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By Sandra Block

Elder care shifting away from nursing homes

Michelle Booth of Foster City, Calif., has never been much of a morning person. But seven days a week, she gets up at 7 a.m. to make breakfast for her parents.

On weekdays, a bus takes them to senior day care, which gives Booth, 54, a few hours to run her home-based business. At 4 p.m., she picks up her parents. She has dinner ready at 4:30. Once they're in bed, she does chores and unwinds by watching TV. She rarely goes to bed before 3 or 4 a.m. "If I can get five hours of sleep, it's wonderful," she says.

Booth's mother, Bess, 87, has early-stage Alzheimer's disease. Her father, Hyman, 88, has been disabled by strokes. They require round-the-clock care, making it hard for Booth and her 14-year-old daughter, Alystar, to leave for a weekend, or even a day.

Booth's parents took her in a decade ago, after her marriage ended, and helped care for her daughter. Now, she says, "The roles are reversed." Yet, she has no plans to put them in a nursing home:

"I can't even imagine seeing them in a home. If their physical needs become such that I couldn't handle it, I'll have to sort that out."

COMMENTS: [If you're taking care of an elderly parent, how do you manage the costs? Share your experiences in the comments below.](#)

As the parents of America's baby boomers move further into old age, Booth's life could increasingly represent the face of elder care in the USA. Adult children, worried about costs and the loss of their parents' independence, have long viewed nursing homes as a last resort.

But a shift away from institutionalized care is growing. The percentage of people over 75 in nursing homes fell from 9.6% in 1985 to 6.4% in 2004, according to the AARP Public Policy Institute.

Elder care experts say the decline reflects the growth of less-restrictive types of care, ranging from assisted living to supervised adult day care. These alternatives are usually less expensive than nursing homes and often provide a superior quality of life.

Still, nursing homes, for all their drawbacks, provide 24/7 care in a federally regulated site. By contrast, most alternatives impose heavier responsibilities on family caregivers, notes Caroline Harada, a geriatrician at the University of Chicago Department of Medicine. As a result, baby boomers are likely to become increasingly entwined with their parents' care.

"When people are in these less-supported living environments, the family has a much greater role to play in ensuring the patient gets all the care they need," Harada says.

This expanded role comes as unpaid family caregivers are already providing an average of 21 hours of care a week, according to an AARP study set for release today. In 2006, the economic value of unpaid caregiving equaled \$350 billion, the study found — more than the nation's Medicare spending in 2005. Among the challenges for adult children as caregiving evolves:

Costs.

The average annual cost for a semiprivate room in a nursing home is nearly \$67,000, reports the MetLife Mature Market Institute. In parts of the country, it's much higher. Still, if a senior citizen exhausts all her assets, Medicaid will cover her nursing-home care.

Not so with other types of long-term care. Except in isolated instances, Medicaid doesn't cover assisted living or home-based health care. That means families often have to pay those costs. The average cost for an assisted-living facility was \$35,616 a year in 2006, according to the MetLife Mature Market Institute. The average cost for a home health aide is \$19 an hour.

Daniel Baum, author of *Assisted Living for Our Parents: A Son's Journey*, helped his mother, Ida, enter an assisted-living facility when she was 89. Baum says she "took great pride in that home and being her own person." But she was living alone in a crumbling neighborhood in a Midwestern city, and Baum lived about 800 miles away in Toronto.

Baum says he felt assisted living would allow his mother to preserve her independence while still receiving the help she needed. He sold her home and used the money to pay her rent, "but her money was gone by the end of the second year," Baum says. After that, Baum paid the bills until his mother died three years ago at age 96. He estimates he contributed \$200,000 toward his mother's care.

Baum, now 72, was able to raise the money by tapping his retirement funds. That's not always an option.

Diane Northcutt, 57, of Charlotte, had to move her mother into a nursing home two years ago after several strokes left her incapacitated. Northcutt's father couldn't care for her alone, and her mother's diabetes and other illnesses had drained the couple's finances.

Northcutt thought her mother could stay at home with help from home health care aides, but when she contacted Medicaid, "The representatives informed me under no circumstances could we have funds to keep Mom at home," she says.

Reluctantly, Northcutt moved her mother into a nursing home. Her mother died April 27 from an infection that Northcutt thinks could have been avoided if her mother had stayed home. It was a slow, painful death that still gives Northcutt nightmares. "If she had died in a natural way and her heart had given out or she suffered a stroke, we could have accepted that," she says. "What

happened to her — it's very haunting."

In her grief, Northcutt has become an activist, advocating for changes to Medicaid that will provide funding for home health care. If Medicaid had paid just a third of the cost of her mother's home health care, "We could have picked up the rest," Northcutt says.

"You're just trapped in the system the way it is," she says. "They won't let you do anything else."

Some states are moving toward allowing Medicaid to cover non-institutional care. But in most cases, "The family has to spend its own money to keep the person out of a nursing home," says Gail Hunt of the National Alliance for Caregiving.

About half of caregivers spend an average of \$200 a month to support a friend or relative, a survey by the alliance and AARP found. About 23% of those surveyed said caregiving was a financial hardship.

Michelle Booth received a grant from the Family Caregiver Alliance, a San Francisco-based non-profit, that lets her occasionally hire someone to stay with her parents when she's away. But the grant expires this month. "Then, I'm on my own," she says. "It's hard to find time for a social life."

"I would love to see some sort of government program that provides income to people who have family members at home," Booth adds.

As more families seek alternative forms of care, a backlash is growing against funding for nursing homes. AARP has joined a lawsuit to block San Francisco from rebuilding its Laguna Honda nursing home. Critics argue that the \$620 million allocated to rebuild the facility could be better spent on programs that let seniors stay at home or in less restrictive settings.

Quality of care.

Elder care experts say the fast growth of assisted-living facilities has contributed to a decline in nursing home residents. About 1 million Americans live in assisted-living facilities, up from about 210,000 in 1990.

But families should be aware: The quality of care varies among facilities that call themselves assisted living. That term covers a lot of territory, from an apartment complex with meals and limited medical staff to a facility with full-time health care. "Thirty years ago, if your parent was so frail he needed insulin and help showering and bathing, you would have no other options but a skilled nursing facility," says Linda Fodrini-Johnson, director of Eldercare Services, a care provider in Northern California. Now, "Families have more choices, and when you have more choices, decisions are difficult. The burden is on you."

Complicating matters, regulation of assisted-living sites varies depending on where you live, says Kathy Cameron of the National Alliance for Caregiving. "With nursing homes, there's federal oversight," she says. "It's very different with assisted living. We have great states and states with very few regulations and few actual inspections."

Along with finding a facility that's affordable and provides good care, caregivers must decide

whether it will remain suitable for their parents as they continue to age.

Daniel Baum says his mother thrived during her first two years in assisted living. But when a close friend died, she became depressed and suffered a succession of falls. Each time, the staff called an ambulance, even if she wasn't seriously hurt. This led to "aggressive medical care, enormous disorientation and confusion," Baum says.

He believes the facility sent his mother and other residents to the emergency room because it was cheaper than having a nurse practitioner on staff. When a resident is sent to an emergency room, Medicare pays most of the cost.

Supervision.

In a 2004 survey by AARP, 15% of caregivers said they lived an hour or more from their parents. Some live hundreds of miles away. That can be stressful when a parent is living in her own home, or even in assisted living. "In assisted living, when something happens at 2 a.m., they'll call a family member," says Jennie Chin Hansen, president-elect of AARP.

Ruthann Reim McCaffree, 63, of University Place, Wash., says her mother made her vow not to move her from her home in Campbell, Calif. That wasn't an issue until four years ago, when her mother failed her driver's license test. "That put her into a tailspin," McCaffree says.

McCaffree's mother started to lose her short-term memory, then fell and broke her hip. McCaffree was able to get her mother back in her home, but a year later, she fell again. That led to a series of stays in five long-term-care facilities, none of them a good fit. McCaffree finally moved her mother into a nursing home in August; she died in December at age 87.

During the four-year period, McCaffree shuttled between California and Washington. Income from her career counseling business dropped because she had to hire people to do things she'd normally do herself. And in the midst of caring for her mother, she lost her husband, who died in 2003.

After her husband died, McCaffree hired Mary Lynn Pannen, a geriatric care manager. Geriatric care managers are professionals, often registered nurses or social workers, who help families manage and monitor care for aging parents. They typically charge hourly rates ranging from \$80 to \$200.

Pannen, president of the National Association of Professional Geriatric Care Managers, says the managers are often hired by adult children who live far from their parents and need someone to provide hands-on help. "I can visit once a week, once a month, keep in touch by phone" she says. "The care manager becomes your eyes and ears."

Carol Troup, 42, of Seattle, says a geriatric care manager helped her family find someone to visit her parents' condo in Tacoma, Wash., a couple of times a week to do household chores and help her parents get around. Troup's mother, 79, is in good health, but her father, also 79, has Parkinson's. As her father's health worsened, caring for him became harder for Troup's mother. Because Parkinson's is a degenerative disease, Troup and her three siblings have discussed the prospect that their father will someday need a nursing home. Troup says her father has always been fiercely self-sufficient and "doesn't take help very easily."

"Nobody wants to be the one to say, 'We're going to take away your last shred of independence,' " she says.

Yet, even with the growth of alternatives to nursing homes, some families find they have no choice, says Bonnie Lawrence of the Family Caregiver Alliance. A parent with serious health problems or advanced Alzheimer's may need more care than a relative or assisted-living facility can give, she says.

Even when a parent is placed in a nursing home, families play a vital role, Lawrence says: "They need to be advocates for their loved ones, they need to visit frequently, check on care and communicate with the medical staff. In no way is your role as a caregiver diminished. It's still very necessary."