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## Long-Term Care and a Good Quality of Life: Bringing Them Closer Together

Rosalie A. Kane, DSW<sup>1</sup>

Long-term care policies and programs in the United States suffer from a major flaw: They are balanced toward a model of nursing home care that, regardless of its technical quality, tends to be associated with a poor quality of life for consumers. This article proposes quality-of-life domains—namely, security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being, and functional competence. It argues that these kinds of quality-of-life outcomes are minimized in current quality assessment and given credence only after health and safety outcomes are considered. Five trends are reviewed that might lead to a more consumer-centered emphasis on quality of life: the disability rights movement, the emphasis on consumer direction, the growth of assisted living, increasing attention to physical environments, and efforts to bring about culture change in nursing homes. Building on these trends, the article concludes with strategies to move beyond current stalemates and polarized arguments toward forms of long-term care that are more compatible with a good quality of life.

*Key Words:* Public policy, Nursing homes, Home care, Assisted living

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Long-term care (LTC) in the United States requires serious and creative attention. It is largely off the political radar screen in any meaningful way, and public rhetoric about it seems off the point. The year 2000 marks a historic opportunity to build on current needs and positive models to build better long-term care. The umbrella questions inspiring this article are not research questions but require reflection on existing research and scholarship. For example, what can and should we expect for a good life for those receiving LTC? Why are discussions about LTC so polarized? Why is forward progress in the direction preferred by consumers of LTC so difficult to achieve? What strategies hold promise to improve long-term care?

Plenty of suggestive research is available to aid in examining broader current LTC policy and practice and its effects, but the relevant scholarly work is not neatly collected and arranged to offer policy and practice insights; some assembly is required. The conclusions here partly result from sifting through findings from my own and others' research. Relevant scholarship includes preference studies, health services outcome studies, the results of social experiments in LTC, social science studies that elucidate the nature of well-being, and anthropological, philosophical, and legal studies. Also relevant are the accounts of biographers and novelists, the latter often based on firsthand experience. For example, the "data" of the late Janet Tulloch, for decades a resident of a nursing home in Washington, DC, and a keen observer of life in nursing homes, should not be discounted because she was a consumer and some-

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Address correspondence to Rosalie A. Kane, DSW, National Long Term Care Center, 420 Delaware Street SE, MMC 197, Room D-527 Mayo, Minneapolis, MN 55455. E-mail: kanex002@tc.umn.edu

<sup>1</sup>Division of Health Services Research and Policy, School of Public Health, University of Minnesota, Minneapolis.

times fictionalized her observations (Tulloch, 1975). When she notes that a care plan can be an “instrument of terror” for a nursing home resident (Tulloch, 1995), her comment should be taken as seriously as that of a sociologist who performed more conventional research.

Most people who reach middle years also can test their generalizations about LTC against the experiences of family members and friends. Reflecting on personal “data” is a good antidote to the hubris of presuming to discuss, let alone measure, a good quality of life for those faced with the realities of LTC and the conditions and circumstances that generated its need. As of this writing, the most vivid part of my database includes the experiences of my father (age 93 and healthy but with encroaching macular degeneration) and my mother (age 86 and functionally limited because of osteoporosis), who are so far managing at home; my mother-in-law, who is experiencing physical and cognitive post-stroke problems in a New York assisted living setting; my maternal aunt, who had intensive and escalating needs for both formal and family care during the 3 months between diagnosis of liver cancer and her death in her own home close to her 80th birthday; a paternal uncle, whose Parkinson’s disease limits his functioning drastically, first at home with his wife and now in an assisted living setting in Ontario; a paternal aunt, whose multiple sclerosis necessitated years of in-home care and about 6 years of nursing home care before her death; and other now mostly deceased uncles and aunts and more distant relatives who collectively illustrate a wide variety of chronic illnesses and social circumstances with an admixture of mental health problems and, for a few, Alzheimer’s disease. This collection of family stories immediately reveals that one solution cannot fit all. So, too, do findings from a 5-year longitudinal in-depth study of 300 family caregivers (Kane & Penrod, 1995; Kane, Reinardy, Penrod, Huck, & Finch, 1999), which shows that the dominant tendency in family care (i.e., female, average age in the late 50s) masks the incredible variety that occurs in the real world and the imaginative way ordinary people invent solutions to problems that disability creates in their everyday lives.

At the risk of being trite, those thinking about LTC for older people must consider the meaning of life for life’s last decades. In actuality, LTC discussions often bog down in technicalities, which, though important, fail to strike at the heart of the matter. Technical topics include identifying the best assessment tools for eligibility for publicly funded LTC, developing better ways to key payment for care to the cost of providing it through case-mix adjusted formulas, determining the likely market for LTC insurance, or estimating the cost and benefit of tax credits for family members providing LTC under various circumstances. Perhaps most ubiquitous, contentious, and anxiety-provoking of all technical LTC topics is the woodwork effect: that is, the propensity for people who would shun nursing homes to come out of the woodwork to use more attractive forms of

LTC, thus turning a potentially cost-effective alternative service into an expensive add-on (Kane & Kane, 1987; Kemper, Applebaum, & Harrigan, 1987; Weissert, 1985). Indeed, it is high time to retire the woodwork effect as a concern. A confirmed woodwork effect could even be a sign of *success* if it meant that a state or community had effected wider access to the kind of LTC programs that people want to use. Rather than eliminating the spread of more user-friendly LTC, gerontologists are challenged to alter the essential nature of all LTC into more desirable forms while keeping down the price of services in all sectors (nursing homes, assisted living, and home care). Examples of successful state efforts in that regard are available (Alexih, Lutzky, & Corea, 1996; General Accounting Office [GAO], 1994; Kane, Kane, Ladd, & Nielsen, 1998). Eyes tend to glaze over when the technical issues are discussed. Neither the general public nor the press finds LTC particularly fascinating. The older public and their family members tend to face LTC as an issue only when an individual crisis requires action; there is virtually no constituency among the elderly population for fundamental LTC reform. The press concentrates on covering quality problems (Eisler, 1996; Tofani, 2000; Goldstein, 2001a, 2001b; Steinhauer, 2001). Apart from human interest stories and periodic excitement about potential cures for the conditions necessitating LTC, good news is no news for those who cover the LTC beat in the media.

However, LTC is a subject that should be capable of engaging the imagination positively. For many people, LTC decisions dictate the last chapter of their biographies—the chapter that should make sense of the story. LTC shapes where people live, how they live, whom they see, what they do, and the relationships transpiring within families and communities. How we choose to view LTC as a society, therefore, entails considering subjects as profound as the meaning of life. LTC is intimate care, and how it is given, when it is given, and by whom it is given shapes the biography of the LTC consumer and, by extension, the biography of family caregivers and the collective biography of the whole family.

By LTC, I refer to any personal care and assistance that an individual might receive on a long-term basis because of a disability or chronic illness that limits his or her ability to function (Kane & Kane, 1987; Kane, Kane, & Ladd, 1998). Nursing home care is obviously part of LTC, but so too is care that people receive while living in a wide variety of other settings, including private homes and apartments and a wide array of congregate living settings with services that have sprung up, in part, because of consumer demand for a place more habitable than the typical nursing home (Kane & Wilson, 1993).

The currency of language easily becomes tarnished and soon, perhaps, the term “long-term care” (LTC) will be passé. “Long-term services” is already a preferred term among some people with disabilities (National Institute for Long-Term Services, 1996). Recently the Robert Wood Johnson Foundation has

grouped its LTC efforts for people of all ages under the umbrella term “supportive services.” But whatever it is called, LTC is the mixture of concrete tasks that enable a person with a disability to flourish as much as possible despite that disability; these tasks are sometimes arduous, sometimes time-consuming, sometimes tedious, and often unpredictable and inimical to scheduling. Gerontologists use the shorthand jargon ADLs (activities of daily living) and IADLs (instrumental activities of daily living) to refer to the areas of functioning for which the LTC consumer requires assistance. These terms, while useful, tend to distance us from the phenomenon of the person whose life is complicated by the need for help, whose life may sometimes be sustained by the care, whose aspirations might be made possible because of care received, and whose life is too often made more than necessarily miserable by the circumstances and conditions of LTC.

Bluntly put, LTC policies and practices in the United States are flawed, particularly for those LTC consumers who are old. Moreover, the quality of life for LTC consumers is compromised by a societal reluctance to come to grips with these flaws. Without collective agreement on what is a good or even an acceptable quality of life for someone who needs LTC, the gerontological community cannot even cast relevant research questions or conduct program evaluations in a way that gets to the heart of the matter. And until a realistic view of the goals of LTC and the range of what is possible for an LTC provider to produce is forged, there is danger of unfairly scapegoating LTC providers for their inability to bring about universal happy endings. We are at risk of turning the great bulk of well-intended, hard-working LTC providers into a depressed and beleaguered group who are too fearful of missteps to exercise creativity or even common sense in their daily work.

Anyone following the pendulum swings in nursing home regulation since the enactment of Medicare and Medicaid in 1965 knows that the current climate is particularly unforgiving, intolerant of mishaps or bad results (Kapp, 1997). Regulators and policymakers often expect too much of nursing homes and of other LTC providers. Care managers and health care professionals may also expect too much of themselves if they aspire to eliminate all bad outcomes for clients on their watches. With such grandiose goals, professionals may hasten clients into more protected settings where, of course, the original actors tend to lose track of them and their ultimate outcomes (Kane & Caplan, 1993). Ironically, excessive expectations for promoting health and safety are often accompanied by low expectations and excessive compromise regarding quality of life. Real change in the way most Americans can expect to receive LTC is strikingly difficult to achieve. Communities will need to rethink LTC drastically if fundamental alterations are to be achieved. Politicians talk about facilitating LTC insurance and providing tax credits for LTC, but glide over the actual details of the service that would be purchased with the insurance or tax credits.

The rest of this article is divided into four sections: (1) an opinion about what is wrong with LTC policy and practice; (2) concepts that define a good quality of life in LTC; (3) identification of LTC trends that offer some hope for improvements in quality of life for LTC consumers; and (4) brief suggestions about strategies for bridging the chasm between LTC and what most people would recognize as a good quality of life.

### *Problems With LTC*

In the United States, the bulk of public dollars go where older people do not want to go: to nursing homes (Kane, Kane, & Ladd, 1998). Little imagination is needed to recognize why older people prefer to avoid typical nursing homes and why family members experience guilt and anguish when they see no other choice. Few can conceive of living in the constrained circumstances of the nursing home, particularly if a room and bath are shared. Few can picture adapting to rigid routines for daily life. My father, age 93 at this writing, typically has wine with his evening meal and rarely goes to bed before the 11 o'clock news is finished. If he needed nursing home care, he would be expected to adapt to a different life rhythm. Though he is a brilliant competitor in duplicate bridge, he would be expected to make do with bingo and valentines. More than a quarter of a century ago, Elaine Brody likened the one-size-fits-all nursing home to the Procrustean bed of the myth; victims were chopped or stretched to fit the bed (Brody, 1973). This metaphor is still apt. Research in learned helplessness (Avorn & Langer, 1982; Langer & Rodin, 1976) informs us of the destructive effects such regimens have on the human spirit, creating listlessness, depression, and abandonment of efforts to exert control. A well-publicized report from the SUPPORT study indicated that almost 30% of a sample of seriously ill older people would “rather die” than move permanently to a nursing home (Mattimore et al., 1997). These reactions predominate across cultural and ethnic groups. A poster displayed at the year 2000 annual meeting of The Gerontological Society of America reported a response of an 86-year-old African American nursing home resident to the standard question: How would you rate your mental health, excellent, good, fair, or poor: “My mental health is starving because I can’t go nowhere.” Said another respondent of the same age and race: “It’s just like not living” (Adamek, 2000). “Just not living” and “rather be dead” are such dismal outcomes for life in nursing homes that the various quality-of-care indicators should be rendered almost irrelevant against such indictments.

The quality of LTC has been a perennial subject since federal and state governments began investing large public sums in financing LTC after 1965. In 1983 the Institute of Medicine took a far-reaching look at quality in one sector—the nursing home. Its 2-year study and 1986 report ushered in the regulatory reforms of 1987 (Institute of Medicine, 1986).

Now more than a decade later, as policy-making bodies examine quality in nursing homes and other forms of LTC, getting agreement on the state of current quality is almost impossible. Some people argue that almost no improvement has been made in the quality of nursing homes since 1987, citing GAO reports (GAO, 1998, 1999a, 1999b) and other exposés (Office of the Inspector General [OIG], 1999a, 1999b) that point to serious care violations (e.g., residents who are unfed, unattended in physical pain, suffering infections, malnutrition, neglect, and abuse) and that call for much more stringent enforcement standards. These same advocates tend to argue that persons using in-home services and assisted living in all likelihood suffer from the same quality problems as do nursing home residents, but that data shortfalls prohibit knowing it.

Arguably, however, positive strides in quality of care have occurred in nursing homes since the 1987 regulatory reforms. It seems counterproductive and unnecessarily polarizing to deny these strides. Physical restraints are drastically (though not enough) reduced; geriatric medicine has, at least to some degree, made its way to nursing homes (Evans & Strumpf, 1989; Kane, Williams, Williams, & Kane, 1993). Nurse practitioners are more evident (Mezey, Lynaugh, & Cartier, 1989; Mezey & McGivern, 1986). The Minimum Data Set for nursing homes (Morris et al., 1990) has permitted tracking quality indicators and doing something about them. But even if there were no quality-of-care problems in nursing homes, conventional nursing homes arguably fail the quality test because of the severe strictures on life in these settings. Put simply, the total disenfranchisement associated with living in a nursing home is too high a price to pay for even high-quality technical care. True, some nursing homes all over the country are working to transform the experience of living in and working in a nursing home, a movement discussed below (Fagan, Williams, & Burger, 1997; Lustbader, 2001). Some commentators find this growing attention to quality of life in nursing homes exciting and encouraging, whereas others think these efforts are almost trivial in relation to what they view as extreme quality-of-care problems in nursing homes.

How good are in-home services and personal attendant services, the bedrock of LTC? The data available about the quality of home care (aside from Medicare home health care, which is not an LTC program) differ in nature from data on quality of nursing home care. The kinds of reports that emanate from home care research speak to consumer satisfaction—and generally speaking, consumers tend to be satisfied with home care; the ability to be at home with the help of home care is seen as good in itself. Undoubtedly, home care has been spared the same rigorous and unforgiving standard as nursing home care. One approach to this inconsistency would insist on comparable data so that home care could be held to account. Another approach would consider what is intrinsically good about home care that puts

it in a different category of inspection, and determine how those good features could be, at least in part, replicated in congregate living situations now going under names like nursing homes, assisted living, adult family homes, residential care facilities, and the like. Given all the cultural associations with home—autonomy, familiarity, history, relationships, privacy, dignity—it is perhaps understandable that consumers have little desire to subject their home care service to the same criteria used to look at quality of nursing homes. Indeed, the main critique of home care services, including the most flexible form of personal assistant services, sometimes called personal attendant services, is that they are often unavailable through public funding for older people needing LTC. Likewise, in-home care is often too skimpy and wrongly timed and configured. Moreover, those who fail to qualify financially for public programs complain that information about purchasing care is often hard to come by and, once found, the care is too expensive for many middle-class citizens (Morris, Caro, & Hansan, 1998).

And what about new congregate care settings? The last decade has witnessed a revolution in forms of residentially based LTC, with new ways of combining housing and services (Kane & Wilson, 1993). Again, opinions are sharply polarized about this phenomenon, sometimes called “assisted living.” Assisted living, at its best, offers an opportunity for older LTC consumers to combine getting the services they need with continuing their lives in the most natural, normal, and meaningful way possible for them. When it works well, it could bring the qualities of home care prized by consumers, with each LTC consumer having control over the rhythms of his or her own life in a self-contained apartment where he or she (or his or her family or agent) calls the shots. Surely, many consumers are choosing this type of care when they must leave their own homes, and when they have the resources or options to select assisted living. Assisted living is licensed and inspected by states, and no federal standards currently govern it. It is a social model of care that in some states is required to have very little nursing presence. To some commentators, assisted living is equated with fraud, false promises, and potential neglect, whereas for others it is seen as a beacon toward a more habitable form of LTC.

In short, wise people armed with identical data are divided on the actual quality of all forms of LTC. This disagreement arguably stems from a failure to confront what we as a society expect of LTC, and what tradeoffs we would make if all good outcomes are impossible. One little-tested assumption is that safety—defined vaguely or not at all—is the be-all and end-all of LTC. Embedded in most of our rules and regulations is the idea that LTC should aspire to the best possible quality of life *as is consistent with health and safety*. But ordinary people may prefer the best health and safety outcomes possible *that are consistent with a meaningful quality of life*. Without agreement about what we mean by quality and the

yardstick that we use to describe it, including the place of quality of life, strident disagreement will persist on how good or bad LTC quality is.

To summarize the problems, LTC fails the quality, access, and cost tests. Quality is a lost cause when the predominant forms of LTC are devalued by the consumer. Access to care at home and in places worthy of the name “home” is hard to come by, even for those who have at least some means to pay (Morris et al., 1998). Public and private costs are high and rising. Moreover, costs tend to exclude the high economic costs—let alone the emotional and health toll—of family caregivers (Arno, Levine, & Memmott, 1999), who are, in the words of the title of a recent book, “always on call” (Levine, 2000). Beyond that is a current crisis in the LTC labor force—sometimes referred to as the staffing problem. Put simply, the result of full employment is a shortfall of people to work in all LTC sectors. Formulaic solutions to perceived quality problems in nursing homes—for example, higher legislated staff ratios (Harrington et al., 2000)—seem beside the point as nursing homes and other programs are struggling merely to staff at the levels current law and common sense dictate. A better approach might be to experiment with ways to organize care and services to achieve desired goals, create rewarding jobs, and determine how to best use the leadership skills of licensed nurses rather than legislating mandatory nurse-to-consumer ratios.

### Quality of Life

A good quality of life (QOL) should be elevated to a priority goal for LTC rather than a pious afterthought to quality of care. But QOL cannot be emphasized absent some common understanding of the phrase. In our current work, we distinguished 11 domains of QOL, each of which will be discussed briefly (Kane et al., 2000). Each is expressed as an outcome experienced by an individual rather than by the structural features or processes thought to be associated with the outcomes. If outcomes such as these can be successfully measured, then one can plausibly examine how various programs and practices are associated with the outcomes rather than taking for granted current standards for any inputs embodied in conventional wisdom or regulation. Note, also, that each outcome can be measured in its negative and its positive form. Accentuating the positive is worthwhile. It is sadly narrow to define quality as the *absence* of negative outcomes. Absence of bedsores, absence of depression, absence of malnutrition—these are hardly evidence of a good quality of life or goals to inspire generations of care providers.

**Sense of Safety, Security, and Order.**—A good QOL requires a sense of security about oneself in one’s world. A person needs to be able to trust that he or she is living in a benign environment where people are well intended, and where the ordinary ground rules of life are understood. The opposite of this se-

curity is a world that feels crazy, lawless, unpredictable, or worse, one that seems dangerous. This QOL domain seems basic, perhaps a foundation block in a Maslovian type of QOL hierarchy.

**Physical Comfort.**—Also basic is physical comfort. This includes being free from physical pain and discomfort, including shortness of breath, nausea, constipation, joint pain, and so on. It includes being comfortable in terms of temperature and body position. To some older people, it even includes crisp, freshly laundered sheets. It certainly includes having one’s pain or discomfort noticed and addressed.

**Enjoyment.**—We rarely think of enjoyment as something worthy of measuring and building programs and settings to achieve, but it certainly is one of the attributes that most of us aspire to in our own lives. Therefore, it is not unreasonable to extrapolate its importance to the lives of those receiving LTC.

**Meaningful Activity.**—LTC consumers need to perceive that their lives are replete with interesting and meaningful things to do and see. What is meaningful will differ according to the physical status of the individual. Some people can participate actively in a wide range of activities; others by choice or preference are in spectator roles. Still others, as Kivnick (1993) has demonstrated, can make meaningful contributions to their families, the nursing homes, or the community at large despite their physical dependency on care.

**Relationships.**—Banal as it sounds, relationships make life worth living, whether they be relationships of love, friendship, or even of enmity and rivalry. Carter Williams writes of a nursing home resident who asked a friend to visit often “so I will know I am alive” (Williams, 1999). Reciprocal relationships where the LTC consumer is able to give as well as receive support, advice, and confidences are best of all (Lustbader, 1991). These relationships may be with family and friends, with other residents (in congregate services), and with paid caregivers.

**Functional Competence.**—As an outcome, functional competence means that within the limits of the person’s physical and cognitive capacities, the LTC consumer is as independent as he or she wants to be. Many conditions are embedded in this definition just as preferences, aspirations, and capabilities differ. This domain of QOL is extremely sensitive to the physical environments in which older people live and receive care as well as the policies adopted by formal caregiving organizations.

**Dignity.**—The next four domains of quality of life might be expected to be correlated with each other, and their relevance may depend more than other domains on cognitive functioning sufficient to process them. Dignity, embedded as a requirement in nursing

home regulations, refers to the perception that one's dignity is respected rather than the important but different notion that each person is treated with dignity regardless of whether he or she can perceive indignities. This concept may be less pertinent to the more cognitively impaired, since considerable self-awareness is needed to experience a sense of indignity. Anecdotal, however, we found that some residents with substantial dementia resonated to the concept of dignity. One such person, who had answered most questions with what seemed to be uncomprehending acquiescence, answered a general question about her dignity being respected with a prompt negative followed by a comment that revealed adequate understanding: "That's just the problem here, they treat us as though we are children!"

**Privacy.**—By privacy, an outcome related conceptually to dignity, we refer not to having a private room and bath, but rather to experiencing a sense of privacy—that is, being able to be alone when one wishes, to be together in private with others when one wishes, and to be in control of information about oneself. In a seminal work, Westin (1967) specifies four aspects of privacy, namely, solitude, intimacy, anonymity, and reserve, and suggests four reasons why these types of privacy are needed: (1) to exercise autonomy and maintain individuality; (2) to achieve emotional release particularly important at times of loss, shock, or sorrow; (3) to conduct self-evaluation, which requires private information processing and reflection; and (4) to achieve limited and protected communication. Pastalan (1970) argues that these privacy purposes are important to older people and that their environments should be designed to realize such privacy, which is obviously more easily achieved in residential settings with private rooms and baths (Kane, Baker, Salmon, & Veazie, 1998). Some minimum self-awareness and ability to process events cognitively is, of course, a prerequisite for the privacy domain to be relevant. Even if persons with severe cognitive disabilities prove to have better or worse QOL in private rooms, the dynamic may be related to meaningful activity, enjoyment, comfort, or some other domain rather than privacy itself.

**Individuality.**—Individuality refers to the consumer's sense of being known as a person and being able to continue to experience and express his or her identity, and to have desired continuity with the past. From a psychological viewpoint, Tobin has written convincingly that the hardest task for many residents is to maintain their own identity against all the forces that erode their sense of self (Tobin, 1991). Research has shown that LTC providers in all settings pay insufficient attention to learning about the LTC consumer as a person, a prerequisite to helping the person preserve his or her sense of identity (Degenholtz, Kane, & Kivnick, 1997; Kane & Degenholtz, 1997; Kane, Penrod, & Kivnick, 1994).

**Autonomy/Choice.**—Autonomy refers to the perception that one is making decisions and choices and directing one's own life. A series of studies sponsored by the Retirement Research Foundation (Hofland, 1988, 1990), as well as earlier, more basic psychological studies on perceived control (Seligman, 1976), attest to the importance of this property of autonomy to the well-being, mental health, and even physical health of cognitively intact older people. Ample research also attests, in the words of Lidz and colleagues, to the "erosion" of autonomy in LTC (Lidz, Fischer, & Arnold, 1992; Kane et al., 1997).

**Spiritual Well-Being.**—Finally, though elusive and related to both psychological and social well-being, spiritual well-being cannot be ignored as a domain of QOL (Olson & Kane, 2000). Spiritual well-being may incorporate but go beyond and can be independent of religiousness. Moreover, these constructs, however imperfectly measured, have been associated with health outcomes. The National Institute on Aging and the Fetzer Foundation did substantial work in the 1990s to specify constructs and measures in the spiritual arena (Fetzer Institute, 1999).

Collectively, the 11 domains of quality of life discussed above resonate to two separate and complementary types of human needs or impulses, both the stuff of novels as well as psychology and sociology, namely, the individualistic versus the community-centered road to fulfillment. Both are important and, though it is by no means certain that all people weight these 2 general or 11 more particular facets of QOL the same, both are compromised by conventional LTC delivery. However these or other QOL domains are weighted and specified, arguably only the LTC consumers most concerned can report on their subjective experiences on these dimensions. With the ability to measure these constructs with the consumer as the source of data, an ability that can only improve with frequent, serious application, it becomes possible to study the characteristics of care programs, care providers, and care environments that support QOL outcomes and to test a wide variety of hypotheses about their interrelationships.

People who need LTC are often compromised in their QOL by the very circumstances and conditions that necessitate the LTC in the first place. Taking another tack, Gubrium (1993) points out that individuals bring their own personality to their LTC experiences so that the identical experience from an objective viewpoint may be viewed positively or negatively by different people. Unfortunately, although considerable consensus has emerged on the major personality traits and how to measure them (Costa & McCrae, 1997; John & Srivastava, 1999), no personality measure has been well-tested in a frail, elderly population where self-completion may also not be an option. (This remains an important area of developmental research for gerontologists.) Finally, many researchers suggest that factors extraneous to formal LTC, such as the presence of caring friends and family, will

have a strong effect on QOL. These points make skeptics doubt that LTC providers can improve or sustain QOL; however, if the circumstances of LTC can make life worse, surely they can also make life better. Despite the powerful forces of biology, personality, and luck of the social draw, there is ample evidence that the behavior of caregivers and the environments in which care is given can influence QOL for better or worse. LTC cannot promise a good life, but the challenge is to avoid foreclosing imaginative consideration of how a different vision of LTC could lead to a net improvement of QOL after controlling for other determining influences.

### *Trends in LTC*

Five trends affecting LTC in the last decade form a context against which attention to QOL has a chance of yielding results:

**Disability Rights.**—The disability rights movement and the struggle of younger people with disabilities to receive care in the least restrictive environment was a prominent theme of the end of the 20th century, leading to and fueled by the Americans With Disability Act. The 1999 Supreme Court Olmstead decision asserted this right and, in an ambiguous ruling, enjoined states to develop plans for less restrictive care in care settings of the consumer's choice (Velgouse, 2000). Whether older people will benefit much by this movement is in the hands of policy makers and other professionals, who would first need to conceptualize old people as having basic wishes similar to younger people. In part, it is also in the hands of older people with health needs, who would need to regard themselves as having a disability for which accommodations should be made.

On the crest of the Olmstead wave, it may be possible to challenge waiting lists for home- and community-based care, and programs that distinguish the freedoms offered to people with disabilities on the basis of their age. The contrast between LTC for the young and the old is striking. Personal attendant services are designed to permit younger LTC consumers to go about their school, work, and leisure lives broadly in the community, whereas home care for elders requires a homebound status. Many care attendants help their younger clients move freely outside their homes, but the cardinal offense of an older person is to be away when the home care worker comes. This inequity of treatment is becoming clearer as some people have aged with a disability and experienced a sharp reduction in what is made possible by subsidized programs once they turn 65.

**Consumer-Directed and Consumer-Centered Care.**—Consumer-centered and consumer-directed care were slogans of the 1990s. This trend is manifested in Medicaid home- and community-based waiver programs that utilize “client-employed” workers; an evaluation of a large statewide consumer-directed

home care program in California showed no untoward results because of the increased flexibility in the client-directed program, where about half of the hired caregivers are relatives of the consumers (Benjamin, 1998). Another manifestation is the large-scale “cash and counseling demonstration” taking place now in three states, where the Medicaid benefit is cashed out for those who opt for a monetary though discounted benefit (Mahoney & Simon-Rusinowitz, 1997). Many projects developed under the Robert Wood Johnson Initiative, “Independent Choices,” including several that examine the applicability of consumer-directed care for elders with dementia via an agent or coach, test the boundaries of the concept; they include demonstration efforts to strengthen the infrastructure to make consumer-centered programs work better (e.g., training consumers to be more savvy employers, and developing emergency community-wide systems to access care when providers fail to show up). Models developed successfully in the developmental disability field, where the consumer is given a budget from which to draw (Nerney & Shumway, 1996), have finally spread to some older people, despite the fear and trepidation of professionals who are entrusted with their well-being. Researchers who formerly studied case management and the allocation of services are now examining models of quality assurance that are truly consumer-focused, exploring ways to get the voice of the service user into the definition of quality at the front end and the reporting of it at the back end, and trying to determine how to balance prescriptive regulatory approaches with other ways of monitoring and improving quality. The chosen models must also work for people who can and wish to pay for the care themselves. By their licensing and quality assurance activities, state governments have enormous potential to shape LTC even for those who pay privately.

A 2001 Institute of Medicine report on LTC quality explicitly recognizes the trend toward and interest in consumer-directed and consumer-centered care (Wunderlich & Kohler, 2001). It acknowledges that a consumer-centered approach would “necessitate a fundamental shift in the approach to determining and evaluating the quality” including “going beyond health and safety outcomes to include outcomes such as quality of life and autonomy” (p. 31). The report enunciates a cautious recommendation “to develop and fund a research agenda to investigate the potential quality impact associated with access to, and limitations of, different models of consumer-centered long-term care services, including consumer-directed services” (p. 18). A separate statement written by 7 of the 17 committee members states that “quality of life, as perceived by the long-term care consumer (or, when appropriate, his or her agent) is an essential part of the quality of long-term care” and recommends that “state governments work with providers and consumers to design and make available in each state an array of community-based long-term care options for individuals of all ages with long-term

care needs” and that individual consumers “be afforded the opportunity to specify the degree of control and influence they are able to or wish to assume over the direction of their care” (p 289). Both the majority recommendation and the stronger view of the minority create an opportunity to usher community-centered approaches into the mainstream. That consumer-centered care was considered controversial illustrates the extent to which paternalism governs LTC policies and practices for older people; that it was considered so extensively or even at all in an Institute of Medicine report suggests a shift of attention and offers hope for progress.

How quality is defined and quality outcomes are ordered are critically important. For example, consider an LTC consumer who, in the words of her obituary, died “at home with humor and dignity in her eightieth year.” A photograph shows her propped up in her bed at home a few days before her death holding a whole lobster (of which she nibbled a few bites) and smiling broadly. She was surrounded by her family when she wanted them, was alone when she wanted to be, and had as much control as she wanted and was able to take. She also had a decubitus ulcer—the cardinal crime against LTC quality. If there were a database to track it, her care would likely have been considered a quality problem, yet according to the outcomes she most desired, the totality of her care had almost the best imaginable quality. A consumer-focused review of the quality of her LTC would give it high marks, whereas a more typical view would severely fault the decubitus ulcer, paying lip service to quality of life, but finding any poor physical outcomes to be intolerable.

*Assisted Living and the Unbundling of Housing and Services.*—The movement to new forms of housing with services, already alluded to, is a major phenomenon and a testimony to the choices of those who can vote with their wallets. Trends in housing with services, mapped every 2 years by Robert Mollica of the National Academy of State Health Policy, are unlikely to be turned back; as a conservative estimate from reporting states, in June 2000 almost 300,000 assisted living facilities served almost 800,000 residents, representing substantial growth from 2 years before (Mollica, 2000). Moreover, 38 states covered such services under their Medicaid programs for people who qualified financially. A matter of compelling interest is whether it is possible for Medicaid to cover assisted living while maintaining the autonomy-enhancing and dignity-enhancing features that appeal to the private market; these may be dismissed as amenities that should not be offered to the poor. The idea that Medicaid programs should be undesirable to create disincentives for use dies hard. Yet, citizens using Medicaid for LTC are typically middle-class nursing home residents whose private resources have become exhausted by extreme old age and previous health and LTC expenditures. Like it or not, Medicaid is the mainstream funder on “public-private LTC partnerships.”

Assisted living offers a chance to positively alter the LTC landscape if it can combine three ingredients: a homelike residential environment, a true service capacity, and a philosophy of consumer choice, dignity, and normal lifestyle—all wrapped up in a package that middle-class and low-income people can afford, and public entities can afford to subsidize. In actuality, entities licensed as assisted living or other nonnursing home categories of residential care vary widely within and across states. Furthermore, as a review of literature, including goals expressed in trade literature and advertisements showed, some assisted living programs definitely aim for a light-care segment of the market (Manard, Cameron, & Kaplan, 1996). Some advocates for elderly people and state regulators are grappling with how to channel this market phenomenon, ensuring its safety and quality while preserving the attributes that make it desirable. Once again, the lack of societal consensus on LTC plays out in disagreements about what governments should do about assisted living. Research is beginning to show that some people with conditions that could well be served in nursing homes are now in other kinds of residential settings, and some research findings suggest their outcomes are comparable or better than those of nursing home residents (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001). The presence of so many people with substantial levels of disability in assisted living settings creates “facts on the ground.” Either residents must be asked to move out when their disabilities reach a certain point, or assisted living providers must be able to provide reasonable levels of care within the context of what one hopes will be improved living circumstances. Once the principle of separating housing and board conceptually from care and services is established, the details can be worked out about how the services might be constructed and the kinds of outcomes for which assisted living providers are responsible.

*Culture Change in Nursing Homes.*—As suggested earlier, some nursing homes are committed to changing in ways that enhance quality of life. Many of these efforts center around the Pioneer Network in Long-Term Care, formerly the Nursing Home Pioneers, a loosely organized grouping of providers and others who are dedicated to exemplifying in practice the following values: responding to the spirit as well as the mind and body needs; putting persons before tasks; seeking to enjoy residents and staff as unique individuals; acting on the belief that as staff are treated so will residents be treated; beginning decision making with the resident; and accepting risk taking as a normal part of adult life (Fagan et al., 1997). The Pioneers embrace a wide variety of activities that accord with these general principles. Among them are practitioners of the Eden Alternative for combating boredom, loneliness, and lack of meaning in nursing homes, which itself is a social movement (Thomas, 1994, 1999). Also included are a variety of more localized efforts in individual nursing homes

and even whole corporations to break down the rigidities of routines, to foster more normal and natural relationships between residents and staff, to include residents in decision making (even to the point of, in one example, including residents on personnel committees), to permit spontaneity, to foster neighborhood grouping of residents; to include individualized end-of-life care and rituals to mark death, and to empower both residents and certified nursing assistants. The efforts also include approaches to transform daily experiences of bathing and meals into enjoyable rituals rather than, as often perceived now, torture (Rader, 1995). The Pioneers are struggling with the joint challenges of creating genuine community when feasible and permitting room for individual lives as well. Like any social movement, progress is expected to be painstakingly slow and difficult, and the quest for a quick fix needs to be resisted (Dannefer, 2000).

The ideas of the Pioneer Network are hardly novel, just hard to implement. Nursing home administrator Herbert Shore, whose life was remembered at a memorial service at the 2000 meeting of The Gerontological Society of America, characterized the needs and desires of the older consumer in a 1970 report to his board (Shore, 1970):

Older people *need* security—economically (in terms of shelter, housing, and spending money), physically (in terms of medical care and adequate diet), and socially (in terms of status, friendship and belonging). Older people *want* recognition—for what they can do mentally and manually, for their capacity to make a contribution to their community, country and world, for social and political consciousness, and their ability to plan for themselves. Older people want response: to be liked for what they are, to hold friends and make new acquaintances; and older people want new experiences and adventures: to continue to learn and grow and develop, to enjoy the new and different, to extend interests, expand horizons, satisfy curiosity, to create for expression in artistic and aesthetic areas. They need to relax. They need freedom, dignity and respect. They can fall in love, be deeply hurt, and can be extremely happy. Like every other human being, they need social contact. (From a compilation of writing of Herbert Shore prepared in his memory by Elma Holder, National Citizens Coalition for Nursing Home Reform, Washington, DC.)

In that 30-year-old report, Shore also suggested that if staff are to give, “they need to be secure in self, gain satisfaction in giving, and must receive recognition, love, and compensation.” He deplored “cultural hangups on who does what”—a precursor of the universal worker ideas of today. In a column notable for quoting both Daniel Patrick Moynihan and Thomas Aquinas on the same page, his denouement stated: “. . . the major challenge is to provide for a continuity of life experience (no showcase for public relations, not tokenism but meaningful life—with freedom of choice, when and if to participate, a program of social health, personal identity, independence, pri-

vacy, stability self-direction, re-engagement, discovery and re-institution of normal elements of daily social living.” These principles are almost identical to those of the Pioneer Network in the year 2000. The key in both instances is refusing to let LTC take over life itself or to place LTC consumers outside the full range of human needs and interests.

*Attention to Physical Environments.*—Long ago Lawton pointed out the importance of physical environments in shaping competence—and the need for environments that minimize stress but create pressure or stimulation and interest (Lawton & Nahemow, 1973). Rudolph Moos has mapped out strategies to assess environments in exquisite detail, but until recently little has been done to “normalize” physical environments as well as to adapt them to enhance functional opportunities (Moos & Lemke, 1996). We are still, tragically, building brand new nursing homes in this country with double-loaded corridors and shared rooms and baths, and many experts fail to take seriously the importance of mandating a threshold of private rooms and baths even in assisted living. But on the positive side, currently there is unprecedented interest in physical design of living quarters for care, as well as specialized furnishings, fixtures, and equipment to enhance functioning. Long overdue attention is being paid to chairs, switches, knobs, fabrics, colors, and materials. One well-publicized large facility has been completely rebuilt to move “from hallways to households” of 8 to 10 residents who enjoy a residential-style large kitchen, a dining area, their own washers and dryers, and living space (Dannefer, 2000).

In our own work, we have begun and hope to be able to do more to empirically link the details of physical design with quality-of-life outcomes. Minute aspects of the physical environment can, we believe, be associated with better or worse outcomes on the full range of quality-of-life domains that we have discussed. For example, in facilities without bathrooms accessible to residents at their front door, near their dining and activity rooms and in other strategic places, residents are likely to cleave to their rooms. In facilities without mirrors at wheelchair height, residents cannot groom themselves. In fact, assisted living facilities have managed to enhance the functional abilities of their residents through environmental supports such as roll-in showers and well designed kitchenettes.

### *Strategies for Change*

*Develop Infrastructure With Attention to Unit Prices.*—Subversive ideas, also known as fresh thinking, must be encouraged, including changing professional roles, breaking down boundaries of organizations, and considering delegation of nursing roles. Similar creativity is needed in considering how states can best exercise their two roles: paying for care for people with low incomes, and defining the nature of care through licensing rules. If nursing homes are changed from inside, and assisted living and home care com-

binations are developed as well, we may reach a point when all the conventional categories are questioned. Certainly it would be helpful to stop confounding the place of care with the intensity or level of care. Professionals should desist from making hierarchical decisions about “appropriate levels.” Ideals of continuum should give way to ideals of a repertoire of choices with recognition that choices are plausible based on consumer’s values and circumstances. Advocates for older people should seize on the Olmstead decision and embrace the Americans With Disability Act as a vehicle for making affordable solutions possible in real communities.

*Develop Sources of Information for Consumers.*—Even as we break down boundaries across service sectors, consumers need some dictionary or index to understand the new forms of LTC. Federal regulation of assisted living is premature and may never be indicated, but surely nomenclature needs to be clear enough that consumers can shop and researchers can study outcomes with some certainty that they are comparing apples and apples.

*Develop Feedback Mechanisms for Providers.*—Quality improvement calls for information about quality—including the quality that consumers care about most, that is, the elements that enhance or detract from quality of life. Information is needed at the macro level to characterize the work of provider organizations and the microlevel of an individual consumer of LTC. Providers also need to learn how to discuss quality-of-life issues with consumers and use that information to improve services.

A corollary of improving information for providers and policy makers is to work toward comparable information across settings. This is a difficult methodological problem with political overtones. Decisions need to be made, for example, about how to treat functional abilities. Should researchers exclude information about consumers’ IADL functioning, self-medication, and bathing independence to create a level playing field given that nursing home residents are often prohibited from independence on these spheres? Conversely, should researchers include such information on the basis that superior consumer functioning may result from the policies and physical environments of the less regulated settings? Also, how should baseline performance be regarded when settings are compared? Assisted living residents function better at baseline, not because they are in better health, but because the environment permits them to function better. We may understate the accomplishments of assisted living and home care by using ADL and IADL abilities at baseline to case-mix-adjust samples, making it appear that alternate settings select less frail people. Finally, as both a methodological and political matter, the quality-of-life outcomes that have been stressed here largely must be measured by report of the LTC consumers concerned; yet, a huge investment has already been made in a nationwide assessment tool for nursing

home residents, the Minimum Data System, which largely excludes these outcomes and that gathers data by ratings by care providers’ ratings. There is a great incentive to move this tool to home care and assisted living so that LTC consumers can be compared across settings, yet doing so may leave the field with an inadequate yardstick to examine relative progress in quality of life either within nursing homes or across settings.

*Create Supportive Environments.*—It is axiomatic that shared rooms and baths should be decommissioned and old facility stock no longer be replaced with more of the same; whether to do this should no longer be a research question. Research and demonstration of other ways that environmental features can enhance functioning is sorely needed, however. Also needed is better access to specialized equipment (from phones and computers to prosthetic aides to furnishings). Supportive environments also include transportation for those who cannot drive or readily use public transportation, including those who have relocated into new congregate living settings.

A caveat is also in order. There is certainly a danger of romanticizing the fact of being at home, and ignoring the isolation that older people, especially those living alone, can experience in the community. There is also a danger in assuming that everyone values private space equally; though the empirical evidence for this preference crosses age, ethnicity, and social class boundaries, individual differences can also be found within samples of older people on their relative preferences for privacy, and for autonomy versus protection. Moreover, loneliness and isolation are experienced in back bedrooms where seniors receive home care and also in shared rooms in nursing homes. The challenge is to try to maximize the sense of privacy that many people see as part and parcel of a good quality of life as well as other domains such as meaningful activity, enjoyment, and relationships.

*Accept Risk.*—Nothing is perfect, and accidents happen. In the words of the Pioneer Network, risk is a normal part of adult life. This stance requires consideration in advance about how to balance outcomes. The concept of managed risk contracting (sometimes called negotiated risk contracting), whereby informed consumers or their agents can accept risks, is worthy of study and true implementation. At this point some nursing home leaders, many assisted living leaders, and some home care case managers and state officials are discussing managed risk. In some states, it is embodied in assisted living or broader LTC regulations. To implement such a strategy, providers need clear messages that they will not be punished for untoward events; also, we need to build in mechanisms to prevent abuse of caregiving responsibilities in the name of freedom for consumers.

*Take Back the System.*—LTC for older people needs to be discussed in new ways with attention to the hopes and fears of all parties, including providers, ad-

vocates, well older people, and older people getting care and their families. Discussion is needed about the circumstances under which older people could better tolerate their more physically and even cognitively impaired age-cohort peers in their midst, and whether such acceptance would be a reasonable tradeoff for confidence that nobody would be relegated to substandard quality of life as their care needs increased. All parties to such discussions should freely consider their own personal and family experiences and preferences along with relevant research to help focus the inquiry on important human and social values.

We also need to consider deeply what constitutes a reasonable quality of life for people with dementia. One is likely to be considered naive or quixotic to recommend a more normal system of life and care for people who have lost cognitive capability and whose function is anything but normal. The urge is to protect, to regiment, and to sequester such individuals. But LTC is ordinary life, and people with dementia live among us as part of family units and communities. A few years ago, at a 60th wedding anniversary party, I noted with satisfaction that several members of the original wedding party with visible Alzheimer's disease were guests at the event and involved to the best of their abilities.

LTC discussions should begin by considering how citizens believe people with physical and cognitive disability should and want to live in their old age. Mechanisms are needed for encouraging problem solving. Perhaps neutral parties, such as universities, could convene all interested stakeholders to discuss how to avert the tragedies of the next double-roomed nursing home, the next program that narrowly limits services to people under 65, or the next rule that is designed to help with quality but actually drives up costs beyond most people's ability to pay. A gerontological research agenda should be developed to explore how well various new models of LTC work, to take the preference pulse of consumers, and to explore the fears that are held about the mishaps that might occur on the road to a better form of LTC. Sheer advocacy may be needed, but needed also are the powerful research questions that move us ahead. The litmus test must continue to be normal, ordinary life coexisting with LTC. In all reform, including financing, we must keep our eye on the quality-of-life ball, or the game is lost.

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