

Every day I see patients suffering because government regulations prevent me from prescribing frontline drugs, or because our system of price controls and delays in approval mean that they are not available at any cost.

Just three years ago, I personally needed to drive periodically to Washington state to get medication that was not available in Canada. This is the system that some politicians say they would impose on the United States.

Provision of pharmaceuticals for the elderly, the poor and the chronically ill is an important objective in all civilized societies, but Canada does not provide an example to emulate.

Americans deserve something far better than Canada's ramshackle health-care system. Come to think of it, so do Canadians.

UNITED STATES HOLOCAUST MEMORIAL MUSEUM

SPEECH OF

HON. NITA M. LOWEY

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Thursday, September 7, 2000

The House in Committee of the Whole House on the State of the Union had under consideration the bill (H.R. 4115) to authorize appropriations for the United States Holocaust Memorial Museum, and for other purposes:

Mrs. LOWEY. Mr. Chairman, I rise in strong support of H.R. 4415.

The United States Holocaust Memorial Museum stands in our nation's capital in solemn testimony to the terrible power of senseless hatred and the ultimate triumph of faith and the human spirit. It guards the memory of the six million Jews and millions more who fell victim to Nazi Germany's genocidal persecution during World War II. And it stands as a symbol for those who survived this tragedy, assuring them that we are committed to keeping their stories alive.

An investment in the Holocaust Memorial Museum is an investment that strengthens the very fabric of our society. The nearly 15 million people who have visited the museum since its establishment have seen the pictures of murdered families, loyal and productive members of society, who were sent to their deaths for the crime of being Jewish. They have seen the gaunt bodies of survivors, liberated by allied troops from the death camps, facing the reality of families destroyed and lives shattered. They have seen the examples of the righteous, like Raoul Wallenberg, who risked their lives to defy Nazi hatred and save their Jewish brethren. Because of this museum, 15 million people know the price society pays when contempt triumphs over compassion, when people blinded by hatred are allowed to reign free.

In light of the events of the past decade, of the strife we have seen in Bosnia, Rwanda, Kosovo, and other places, it is more important than ever that we offer our full and unwavering support to the educational and cultural mission of the Holocaust Memorial Museum. It is a powerful rebuke to those who would divide us, both at home and abroad. It is a clear statement, a tangible symbol, of our active, ceaseless resistance to the darker impulses of humanity. It is a manifestation of our commit-

ment to end hatred and bigotry in all their forms, to liberate those who face misfortune and oppression, and to cherish the differences among the world's inhabitants. The museum is at once a monument to the past and a challenge for the future.

As a first step toward meeting this challenge, I urge my colleagues to support this bill.

INTRODUCTION OF HOUSE JOINT RESOLUTION REGARDING QUALITY OF CARE IN ASSISTED LIVING FACILITIES

HON. FORTNEY PETE STARK

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Tuesday, September 12, 2000

Mr. STARK. Mr. Speaker, I join today with my colleague Representative COYNE to introduce a House Joint Resolution relating to the quality of care in assisted living facilities.

As long-term care has emerged as a vital issue for the health and well-being of our nation's elderly, assisted living is emerging as a popular model. More and more consumers are drawn to the ideals of privacy and independence that are promoted by the assisted living industry. States have followed the trend by increasingly providing public funding via Medicaid's Home & Community-Based Services waiver for assisted living services.

Despite assisted living's popularity; however, there remain many questions regarding the direction of this industry. Assisted living facilities are defined and arranged in a variety of ways. Some view assisted living as housing residences while others view them as medical service providers. Many facilities often do not allow "aging in place" despite pictures painted by their marketing brochures. States have responded with varying definitions, regulations, and oversight, resulting in unequal consumer protections throughout the country.

Quality of care in assisted living facilities has been an issue of concern. A GAO study found that 25 percent of surveyed facilities were cited for five or more quality of care or consumer protection violations during 1996 and 1997, and 11 percent were cited for 10 or more problems. I understand that steps have been taken to address these concerns, but news reports of lawsuits filed on behalf of assisted living residents continue to illustrate the impact of poor quality on the health of elderly residents.

Just a few weeks ago in my district, an elderly woman passed away in an assisted living facility due to hemorrhaging from her dialysis shunt. Two times, she pressed her call pendant for help, but both of these calls were cleared and reset 10 minutes later. The facility did not place a 911 call for assistance until 1 hour and 34 minutes later. There was no nurse on duty, and all four resident aides in the facility at the time have denied responding to the calls or clearing/resetting the call system. This situation is still under investigation, but it highlights the seriousness of inadequate quality of care in these facilities.

A new Milbank Memorial Fund publication entitled, "Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century," by Robyn I. Stone is an excellent review of issues facing assisted living. As the article in-

dicates there are many questions concerning the current and future state of the assisted living movement. Because of these questions, I am proposing a White House Conference to help advance our knowledge and awareness of these issues, and if appropriate, recommend public policy steps that are necessary to ensure the optimal development of this industry.

Mr. Speaker, I urge my colleagues to join me in increasing our understanding of the assisted living industry. By focusing on consumer protections and quality of care, we will work to ensure the health and well-being for our country's elderly.

I submit an excerpt from the Robyn Stone paper along with a May 8, 1999 New York Times editorial calling attention to problems in this sector:

ASSISTED LIVING

Another trend that is attracting attention from policymakers, private developers, and consumers is assisted living. One significant problem with this trend is the lack of a consistent definition used by providers, regulators, and policymakers. Some argue that "assisted living" is just a '90s label for a long-term care setting that has been around for centuries—another example of "old wine in new bottles." Homes for the aged, frequently associated with nonprofit fraternal and religious organizations, proliferated in the nineteenth and early twentieth centuries to supply room and board for poor, infirm elderly people. Over the past three decades, sporadic attention has focused on scandalous mistreatment of residents in board and care homes, a version of homes for the aged that also became a refuge for the people with chronic mental illness in response to the deinstitutionalization frenzy of the 1960s.

In the 1980s the term "residential care facility" became fashionable as a catch-all label for places providing room, board, and some level of protective oversight. Hawes et al. (1993) have estimated that about a half million people live in residential care facilities or board and care homes in the United States. Perhaps twice that number are living in unlicensed facilities (November et al., 1997).

It is somewhat ironic that homes for the aged, board and care homes, and other types of residential care were replaced in the late 1960s and 1970s by nursing homes modeled after hospitals. "Nursing homes" have delivered far less nursing care than the name suggests. Today residential care is again in fashion. It is viewed as a desirable alternative to nursing homes because of its ostensibly less institutional character and its emphasis on a social, rather than a medical, model. A number of states, including Oregon, Washington, Florida, and Colorado, have aggressively tried to use residential care as a less costly substitute for institutions. One recent study estimates that anywhere between 15 and 70 percent of the nursing home population, nationwide, could live in residential care instead (Spector et al., 1996). Kane (1997) has questioned the judgment of hospital discharge planners who refer elders with disabilities to nursing homes, rather than alternative arrangements, because 24-hour care is supposedly available. She notes that remarkably little nursing care is provided in nursing homes. For example, a survey of nursing home residents in six states found that 39 percent of the residents received no care from a registered nurse in 24 hours; residents who did receive such care received an average of only 7.9 minutes; care by a nursing assistant averaged 76.9 minutes daily (Friedlob, 1993). Despite these arguments, empirical research has been equivocal on the

issue of the "substitutability" and cost savings of residential care compared to nursing home placement (Kane et al., 1991; Newcomer et al., 1995b; Sherwood and Morris, 1983). In fact, residential care is more likely to be a substitute for living in one's own home than in a nursing home.

What appears to distinguish assisted living from residential care in general and from the somewhat pejorative "board and care" is a matter of philosophy and emphasis on care, not just housing (Kane, 1997). Some have also suggested that assisted living is the rich person's residential care while board and care is for poor people who rely on federal Supplemental Security Income (SSI) and state supplements (SSP) to cover the costs. A recent survey of assisted living regulations in 50 states indicates that four states—Alabama, Rhode Island, South Dakota, and Wyoming—use the terms "assisted living" and "board and care" interchangeably (Mollica and Snow, 1996). For the other states, key characteristics differentiating assisted living from other types of residential care are: an explicit focus on privacy, autonomy, and independence, including the ability to lock doors and use a separate bathroom; an emphasis on apartment settings in which residents may choose to share living space; and the direct provision of, or arrangement for, personal care and some nursing services, depending on degrees of disability.

As noted in an earlier section on care settings, Hawes et al. (1999) recently completed the first national survey of assisted living, using a national probability sample of facilities that met several criteria. These include having 11 or more beds, primarily serving an elderly population; and providing 24-hour staff oversight, housekeeping, at least two meals a day, and personal assistance with two or more activities of daily living (ADLs). According to preliminary findings from a telephone survey, most facilities offer consumers a range of privacy options. Single rooms were the most common residential unit (52 percent); the rest of the units were apartments. The most common type of single room was a private room with a full bathroom; the most common apartment was a one-bedroom for single occupancy.

While most facilities reported a general willingness to serve residents with moderate physical limitations, fewer than half were willing to admit or retain residents who needed assistance with transfers from a bed or chair. Furthermore, fewer than half of participating facilities would admit (47 percent) or retain (45 percent) residents with moderate to severe cognitive impairment; only 28 percent would admit or retain residents with behavioral symptoms such as wandering.

In assessing the extent to which these facilities' characteristics match the philosophy of assisted living, Hawes et al., (1999) concluded that only 11 percent offered high privacy and high service. Another 18 percent provided high privacy but low service. Twelve percent offered low privacy but high service. The researchers noted that residents of these assisted living facilities had considerably more privacy and choice than residents in most nursing homes and in the board and care homes they had investigated in a previous study. Nevertheless, facilities varied widely. A substantial segment of the industry provided environments that did not reflect the philosophy of assisted living. Furthermore, the many facilities whose admission or retention policies excluded people with the cognitive impairments or severe physical disabilities suggests that assisted living is not an environment where those who experience significant functional decline can "age in place."

While assisted living does warrant serious consideration by policymakers, providers,

and consumers, a number of impediments to its development need attention. Today, the assisted living market is primarily composed of the well-off elderly, with little available to moderate- or low-income consumers, as the recent study by Hawes et al. (1999) confirms. This gap is due, in part, to the limited sources and inadequate amounts of public financing (primarily SSI and SSP), which could help subsidize room, board, and care for financially strapped individuals and their families. The most common monthly rate for facilities offering either high service or high privacy was approximately \$1,800 in 1998.

Other impediments to assisted living include concerns, expressed by state policymakers and potential private providers, about balancing consumer choice and privacy on one hand with health, safety, and liability considerations on the other. One major issue reflecting this concern is the degree to which states are willing to moderate their nurse practice acts to allow the delegation of certain tasks, such as administering medication, caring for wounds, and changing catheters (Kane, 1997). A number of states, such as Oregon, Kansas, Texas, Minnesota, and New York, have included nurse delegation provisions, but the latitude and interpretations of the provisions vary tremendously. Not surprisingly, they have met serious resistance by many nurses' organizations, for whom professional turf is as significant as care issues.

The motives of the assisted living industry have also been questioned. The industry includes more real estate developers and hotel managers than care providers. Furthermore, as nursing homes look for new markets and reimbursement strategies that circumvent government regulation, many skilled nursing facilities may simply lay carpet, install door locks, and hang out the "assisted living" shingle. Finally, there are questions about the amount of assistance that these facilities actually provide. According to the study by Hawes et al., 65 percent of the participating facilities supplied "low service"; that is, they did not have an RN on staff or did not provide nursing care, although they did provide 24-hour staff oversight, housekeeping, two meals, and personal assistance. Another 5 percent, categorized as "minimal service," supplied no personal assistance with ADLs. Given that many facilities do not admit or retain people with severe physical disabilities or cognitive impairment, the level of care is additional cause for concern.

[From the New York Times, May 8, 1999]

THE NEED FOR CARE AS WELL AS PROFIT

Among other things, the 1990's will be remembered as the decade when developers and older, affluent, anxious Americans discovered each other with enthusiasm, with results both encouraging and worrisome. The concept that both they and Wall Street have embraced is called assisted living. There is no common definition of it. Each of the 50 states regulates it differently, and the Federal Government not at all. But to older retirees who can pay to live in the new and re-conditioned spaces sprouting across the country, the assisted living communities offer something irresistible. It is the promise of Pleasantville, where they can live out their lives gracefully, with hotel services, assistance when they need it, and the chance to hold off or avoid what many of the aged most fear—the nursing home.

For developers, some with no experience in caring for the aged, the attraction is clear. The number of old people of financial means is growing. Some 6.5 million now need some help with the chores of daily living. That figure is expected to double by 2020. Ten years ago there was not even an industry trade

group. Today the Assisted Living Federation of American estimates there is a kaleidoscopic collection of about 30,000 such facilities in the United States, with a million old people living in them, almost all of whom pay their own way.

Some facilities fall into state licensing categories and some do not. Their average national monthly rate per person is \$1,500 but elegant two-bedroom units on Long Island may rent for \$5,000 or more. The National Investment Conference, a group that specializes in the senior housing market, found in a survey of 73 assisted living developments released this year that the median profit margin was 29 percent. For a quarter of the properties, it was more than 35 percent. Those numbers warm Wall Street, but do not guarantee that the communities deliver high-quality services.

Because the phenomenon has grown up around existing rules, many kinds of places can advertise "assisted living." A Government Accounting Office survey, performed at the request of the U.S. Senate Special Committee on Aging, found that about half the residents sign up without being sure what services the facilities provide, how much they cost or what medical care the residents can count on. A quarter of the places surveyed were cited for five or more problems involving quality of care or resident protection within two years.

When Albert Fleischmann, 85, a St. Petersburg Yacht Club member and retired owner of a hardware chain, moved into an assisted living facility in Pinellas County, Florida, in 1997, his daughter was reassured. Patricia Fleischmann Johnson heads a charity that serves as guardian for 134 people in such places. But when Mr. Fleischmann suffered a heart attack at his table in the dining room this year, he was ignored. He called his daughter. She took him to the hospital. She then called back to ask the facility how he was, and was told—as if he were there—that he was "fine." Because Mr. Fleischmann likes the place, he is still there. But his daughter, who testified before the Senate committee, is more concerned now, and she is not alone.

There are no pending bills in Congress, but 32 states are expected to consider legislation this year to increase regulation of the assisted living industry. They should do so. With so many frail lives and so much money involved, this issue is not going away.

HONORING DR. SAM CALLAWAY

HON. SCOTT McINNIS

OF COLORADO

IN THE HOUSE OF REPRESENTATIVES

Wednesday, September 13, 2000

Mr. McINNIS. Mr. Speaker, it is with deep sympathy that I wish to recognize the life and exceptional contributions of Dr. Sam Callaway. Sam Callaway passed away on July 12, 2000 at the age of 86. Dr. Callaway served the community of Durango, Colorado for forty-two years, beginning his practice in 1946 and retiring in 1998. Dr. Callaway cared for his patients, giving both time and compassion to each person he treated. His dedication was evident in his manner, his attitude of interest and in his practice of going to patients in need, day or night. Known for his bedside manner, Sam Callaway was a model of kindness and gentility. Dr. Callaway was not only appreciated and respected by his patients, but also by his colleagues. He was often requested to assist in surgeries. Dr. Callaway