The Effects of Changing Values on the Provision of Long-Term Care

By Charles E. Longino, Jr., and Larry Polivka

What will the long-term-care workforce look like in the future? The answer to this question is not as straightforward as it might at first seem. The answer depends upon the changing values on which long-term care itself is based. This essay will argue that there are some major changes under way that may frame long-term care in new ways in the future, thereby affecting both workforce and resources.

Pyke and Bengtson (1996), reporting on a three-generation study, examine some values of children and grandchildren in Southern California caring for their older relatives and contrast two approaches to caregiving. The "collectivist" approach emphasizes the importance of strong kinship ties, familial responsibilities, and commitment, thereby elevating family caregiving as a desirable and worthwhile activity. In families characterized by this approach, second- and third-generation family members tend to give and offer more help than their older relatives need or appreciate. The "individualist" approach, by contrast, emphasizes independence, self-reliance, and autonomy of family members. Families characterized by this approach tend to have looser family ties, less frequent contact, and lower personal commitment to one another. Here, second- and third-generation family members turn sooner to formal caregiving services and facilities when the burden of caring increases.

Both workforce and resources are affected.

While most families have some elements of both collectivist and individualist approaches, an examination of the two is useful in attempts to understand care and values. Significantly, Pyke and Bengtson note that today's third-generation adult grandchildren have grown up in an era more individualist than those of immediately preceding generations, suggesting that a cultural change in values may affect caregiving in the future. Indeed, this is exactly the point of this speculative essay.

The discussion of macro-level cultural change carries with it a special burden. Culture is not uniform, even in the changes that are moving through it. In a society such as ours that is built upon and embraces diversity of many kinds, it would be foolish to assume that value changes are ever embraced uniformly. Trends beget counter-trends. And the lenses through which we interpret changing values contain subjective filters colored by ideology and special interests. Nonetheless, the population, technological, and organizational origins of changes in values in the United States during the past half century are by now evident.

The Changing Context of Values

The tendency to reify as a distinct group those people born between 1946 and 1964, "the baby boom," treating them as a separate entity, undif-
ferentiated among themselves, is philosophical wrong-headedness and ignores the rich diversity of this group. Still, the shared experience of the early baby boomers of the urban middle class is undeniable. The first half of the large eighteen-year birth cohort pressed against all institutional structures as it aged, like the surge of a tidal wave. Schools on all levels, the job and housing markets, and the market economy itself all felt the pressure. Members of this birth cohort challenged tradition at every turn. Russell (1993) argues that greater value is given to independence, the entrepreneurial spirit, and personal empowerment among middle-class baby boomers than among their parents. Also, among early baby boomers, there is a greater distrust of authority of all kinds, less company and brand loyalty, greater value for leisure over work and informality over formality, and a more relativistic understanding of ethics.

The second or trailing half of the baby boom came to be characterized as inwardly turned, private, self-interested, the “me” generation that greatly valued its personal leisure time. One highly visible segment of this birth cohort came to be known as yuppies. It may be argued that technological and organizational change, rather than population change alone, fostered these outcomes. The rise of a customized market economy, catering to rapidly changing niche markets and aware of the increased value of convenience, quality, and flexibility, made an unbelievable range of goods and services available around the clock, through the mail, and finally on the Internet (Longino, 1994).

A NEW ERA

Since the 1990s, we have entered a new historical era wherein individuals are becoming less embedded in tradition and institutions. Changing family, political, and economic structures produce and affect changing cultural values. Furthermore, we now live in information-based economies and a society characterized by communication networks, which highly value discursive, independent, thought and the creative force of language and speech. In this kind of social milieu, individuals seek greater agency in their own lives, increasing the value of autonomy. And there is a growing recognition of the relativity of much that once seemed rooted in traditions and institutions. Furthermore, especially during the past decade, our response to accelerating change in cultural perspectives and values has produced a kind of multiculturalism and the creation of new forms of culture that draw on multiple sources.

In short, the world is loosening up. Manufactured uncertainty and risk increasingly characterize postmodern society; flexibility is required to respond to these new challenges that outstrip the cognitive and moral capacities of conventions, traditions, and institutions. The policies of the liberal welfare state of the past sixty years are based on assumptions about the proper role of expert knowledge, with authority resting with policy experts rather than recipients of the benefits of policy, who are seen as passive and relatively uninformed. Nowhere have these assumptions been more pronounced than in the area of long-term care. The current pressure for devolution of authority and responsibility to care recipients is in part a result of the lack of responsiveness of the traditional models—especially to the growing cultural diversity of the population and the increasing desire for self-actualization and autonomy expressed by recipients of care. All of this reflects the growing importance of the individual.

Let us be clear on one point. We are not talking about a total revolution in cultural values. Values evolve in a more gradual way. Individualism is not new. A process that began with the Renaissance and accelerated during the Enlightenment and the French and American revolutions has now manifested itself as a kind of hyperindividualism. Is this an unfortunate development? Perhaps it is, in one sense, because we all like a sense of community and the comforts of a secure identity provided by unquestioned traditions and powerful institutions. Nonetheless, if this is the direction of American cultural change, and we think it is, we need to develop a notion of individual autonomy and responsibility that will make the best of the situation. Rampant individualism can push toward anarchy. New traditions and institutions must be created that would allow individual freedom (autonomy and self-expression) and development to take forms conducive to an apprecia-
tion of the views of others and an increased awareness of the need for a balance between freedom and responsibility. This intersubjectivity and balance constitute the essence of ethics.

The fading of traditions and institutions as we have known them does not necessarily mean that people are losing their moral bearings. In fact, they may become more aware of their own ethical responsibilities and the need to think through the ethical implications of their decisions without recourse to the formulaic truths of given traditions. Increasingly, we are all philosophers, and ethics is pervasive, as we become more responsible for thinking through and around traditional ways of doing things.

What is needed, then, is a reordering of our public policies and the institutions that embody them in order to make them mesh with the much more active, reflexive, autonomous and cosmopolitan lives that more people now lead in a culture that is increasingly diverse in many ways. This description will certainly be true of the lives of baby boomers in retirement, even the non-affluent ones, at least as compared to current retirees. We think that what these postmodern trends mean for public policy and our welfare institutions is that bureaucratic hierarchies will have to give way to more flexible and decentralized forms of authority. Power will have to be given to the recipients of benefits in a “democratization” of services. Individuals must be empowered by allowing them greater agency and choice in the bundling of services and other welfare resources and by reducing the power of policy experts and service providers like case managers. In other words, we should move toward giving the subjects of policy the power of greater self-governance by recognizing their autonomy and capacities to create their own life narratives within the limitations of their impairments.

What might the perspective we have sketched here mean for concrete initiatives in long-term care policy for the frail elderly? We think it means that we should begin to transform our current system of long-term care by giving substantial control over resources to the beneficiaries and their families and by changing the relationship between policy experts, policy makers, and service providers, on the one hand, and the consumers of care on the other. We are talking about giving consumers and their chosen caregivers greater freedom to use long-term-care resources in ways they themselves choose—according to their own values and narratives of self. Policy experts, policy makers, and service providers would still have major roles to play, but these would be empowering, consulting, and advocacy roles. The experts and professionals would still be responsible for protecting the interests of the consumer by preventing exploitation and fraud. But even these roles should be negotiated and conducted in culturally sensitive ways. Such an approach would help break the control of proprietary nursing home companies over long-term-care resources and give control of the resources to the consumer.

**Getting Specific**

The long-term-care approach described above is usually called consumer-directed care and is defined by the National Institute on Consumer-Directed Long-Term Care (National Council on the Aging, 1996) as follows:

> A philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. Consumer-direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. Choice and control are both key elements of any consumer-directed system.

The cash and counseling version of consumer-directed care could theoretically be incorporated into any state or federally funded long-term or chronic-care program serving people of all ages and many disabilities. Generally, disabled people would have a choice of a case-managed service benefit or a monthly cash allowance of a monetary value lower than the service benefit. To be eligible for the monthly income supplement, an individual with a disability would have to show in some predetermined way that he or she could effectively use the extra income to meet long-term support needs. Consumers would be able to spend the money in ways they saw fit. They might choose to purchase services from a home care agency or referral services at current rates, pay a friend or a relative to provide personal assistance services, make needed home
modifications, or move to an assisted living facility or other new housing arrangement.

The counseling component would involve an assessment of need and information and advice about the various services and financing and housing options available. Centers for independent living, area agencies on aging or other public or private organizations or individuals that do not have a vested financial interest in the decisions made by the consumers would provide the counseling service. The purpose would be to provide consumers and their families with the information and assistance they need to make their own decisions and manage their own care.

Robyn Stone, in discussing emerging trends in long-term care, points to the momentum being achieved by consumer-directed-care programs (Stone, 2000). Not much is going on at the federal level, except for one program administered by the U.S. Department of Veterans Affairs. Cash benefits for veterans and workers with disabilities is not new at the federal level. However, most experiments, Stone observes, have been at the state level, through Medicaid home- and community-based waivers and state-funded personal assistance programs. At least thirty-five of the fifty states are trying out programs of various kinds that give payments to relatives and other informal caregivers who perform personal and home-based services (Stone, 1997). President Clinton loosed a trial balloon by proposing a $3,000 nonrefundable tax credit for people needing long-term care (with two or more ADL limitations), or for family members caring for them (Stone, 2000).

Germany’s popular 1994 Dependency Insurance Act provides universal coverage of long-term care for disabled people of all ages (Schneider, 1997). A choice is given for cash, vendor payments, or a combination of cash and in-kind benefits. Because of the overwhelming choice of cash, which is less expensive than vendor payments, Germany’s care funds were able to keep their budgets within the prescribed limits.

Florida is one of three states participating in a consumer-directed-care demonstration project funded by the Robert Wood Johnson Foundation. The Florida project includes adults who are developmentally or physically disabled and the frail elderly. The project is expected to last four years and is being carefully evaluated. The project will generate outcome and cost-effectiveness data and can be used to refine and improve the quality of efficiency of consumer-directed care (Polivka and Salmon, 2000).

Will the emergent consumer-directed care be more congenial to the individualist or collectivist approaches to care giving, as described by Pyke and Bengtson (1996) at the beginning of this essay? Although the more libertarian values apparently underlying consumer-directed care may seem to support the individualist approach, it is the collectivists, who want to share care among family members, who will benefit the most from these new mechanisms. Consumer-directed care will provide them with the means to negotiate complex packages of care, bringing family and community care together in creative and appropriate ways. Institution-based care better serves the needs of those individualists who wish not to be so personally involved.

Finally, it is uncertain how the changing value framework for long-term care policy will affect demand for such care in the decades ahead. There may be a hidden danger in consumer-directed care for the long-term-care labor market. A marketplace where homecare workers have to compete with family members tends to depress wages, discourage fringe benefits, and hinder professional development among paid workers (Feldman, 1997).

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REFERENCES


