

Jackie Majoros, Committed Advocate for Long-Term Care Reform

by Amy Brooks Thornton

We are a pretty ageist society," says Jackie Majoros. "You think about abuse and you think about a child being abused. You look at an older person as a victim of abuse, and society has a very different attitude about it."

This fall the National Consumer Voice for Quality Long-Term Care awarded Majoros the Cernoria Johnson Memorial Advocacy Award, recognizing her work's national impact in long-term care. As Vermont's long-term care ombudsman and director of the Vermont Ombudsman Project at Vermont Legal Aid since 1996, Majoros has advocated for more individualized and flexible delivery systems and practices for long-term care beneficiaries.

Specifically, Majoros helped lead Vermont's long-term care transformation from its emphasis on institutionalized care provided in nursing homes to the more flexible and individualized Choices for Care, the state's Medicaid long-term care program for older Vermonters and people with physical disabilities. Implemented in October 2005, the program assists and supports people in a variety of settings—at home, in an enhanced residential care setting, or in a nursing facility. Leading the nation in long-term care reform, by 2006 Vermont was spending 60 percent of its long-term care cost on care in the community, ahead of the national average of 46 percent.

Advocating for the Elderly

Majoros has also worked to strengthen Vermont's home health licensing regulations, advocated to improve adult protective services, helped reform Vermont's guardianship system, and championed the state's advance care planning laws. During the implementation of Choices for Care, she helped ensure that the rules and procedures protected consumer rights and provided for self-direction.

"We are facing a crisis with the aging demographic," Majoros says. Investing in and building a system of home- and community-based services, Majoros argues, can help alleviate the predicament we now confront.

As staff attorney at Vermont Legal Aid's senior citizens law project, which provides legal assistance to seniors and where she represented individuals and groups in federal and state courts and before administrative agencies, Majoros realized how much she enjoyed working with the elderly. "They are a pretty neglected segment of the population. Not only were they really happy to have the legal services, but they were really happy to have someone come to their homes, to have the company."

Knowing the individual and understanding his or her needs and lifestyle and allowing people to self-direct how, when, and where they receive care, with the assurance that their choices of care will be satisfactory, is central to Majoros's work. Just last year, Majoros and her fellow ombudsmen made more than 1,000 visits to long-term care facilities and investigated 521 complaints.

Self-Directed Care

For individuals who need nursing home level of care and meet the financial criteria, Choices for Care has a variety of long-term care options for them to choose from, including enhanced residential homes and home- and community-based services, as well as traditional nursing homes.

When people choose more flexible and individualized options, Majoros says, "they have a certain level of autonomy, which they are not going to have in an institution. In an institutional setting, you lose control about when you get up, when you go to bed,



photo: Amy Brooks Thornton
Jackie Majoros in her office at Vermont Legal Aid.

when you take your bath, who you share your room with, how much furniture you get in your room."

Through the Choices for Care program, if long-term care beneficiaries choose to stay in their homes, they can use an agency to manage their care or self-direct; receive homemaker services, personal care services, or case management assistance; receive a yearly stipend for assistive technology; hire their own caregivers—and much more.

But moving the state from its entrenched nursing home system to home- and community-based services is tricky. The state has "a limited pot of money," says Majoros, and it's "hard to figure out how to downsize nursing homes without putting them out of business." Yet, Majoros notes, "It generally costs less for people to get home- and community-based services."

Paying for Costs of Long-Term Care

The cost of long-term care is frightening. Currently, much of the discussion in the news focuses on the overwhelming cost of college tuition. Yet, just as you finish putting aside enough money for your children's college tuition, which could range up to approximately \$250,000 per child, you are faced with saving for your old-age care.

The Department of Vermont Health Access calculated Vermont's average cost for private nursing home

care per person is \$8,944.04 per month or \$107,328.48 per year in 2014. To understand it relative to college savings, that's about double yearly private college tuition, including room and board.

However, it's hard to know how long you'll need a nursing home. The median stay for end-of-life nursing home patients, according to a study published in the *Journal of the American Geriatric Society* (September 2010), is only five months at a cost of approximately \$55,000. However in 2004, the Centers for Disease Control found the average to be much longer: 835 days, or two years and four months, which costs in today's dollars approximately \$245,000. And this expense is in addition to care an individual may have needed prior to entering the nursing home, such as at an assisted-living facility or at-home care, which are also costly.

per day, an average of \$6,631 per month or \$79,570 per year. How much a stay costs depends on a measurement called "acuity," which determines the intensity of care required for a resident. The higher the acuity, the more care the resident requires, which drives up the cost.

To be eligible for Vermont Medicaid, however, your income must not exceed \$11,700 per year, which is the Protected Income Level (PIL) per person for 2014 in most areas of the state. People can "spend down" to qualify for Medicaid long-term care. If their income exceeds the PIL, they can qualify by paying the excess income to the nursing home and Medicaid pays the balance.

In Vermont, Medicaid covers about 63 percent of nursing home stay cost, high relative to the national average of 50 percent. Medicare pays 16 percent, and private payment covers 14 percent.

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If you qualify for Medicaid, it will cover the nursing home care that you can't pay for. In 2014, the national daily rate for a Medicaid-funded nursing home stay ranged from \$169 to \$267

Private insurance falls at the extreme bottom, paying only 0.07 percent of nursing home stays.

"Sometimes people start with the private nursing home or assisted-living facility, run out of money, and then need to move to a facility that accepts Medicaid," Majoros explains. "It makes it hard because they have to transition. They might have to leave their friends, move further away from their family . . . Most people can't save enough money to pay for long-term care."

Placement Complications

Since the Choices for Care program began, nursing home occupancy rates have dropped. As of October 2014, 463 nursing home beds were available in Vermont. Yet there are dozens of potential nursing home residents who need nursing home level of care but can't find placement because they either have an underlying physical limitation or a mental health diagnosis. Nursing homes often lack appropriate mental health services or special equipment for physical needs such as obesity.

Majoros cites a situation in which a nursing home didn't have the support to take care of a resident's mental health needs. "The nursing home felt he was disruptive [so] they took him to the emergency room. He's been in

the emergency ward for almost three months now. We've been working with the family, hospital, and state to get him placement. The nursing home doesn't want to take him back."

A Staffing Crisis

"With our aging demographic, we just aren't going to have the people we need to provide the care that we need," Majoros says. "Right now, there is a lot of turnover in nursing homes. People are not seeing [the direct care occupation] as a career." Yet, direct care workers "are the most important part of the equation."

Attracting workers to direct care occupations is a critical element of the long-term care solution, Majoros believes. "Make them feel that they are part of the system. Give them some say over how the care is provided." Additionally, she suggests a minimum training requirement and higher wages to elevate the profession—potentially an additional expense for the state.

Luckily, family caregivers play a crucial part in making the system work. "They are really stepping in and filling the gaps," Majoros says, and ensuring the correct care is provided. "We see people in nursing homes all the time who . . . benefit from family caregivers. The system would not work without them." But family members are often stretched and need support, too.

The Best End of Life

Majoros wants people to die well and under the best care, not from neglect or mistreatment. "Someone shouldn't die because they've been starved or they are dehydrated," she insists. "They didn't have to die that day, that way."

The Vermont Ombudsman Project and other stakeholders are pushing for legislation to be written and passed in 2015 to establish a Fatality Review Team to investigate death from neglect and mistreatment in the long-term care system. Majoros and her team want to know: "What went wrong? Is there anything we could have done to prevent it happening? Where was the gap in the system? How can the system work better and prevent deaths in the future?"

"As a society we have to think differently about the aging process," Majoros urges. "And think differently about the kind of care people should expect at the end of their lives."

Amy Brooks Thornton, an educator and multimedia journalist, worked at ABC News with Peter Jennings and was founder and director of Pacem School and Home-school Center in Montpelier, Vermont. □

Class Action Lawsuit to Ensure Medicare Pays for Home Health Services

Vermont Legal Aid and the Center for Medicare Advocacy filed a class action lawsuit against Sylvia Mathews Burwell, the US secretary of Health and Human Services, to stop Medicare's practice of repeatedly denying coverage for home health services for beneficiaries on the basis that they are allegedly not homebound, when Medicare has previously determined them to be homebound (Ryan v. Burwell). The lawsuit was filed on December 19, 2014, in the US District Court in Burlington, Vermont.

Those seeking Medicare monies for home health services are required to prove they are homebound, a process that is both time and paperwork intensive. Once a Medicare judge deems a beneficiary to be homebound, Medicare policies declare a person homebound unless there is evidence of improvement.

However, Medicare has repeatedly denied coverage to previously qualified beneficiaries.

How "homebound" a person must be is central to the dispute. "We have this old rule out there that runs afoul of people getting good care in their home," Jackie Majoros, Vermont's long-term care ombudsman and director of the Vermont Ombudsman Project at Vermont Legal Aid, says. "People want to receive services in their home, but they don't want to be prisoners in their home. It's important for them to be active in their community. . . . As a society we want people to get good services."

The lawsuit seeks to stop Medicare's practice of repeatedly denying coverage after a Medicare administrative judge has ruled that the beneficiary is homebound.

Long-Term Care Advice

Vermont Ombudsman Project
800-889-2047

Senior help line
802-642-5119

Vermont 2-1-1

An in-state free service available 24/7, providing information on community services, such as senior services, disability services, health care, legal assistance, and more. Can be reached three different ways: 211 (local call anywhere in Vermont), 866-652-4636 (toll free in Vermont), or 802-652-4636 (outside Vermont).

Volunteering

Vermont Ombudsman Project
800-889-2047

Receive training and support to visit nursing homes and respond to concerns or problems that residents raise about their care or quality of life.