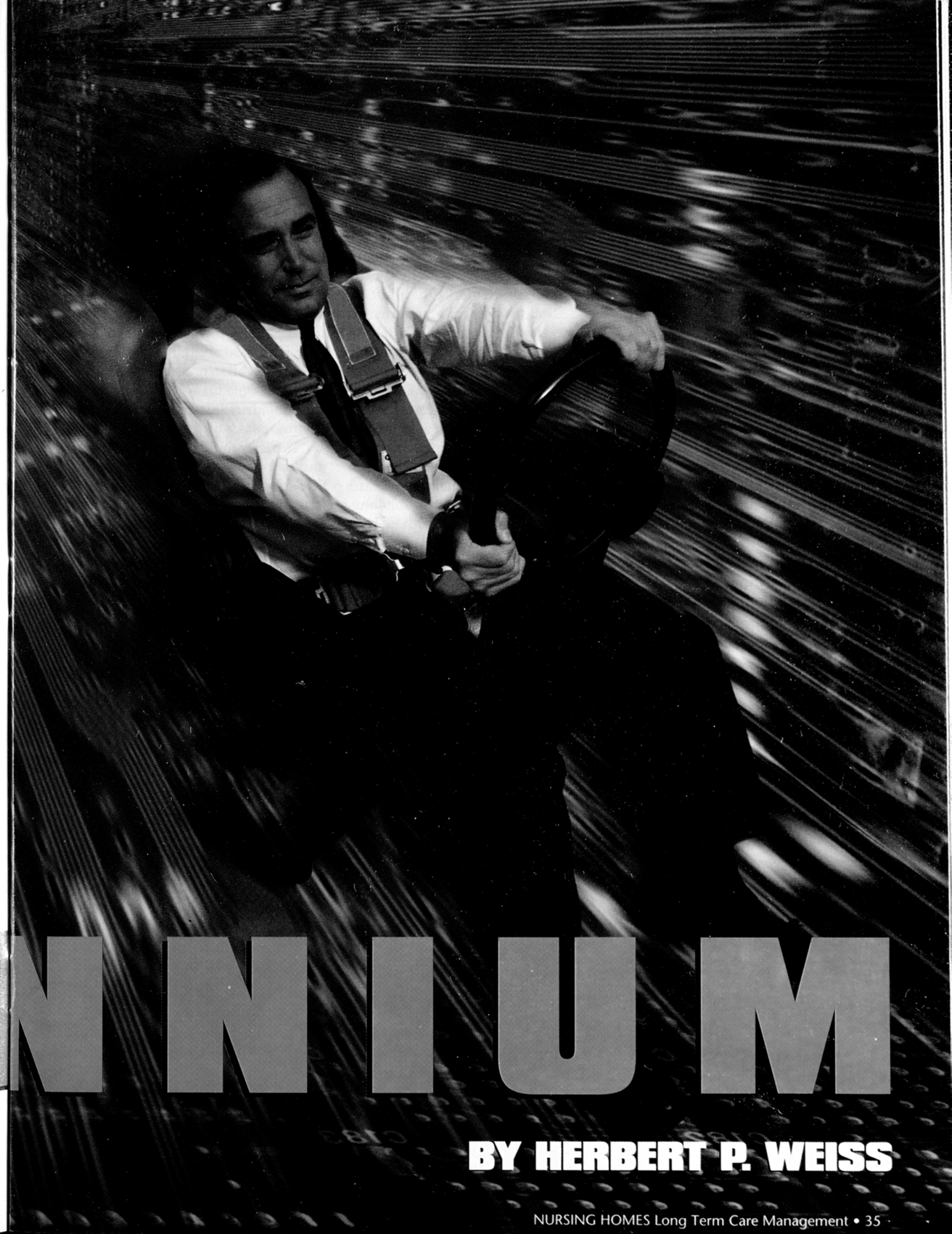
# LONG-TERM CARE AT THE MILLENNIUM

## *A Glimpse from Rhode Island*

BY HERBERT P. WEISS



### How one state is reorienting its funding and delivery priorities

Until the early 1990s, state policymakers watched uneasily as Medicaid costs skyrocketed, growing at a rate of 20 to 25% annually.[1] Meanwhile, as more of the program's dollars were targeted to the nursing home sector, home- and community-based care services (HCBC) became poorly funded. This often forced elderly persons to enter nursing homes rather than being cared for at home by a caregiver backed by a network of HCBC providers, who were often scarce to begin with, because of the lack of Medicaid funding.

As we move into 1999 and the millennium approaches, more states are rethinking their Medicaid payment policies and are moving to create and finance an integrated, seamless long-term care system, to make available more care options to keep seniors at home, if medically possible. Long-term care policy is now becoming consumer-driven, and state policy officials are listening to their elders' calls for change.

Today, increasing Medicaid and state expenditures for home- and community-based services, combined with structural changes in state management of long-term care services, is becoming a popular way of controlling spiraling Medicaid costs and allowing consumers to have greater choice and access to care options, according to an October 1998 report issued by the Public Policy Institute of the American Association of Retired Persons (AARP), based in Washington, DC.

Although funding for home- and community-based services increased sixfold, from $2 to $13.6 billion, from 1987 to 1997, absolute Medicaid dollars to nursing homes and intermediate care facilities for the mentally retarded also surged during that same period, from $19 to $40.8 billion, according to the AARP report, entitled "New Directions

for State Long-Term Care Systems."[1]

The report revealed that states are attempting to move away from Medicaid's traditional bias toward funding of nursing home care. More states are using regulation to revamp their long-term care delivery systems to keep the elderly in their homes, rather than in nursing homes. According to the AARP report, in 1995, 45 states regulated the growth of the nursing home sector through a certificate-of-need process or a moratorium on building new facilities. The report noted that regulators also encouraged the growth of residential housing, board and care facilities, and assisted living facilities. Many states have even capped Medicaid rate reimbursement increases and controlled access to facilities by creating a single point of entry to screen, assess and provide care management to consumers shopping for long-term care.

A bellwether state in this remaking of the long-term care system has been Rhode Island. Its recent experience illustrates what many long-term care providers can expect in the future.

Since the mid-1990s, Rhode Island has moved to revamp its long-term care delivery system. Although it was one of the first states in the nation to adopt a Medicaid waiver that allowed payment for HCBC services, in 1997 some 93%[2] of Medicaid dollars for long-term care services were spent on institutional providers. It is the sort of imbalance in Medicaid funding that confronts policymakers in every state. Due to the successful lobbying efforts of senior advocates and a coalition of more than 100 HCBC provider agencies, called Choices, on June 30, 1998, Rhode Island became one of a handful of states to codify consumer values for long-term care into state statute.

Among 11 goals and values outlined in the long-term care Values Law ( P.L. 98-53 & 321), consumers must: be treated with dignity and respect; actively participate in all care decisions; and be given information to allow informed choices to be made about available long-term care services.

In addition, the Rhode Island law advocates that the long-term care system provide financial support to family and other informal caregivers, control costs for consumers and the public and offer quality of care in all service settings. Finally, this law mandated all long-term care programs and services provided by all state agencies to be specifically designed to foster independence and provide care in the least restricted environment.

"The law would in effect shape our public policy as we implement it through legislation over the years," notes Lt. Governor Charles Fogarty, Chairman of the Long-Term Care Coordinating Council (LTCCC), whose group pushed for the legislative initiative. "As we put forward pieces of legislation or spending priorities, we would



be required to see how they would fit into our value system," Fogarty adds.

On the heels of the 1997 Long-Term Care planning legislation, four state department directors released their "Shared Vision" plan to integrate the state's long-term care system. As mandated by Public Laws 97-194 and 97-359, the Department of Human Services; the Department of Elderly Affairs; the Department of Mental Health, Retardation and Hospitals; and the Department of Health developed the joint plan, ultimately to be shared with the Rhode Island General Assembly. According to the state directors, their 15-page plan, the full title of which is "Toward a Shared Vision: Creating a Seamless Long-Term Care System for Rhode Island," was "not a concrete blueprint for a new long-term care system," but "a process for getting there."

The "Shared Vision" plan calls Rhode Island's long-term care system "fragmented and confusing to both consumers and providers," and recommends reform through achievement of the following five goals:

1. Reduce system fragmentation by developing a seamless continuum of services, available to all, based on a data-driven planning process, with extensive input from all stakeholders.

2. Expand community-based options by taking steps to expand the base of home- and community-based providers willing to accept state-paid clients.

3. Provide accurate information through a coordinated information and referral system that is culturally sensitive, readily accessible and multilingual. This effort would be supplemented by a public education program to enable consumers to make informed choices.

4. Become a prudent purchaser of services through the development, application and monitoring of quality/performance standards.

5. Improve the delivery of programs and services by realigning administrative and operational functions of state agencies.

Among other key points, the report noted that payment of HCBC services should be driven by quality outcomes, and that new programs should be developed to support assisted living as an alternative to nursing home placement for low-income elderly.

In developing the consumer's entry point into the system, the plan envisions a system of key players (e.g., state offices, social service providers, healthcare providers, neighborhood centers and community agencies) that will provide "clear, accurate, up-to-date information" to those requesting information about long-term care services and options. Last year the Rhode Island General Assembly approved a modest $250,000 to put information specialists at 12 senior centers.

Finally, the plan foresees the state moving toward performance-based contracting for service, ultimately with

more ambitious service enhancements. The plan also would create a clearinghouse of best practices for measuring and monitoring quality in long-term care service delivery, from post-acute to respite care.

With the enactment of the long-term care goals and values in June 1998 and the official release of the "Shared Vision" proposal in January 1999, state agency directors have formed work-implementation teams and held a series of two-day retreats to develop consensus between providers and consumers on such key issues as quality, delivery, finance, information and referral, advocacy, and information management. The work groups, consisting of 80 key state officials, members of the senior coalition groups, HCBC and nursing home providers, under the guidance of a representative Steering Committee, meet regularly. From this has emerged a consensus list of long-term care budget priorities for fiscal 2000 that the group will take to the administration and legislature.

As the 1999 legislative session begins, the LTCCC has also developed a set of budget priorities to fund the goals and objectives of its State Plan for Long-Term Care, which includes the "Shared Vision" budget priority list; these priorities have the blessings of providers and consumers alike. Regarding these priorities, Lt. Governor Fogarty says, "We wanted to get these recommendations in place before the Governor's budget comes out so we're simply not reacting to a [FY 2000] budget, but have the chance to influence its creation." In a December 14 letter to Rhode Island Governor Lincoln Almond and key legislative leaders, Fogarty urged them to incorporate these budget priorities for long-term care in the FY 2000 budget.

"Seniors are delighted that everybody is working together to bring about significant changes in our long-term care system," says Owen Mahony, chair of the Senior LTC Action Coalition. "It is especially great to have worked with all stakeholders from the beginning of the process rather than to react to a finished product."

In revamping the state's long-term care delivery system, "it's terrific to have everyone under one tent," states Human Services Director Christine C. Ferguson. "And it feels very much like everyone is on the same page," she adds, noting that it has taken a lot of process to get there. "Providers and consumers are looking at the same system, on what is available and needed, and are pulling together in a shared sense of priority. We're moving to better align our long-term care system with the needs of people rather than having the system run by payment streams," she notes.

Ferguson adds, "Making consensus easier to reach was Governor Almond's early commitment to work hand-in-glove with seniors to improve the long-term care delivery system."

Al Santos, executive director of the Rhode Island Health Care Association, sees the process as "refreshing," as consumers and providers work together to create a more quality-oriented long-term care system that is properly reimbursed.

Adds Barbara Rayner, director of the Department of Elderly Affairs, the two-year process of creating the "Shared Vision" proposal has been consumer-driven. "These are not idle words," she notes, "because seniors are represented on all committees and subcommittees."

But when the dust settles, what type of long-term care system will Rhode Island have created? By working collaboratively with all stakeholders, says Rayner, the state will reach its goal of creating an integrated, coordinated, high-quality long-term care system. **NH**

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## References

1. Coleman, Barbara. New Directions for State Long-Term Care Systems. American Association of Retired Persons. Washington, DC., October 1998: P. ii.
2. Long-Term Care Coordinating Council Budget, 1997.