations include requiring that residents be permitted to make telephone calls to whomever they choose and talk to them privately, call their primary care physicians and specialists and speak to them alone, wear their own clothing, be offered choices of food, and choose bedtimes and rising times.

Kane notes that:

Perhaps the most controversial way that regulation can enhance autonomy is by mandating minimal requirements for privacy and dignity of the environment. Arguably, such standards are needed for anyone to exercise autonomy when unrelated adults live together in a group situation. (1995, p. 80)

The second project finding was that there is often a substantial mismatch between resident and staff perceptions. Long-term-care facility staff members often make paternalistic assumptions that they know what residents like and want, but actually they often do not know. Kane and her colleagues (1990) found that nurses’ aides and residents differed considerably in how each group ranked the aspects of day-to-day life which were most important for residents to control. The two items rated highly by most residents were trips out of the facility and use of the telephone, whereas nursing assistants most frequently rated organized facility activities, such as bingo and arts and crafts, as important, and least frequently rated using the telephone as important (Hofland, 1995, p. 22).

The third project finding was that procedures to assess decisional capacity are seriously flawed and often biased against the elderly. Decisional capacity is frequently treated as a global, all-or-nothing phenomenon rather than as specific to a particular decision. Capacity can fluctuate as a function of anxiety, depression, grief, or a short-term confusional state. Too often, assumptions of incapacity and actual legal determinations of incompetence result from the mere presence of advanced age, frailty, poor health, eccentricities, or a medical diagnosis, such as Alzheimer’s disease or a related dementia. Moreover, once an older person is labeled as incapacitated and a guardianship has been instated, staff often wrongly assume that the person is incapable of making any choices or decisions (Hofland, 1995).

The fourth project finding was that, although nursing assistants provide the bulk of direct care in facilities and are critical for support of resident autonomy, their task-oriented work approach greatly limits opportunities for the exercise of autonomy. Aides usually see their work as implementing routines for such tasks as lifting, turning, dressing, feeding, waking, and communication between aides and residents (Hofland, 1995).

Kane (1995, p. 24) suggests several solutions to this dehumanizing situation including:

Initial and continuing education and training for aides that include discussions of enhancement of resident autonomy in their everyday work would be a good starting point. Also important are the involvement of aides in the development of care plans, modeling of appropriate behavior by senior and professional staff, and assignment of aides to specific residents so that the aides come to know care, and feel responsible for these residents. Most important, autonomy must become a central goal of care, and autonomy enhancing efforts must be rewarded through regulatory and reimbursement mechanisms.

We have only begun to tap the potential of programs designed to accommodate dependency by providing resources for the exercise of autonomy. We have learned enough from our limited initiatives, however, to know how such resources can be effectively employed. Adequately funded in-home and congregate-care (assisted living and adult foster homes) alternatives to institutional care, including forms of consumer-directed care, can provide opportunities for autonomy and interpersonal connection far beyond those currently available. This is true even for those who are seriously disabled, including people with Alzheimer’s disease, who should not be limited to locked units in congregate settings.
The kind of ethical framework that I'm recommending here, an ethics of care with a focus on autonomy, would support the development of a long-term-care program for the frail elderly patterned after the current system of care for persons with developmental disabilities. That is, long-term care for the frail elderly would include a wide range of in-home and congregate-care alternatives to nursing homes and consumer-directed care, including cash-based programs; they would be available to all who preferred this form of care and were minimally eligible. No one would be forced to enter a nursing home because no appropriate alternative program was available. According to this policy scenario, the percent of funding for nursing homes would be reduced from 80% of all public funds to under 50% over the course of a decade.

The development of such programs should not be governed by cost-effectiveness criteria only; the effectiveness criteria should incorporate an ethics of care framework based on the value of autonomy in the lives of dependent people, including the frail elderly. Just such a framework was implicit in the original vision for the development of in-home programs and the assisted living program for seriously impaired and publicly supported residents in most states. This vision featured a commitment to quality-of-life values, including autonomy, privacy, and dignity, that are more achievable in a person's own home or in a homelike, rather than institutional, environment. It is now time to develop what was implicit in the original vision of community-based care as an explicit ethics of care with a focus on autonomy and extend it across the spectrum of long-term-care programs.

REFERENCES
