

*Out of
Isolation:
A Vision for
Long-Term Care
in America*

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* The views expressed by Judith Salerno are her own and do not necessarily represent the views of the National Institutes of Health, the U.S. Department of Health and Human Services, or the United States Government.

The Commission

The National Commission for Quality Long-Term Care is a non-partisan independent body charged with improving long-term care in America. The appointed commissioners reflect a diversity of experience in government, academia, quality improvement, and long-term care. The Commission was convened in October 2004. It grew out of an industry-led quality initiative called *Quality First, A Covenant for Healthy, Affordable, and Ethical Long Term Care*. Funding for the Commission's work is provided by the Alliance for Quality Nursing Home Care, the American Health Care Association, and the American Association of Homes and Services for the Aging. The Commission was originally convened and housed at the National Quality Forum, but is now an independent commission at The New School.

www.ncqltc.org

National Quality Forum

The National Quality Forum (NQF) is a private, nonprofit, open membership, public benefit corporation whose mission is to improve the American healthcare system so that it can be counted on to provide safe, timely, compassionate, and accountable care using the best current knowledge. Established in 1999, the NQF is a unique public-private partnership having broad participation for all parts of the healthcare industry.

www.qualityforum.org

The New School

The New School was founded in 1919 as the New School for Social Research by a group of distinguished independent-minded scholars including historian Charles Beard, economists Thorstein Veblen and James Harvey Robinson, and philosopher John Dewey. Today, The New School, led by President Bob Kerrey, is a legendary, progressive university comprising eight schools bound by a common, unusual intent: to prepare and inspire its 9,300 undergraduate and graduate students to bring actual, positive change to the world.

www.newschool.edu

Out of Isolation: A Vision for Long-Term Care in America

NATIONAL COMMISSION FOR **QUALITY LONG-TERM CARE**

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“Do not cast me away when I am old; as my strength wanes, do not abandon me.”

– Psalm 71

The children of the Great Depression have grown old. In their youth they won a world war, then went on to build a post-war nation energized by an era of peacetime prosperity. Now, as their strength wanes, they increasingly wonder whether they will be cast away into a long-term care system that teeters on the edge of abandonment.

Skilled nursing facilities and home care agencies in America operate in an underfunded, often overlooked shadow world that floats between traditional medical care, with its promise of cure, and custodial care, with its premonition of prolonged decline. Too often, both those who provide care and those who need it feel cut off from a society frightened by frailty and perturbed by the prospect of being unable to perform the ordinary tasks of daily life. Too often, both those who provide care and those who need it feel stigmatized and shunned, as if disability and caring for disability were somehow character flaws.

We the members of the National Commission for Quality Long-Term Care know intimately both the system’s persistent weaknesses and its considerable strengths. We believe the time has come to move long-term care into the mainstream in order to build a compassionate, high-quality, economically sound system of which Americans of all generations can be proud. This task is surely a moral imperative; with of the number of older Americans growing rapidly – the oldest of the 78 million Baby Boomers are now reaching age 60 – it is also a financial and social imperative. The status quo leads not to stability but to disaster.

Transforming long-term care is a matter of both head and heart. Commission members have grappled for years – and for some of us, decades – with the promise and the problems of long-term care. Our ranks include former or current governors, members of Congress, state officials, policy experts, aging advocates, journalists, physicians and health care industry leaders. Just as importantly, we have confronted issues of long-term care in our personal lives. We are the sons and daughters, friends and family of the 1.4 million Americans who live in nursing homes and the millions more who depend upon family and paid caregivers in the community. We ourselves range in age from early 50s to mid-70s – we have looked into the mirror and seen the aging of America.

Shockingly, many Americans say they would choose death over a life lived out in a nursing home. We understand those fears. In our professional lives, we have uncovered scandals, held hearings, passed legislation, implemented regulations, and analyzed the inner workings of the long-term care field. If we have not despaired, it is because we have had our hopes regularly lifted by conscientious caregivers and others in this field who demonstrate every day that they are as concerned about their patients as any family member.

In our personal lives, too, we have witnessed both altruism and abandonment in long-term care. Some of us have watched vulnerable loved ones being selflessly supported day after day, week after week, by compassionate caregivers. Others of us have felt frustration and anger as we have seen loved ones left helpless and unable to meet such utterly basic human needs as eating and going to the bathroom.

Today's long-term care system is better in many respects than it was twenty or even ten years ago. Many who work within that system are more committed than ever to continuous, measurable improvement of care. The field has grown to include a wide range of community and home-based services outside the nursing home and sophisticated rehabilitation and medical care services. This brightening outlook, however, cannot hide a darker reality: the quality of treatment delivered by skilled nursing facilities and home care services varies so much that no individual can be certain of good care.

Those who pay tens of thousands of dollars annually out of their own pocket for care can be confronted by precisely the same problems as those who rely on pinched state budgets that pay a fraction of the private-pay cost. Those who believe that their education and social standing will guide them through the maze of skilled nursing and home care choices can end up as dizzied and depressed by the labyrinth of services and funding sources as the less educated, less savvy and less experienced. One of the reasons is an information problem.

For example, although three-quarters of all nursing home admissions come from hospitals, those institutions generally provide very limited direction and education about available post-acute and long-term care options. Hospitals are motivated to discharge elderly patients as soon as possible because of Medicare's prospective payment system. Long-term care organizations subsequently find themselves with inadequate information from hospital discharge planners about the level of care needed for an incoming resident. This can create major gaps in the continuity of care.

We believe individuals must be able to access reliable advice when they or a family member has become frail and needs assistance. Jerald Winakur, a physician teaching at the San Antonio-based Center for Medical Humanities and Ethics of the University of Texas, movingly described the problem in a recent article. He wrote:

My only sibling, the architect, asks me every time we are together...“What are we going to do with dad?”...He asks me this question not just out of fear and frustration, not only out of a realization that it is time for the adult children of a progressively dementing elderly parent to act, but because he figures that his older brother who has been practicing medicine for almost thirty years should know the answer. I do not know the answer. I do not have a solution for my father or yours-neither as a son, a man past middle age with grown children of his own; nor as a doctor, a specialist in geriatrics, and a credentialed long-term care medical director.

As with the Psalmist of so long ago, wealth and power do not suffice; even in 21st century America, those whose strength has waned too often must rely on little more than the prayer that they will not be cast off. Yet there is a better way.

While the problems besetting the long-term care system in America are deep-seated, they are also fixable. To be sure, there are those, as in any field, who exploit the weak and vulnerable for financial gain. They should be swiftly weeded out by vigorous enforcement of existing state and federal regulations. However, this small group of unacceptable providers is vastly outnumbered by the many conscientious caregivers who labor to provide dignified treatment and social support in an environment where resources are often very scarce. Although scandal snatches headlines, innovative economic and social models of care that support individual autonomy and dignity have quietly begun to sprout throughout the country. With appropriate cultivation, these model programs could spread far more rapidly.

It is possible to build a long-term care system where both caregivers and those cared for feel treated with respect and connected to the community. It is possible to build a long-term care system where transitions between home, hospital, rehabilitative care, home care and skilled nursing facilities are seamless and tailored to the medical and social needs of the individual. It is possible to build a long-term care system where personal autonomy and innovation flourish. This is not a vision of unattainable perfection; rather, it is a blueprint designed to replicate and improve what is already being done in a piecemeal fashion today.

By way of context, the problems besetting long-term care do not differ greatly from those confronted by hospitals and physicians in the middle of the 20th century. Beginning in the 1950s, this nation made an unprecedented investment in building hospitals and training physicians in order to provide reliable, high-quality care for the generation returning from World War II. This massive infusion of funds was also accompanied by a deliberate effort by government, in partnership with leaders of the hospital and physician communities, to address serious and widespread quality problems far more pervasive than those identified by the profession today. The acute-care system is far from perfect, either in consistently delivering the highest-quality care or in responding to patients' needs. Yet it is radically better than it was a half-century ago. The same degree of transformation is possible in long-term care.

The children of the Great Depression have grown old, and pride in their accomplishments has, for many, begun to erode into fear for their future. The first of the World War II-era veterans to be elected president took office in 1960. In his inaugural speech, he challenged Americans of all generations, "ask not what your country can do for you; ask what you can do for your country." If John F. Kennedy were alive today, he would be 89 years old. The time has come to ask what this country can do for them – and for Americans of any generation who've become frail or disabled. We as a nation cannot tolerate a situation where grandparents end up competing with grandchildren for a finite amount of dollars either from the government or from their families.

Advances in public health and in medicine have brought about a decline in deaths for every age group. An extended period of life after the usual age of retirement is now more usual than not. On average a man at seventy-five will live another 10 years and a woman 12 years. Some experts even say that life expectancy may yet grow decades longer. Whether or not that occurs, the changes we already see all around us present unprecedented challenges to every social structure: the family, the workplace, the economy, and public policy.

The latter part of the life journey usually involves gradual physiological changes. It has come to be called the "Third Age," following the "First Age" of childhood and the "Second Age" of working and caring for family. Even as we make generalizations about an aging population, however, the truth remains that every person ages differently, whether by reason of genetic make-up, past life experiences, or simple luck. For some individuals, the changes can be sudden and dramatic. For many others, old age is a time of gradually increased vulnerability to disease and trauma and the beginning of frailty. But despite these realities, old age can also be a time for unlocking creativity and developing new relationships.

Where one lives – one's home and neighborhood – can mean the difference between support and accessibility or isolation and barriers. Those who are frail and coping with substantial disabilities need access to high-quality supportive living and health care services in their own communities, including help in getting and paying for these services. They have a right in their time of need to expect comfort and hope. They have a right to care that accounts for how they lived their lives when they were younger and for how they wish to live their lives now that they are older.

Federal enactment of Medicare and Medicaid in 1965 was a turning point. While Medicare was designed for acute medical care, a little-noted provision included payment for extended care either in an institution or at home when active rehabilitation was necessary. Similarly, while Medicaid was designed primarily to meet the acute and ambulatory care needs of the poor, it did allow payment for nursing home care for those with few resources or whose medical expenses exceeded their income.

Together, Medicare and Medicaid introduced two key elements that transformed long-term care. The first of these was the medicalization of long-term care; the second was an entitlement in the Medicaid program, albeit a limited one, to government funding for that care. Since nursing homes were seen as extensions of hospitals, they were built to look like them and came under the jurisdiction of health regulations and regulators. Meanwhile, government assistance in building nursing homes led to an explosion in the number of facilities and may have discouraged the development of home- and community-based alternatives. The nursing home field remains dominated by Medicaid. As a result, federal and state governments are the principal payers, determiners of eligibility, licensers, standard-setters and overseers of the quality of care.

Many states are completely overhauling their Medicaid long-term care programs by investing substantially in home and community-based care options. While the vast majority of public financial support for the long-term care of older persons still goes to nursing homes, the number of persons supported by publicly funded long-term care programs at home is increasing. More Medicaid assistance has been provided in recent years to residents in assisted living facilities. Changes in funding and technology have had the unintended consequence of leading to far greater severity of illness among those receiving home care – even among frail individuals living alone. Yet while the limited entitlement of Medicaid has increased access for hundreds of thousands of people needing advanced care, it has not been enough.

Meanwhile, skilled nursing facilities are increasingly bifurcated in their populations, caring for either patients receiving short-term rehabilitation or long-stay residents with multiple complex functional problems and medical conditions. They are routinely hobbled by a shortage of workers, ranging from nurses, physicians and well-trained administrators to direct care workers who are given low wages and scanty benefits for a job that is both arduous and distinctly unglamorous. Unlike those who work in hospitals, those who work in nursing homes do not see their labors featured in movies and prime-time television shows. For every individual who enthusiastically embraces a rewarding career in long-term care, countless others lack the necessary incentives and opportunities to do so.

Today's long-term care system strains to accomplish tasks for which it was never designed for a population whose magnitude was never envisioned. It does so while limited by a host of financial and regulatory constraints that can be more likely to stifle innovation than to accomplish their original purpose of protecting the vulnerable. All stakeholders in the system confront a series of challenges. These include:

- *Individuals* face a loss of independence from disability, a shock too often compounded by loss of home, loss of income and assets, loss of family and community activities and loss of choice among long-term care service options. Individuals also face end-of-life decisions including utilization of palliative care and hospice services.
- *Families* provide the most support to those with disabilities, often at great personal sacrifice, but they receive little information, training, financial assistance, or respite nor professional services to support them in their efforts. In addition, the wisdom they possess about the needs of their loved ones is too often untapped.

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- *Direct care workers* who do the physically and emotionally demanding work of providing service receive little respect from either the medical community or the community at large, are paid low salaries with few benefits and confront the demoralizing reality that they often have little opportunity for advancement. A lack of adequate training and proper equipment also results in alarming rates of injury.
 - *Provider organizations* are under pressure to deliver high-quality services, but payments by government programs frequently fall well below what meeting those expectations truly costs. The industry's inadequate capital base means that the financing needed to modernize or replace antiquated equipment or physical plant is often unavailable. Not only institutions, but home- and community-based service providers also have difficulty attracting and retaining trained staff.
 - *Regulatory agencies* are routinely too understaffed to enforce regulations meant to protect and improve the lives of individuals receiving long-term care. Even those regulations that are enforced often have little impact on low-performing providers. Instead, the mediocre survive and those who would innovate in the name of high quality receive few incentives or rewards for their efforts. Regulators and providers alike lack a consistent understanding of long-term regulations and guidelines and both need training to develop consistent expectations.
 - *Medicaid agencies* that must manage competing demands for acute care and long-term care services with limited budgets routinely confront ingrained institutional biases that are only slowly beginning to recognize the role that can be played by home- and community-based services for those in need.
 - *State and federal policymakers* face competing pressures to keep taxes low while dealing with mounting costs for all forms of health care and the need to provide other governmental services. They struggle to improve the quality of care and reshape the acute and long-term health care systems while preparing for the enormous demands for services that the Baby Boom generation is sure to make.

Underlying all these issues is the urgent need to fix the financing of long-term care services. While money alone is not the answer, there is little doubt that we as a society get the long-term care system we are willing to pay for. Long-term care is not just one type of service; different funding sources have evolved for each service, largely by historical accident. While health care for the most part is funded via Medicare, housing for older persons is seen as a private responsibility (despite a network of federally subsidized housing serves 1.6 million primarily low-income older persons). Personal care, meanwhile, relies on a hodgepodge of family caregiving, personal funding, private insurance, block grant programs and, for those who exhaust their resources, public welfare.

In the end, today's long-term care system relies first and foremost on individuals and their families, who provide 80 percent of care with no compensation. For those who need professional medical or institutional services, the payment system is a jumble of Medicare, Medicaid, private insurance and out-of-pocket payments. The result is that family caregivers already coping with enormous physical and emotional stress find themselves further burdened by financial stress, as well.

Over the next 12 months, this Commission intends to lay out a roadmap for comprehensive reform of the nation's long-term care system. That roadmap will encompass six broad areas of system change that challenge us as Americans. They are:

CULTURE TRANSFORMATION

We as a society must transform the culture of long-term care through organizational innovations that improve individuals' quality of life and the quality of their care. Promising initiatives include resident-centered care and the sensitive provision of palliative and hospice care.

EMPOWERING INDIVIDUALS AND FAMILIES

We must empower individuals and families by creating a greater array of high-quality, accessible and affordable long-term care services, especially services available in the homes and communities where those who need those services live. We must provide family caregivers with the information, support and training that enable them to continue their central role in the lives of those with disabilities.

WORKFORCE

We must support those who provide care by improving their work conditions, pay and benefits, and by ensuring them greater opportunities for training and advancement.

TECHNOLOGY

We must use technology more effectively to enhance consumer independence and promote consistently better quality of care. We must design a health information technology infrastructure that addresses the unique needs of long-term care users and providers while ensuring the interconnectedness of electronic information – as well as consumer privacy and security - in both the long-term and acute-care systems.

REGULATION

We must institute long-term care regulations that are anchored in accurate and timely information. Those regulations should be uniformly implemented and should include both strong enforcement provisions and provisions designed to continually improve quality and innovation through appropriate interventions and incentives.

FINANCE

We must ensure that all Americans have access to long-term care financing in their time of need. Public and private financing should work together to enhance individual choice about care options and settings, improve quality, reward innovation, and demonstrate fiscal responsibility.

A CALL TO ACTION

We the members of the National Commission for Quality Long-Term Care plan to initiate a long-overdue national dialogue about the concrete steps we can take today to transform the long-term care system of tomorrow. We will explore the ways in which those working within long-term care, those who use long-term care services and those who finance those services can each take appropriate responsibility for building a compassionate, high-quality and economically sound system of which Americans of all generations can be proud. We believe that a rational and efficient long-term care system can be built upon a sustainable and shared stewardship of the nation's resources.

Those who were only schoolchildren when President Kennedy issued his call to public service have become this nation's leaders and produced children of their own. The torch has been passed once more. If we wait for yet another generation to come of age, if we wait for the demands imposed by the aging of the Baby Boomers, America will pay a steep price. All of us, of every generation, need to look into the mirror and accept the ethical, financial and social challenges posed by the pressing need to reform long-term care.