

Policy Forum

Illinois Families Under Stress: The Looming Long-Term Care Crisis

The demand for long-term care is large and growing rapidly throughout the nation. In Illinois alone there are almost 800 nursing homes with more than 100,000 beds. In addition, about 1.24 million family caregivers provide more than 1.33 billion hours of care each year, conservatively valued at more than \$13 billion. Clearly, both the formal and informal long-term care sectors are quite large. Less evident is that both sectors will need to expand and function very well, both separately and together, to meet the predicted growth in demand over the next decades.

This issue of *Policy Forum* summarizes two expert presentations on long-term care and a panel discussion among five Illinois legislators at the 2008 Family Impact Seminar held at the state Capitol in Springfield on May 1. Jessica Polos of the State of Illinois Comptroller's Office and Joshua Wiener of RTI International discussed the demographic factors that are spurring demand for long-term care and the roles of government and the private sector in providing it. The legislators turned to the political realities of addressing this challenge.

"Population Aging: Are Governments Ready?"

Jessica Polos (*right*) began the seminar by addressing the question, "Is Illinois ready for the increase in the number of senior citizens?" She described the changing population dynamics and demands they will place on state government and families, as well as the national and state trends as the large mass of "baby boomers" (which will reach nearly 20 percent of the population by 2030) heads toward retirement. Illinois' elderly population will not increase quite so dramatically, but it is predicted to be about 18 percent of the state's population by 2030. Moreover, the old-old population – individuals 85 and older – will triple in size, greatly increasing the demand for nursing home care.

A key economic concept in assessing demographic shifts is the "support ratio" of working, tax-paying citizens to the number of seniors needing to be supported. Between 2000 and



2030, the support ratio is expected to fall from 5:1 to 3:1. As this ratio falls, "pay as you go" systems such as Social Security and Medicaid face crises (see Richard Dye's analysis in *Policy Forum* Vol. 20, No. 1¹). Additionally, there are increasing numbers of specialized programs for the elderly, including prescription drugs, home health services, and adult day care, which are also highly sensitive to support ratios.

The costs and demands for families will be shaped as well by other trends, such as marriage taking place later in life. Increasingly, working families will have to support their own children – including coping with rapidly increasing college costs – and their parents simultaneously. This increasingly common circumstance has led to the term "sandwich generation" for those families squeezed on both sides by the needs and demands of their children and their parents.

Medicaid spending is the most substantial financial cost for Illinois identified by Polos. Medicaid covers indigent health services, including nursing home care. In 2005, Illinois spent \$11 billion on Medicaid, and \$2.4 billion – or 22 percent of the Medicaid budget – went toward long-term care services for the elderly. The cost of nursing home care has continued to rise dramatically, by more than \$433 million

¹ Available at <http://www.igpa.uillinois.edu/lib/data/pdf/PF20-1.pdf>



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About the Authors

The 2008 Family Impact Seminar was coordinated by **Peter Mulhall**, Director of the Center for Prevention Research and Development within the Institute of Government and Public Affairs; **Elizabeth T. Powers**, associate professor in the Department of Economics at the University of Illinois at Urbana-Champaign and a member of the IGPA faculty; and **Richard J. Winkel**, adjunct professor in the College of Law at the University of Illinois at Urbana-Champaign and visiting senior fellow at IGPA. The expert presenters were **Jessica Polos**, policy analyst in the Illinois Comptroller's Office; and **Joshua Wiener**, senior fellow and program director at RTI International.

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(38 percent) in the last decade. And although many seniors enter nursing homes without Medicaid assistance, a large percentage spend down their personal resources, eventually requiring Medicaid-paid services. At this time, 50 percent of Illinois nursing home residents are reliant on Medicaid, and two-thirds of them will end up on Medicaid. Other significant Medicaid expenditures include nursing facilities, home and personal care services, and mental health facilities.

Polos also cautioned that Illinois currently splits costs evenly with the federal government, but those matching funds could decline as the federal government examines its fiscal and payment options. In the face of these fiscal pressures, an increasingly used and less costly approach for supporting the elderly is to provide care through home and community services. In Illinois, the Community Care Program provides home and community-based services to seniors as a way to maintain them in their own homes. The process involves an initial assessment of the at-risk person's status and resources. Services include light housework, medical services, and meals. This program appears to work well, and to have resulted in fewer people entering Medicaid-paid nursing homes over the past decade.

These home-care services are paid for by a combination of a federal waiver (Medicaid eligible seniors) and Illinois general revenue funds (GRF). Illinois has rapidly expanded this program, increasing spending from \$141 million in 1997 to \$374 million in 2008. This dramatic 165 percent increase in state and federal dollars is, seemingly, money well spent; it has been estimated that the federal and state governments save about \$1 billion per year by keeping seniors from entering nursing homes. A comparison between community care services and Medicaid-funded nursing home care shows that the average cost of caring for an elderly person increased from \$382 per month to \$570 per month for home care (49 percent increase), while Medicaid-paid nursing home costs increased from \$1,814 per month to \$3,115 per month (72 percent increase). Community care not only demonstrates a substantial cost saving associated with in-home care, but also gives the people what they want: remaining at home is by far the first choice of all seniors and their families.

In addition to providing direct and indirect care services to seniors, Illinois has sought to alleviate financial burdens on seniors with fixed incomes through an array of tax and service discounts. Polos reviewed the major initiatives, ranging from income tax relief (\$899 million in 2005), property tax relief (\$4.2 billion in 2005), real estate tax deferrals, driver's license and vehicle registration discounts (\$8.6 million in 2005), and recreational discounts. It should also be noted that the state legislature, at the urging of the governor, recently passed a law providing free public transportation for all Illinois seniors. These tax breaks and exemptions provide financial relief for all Illinois seniors, but also cost the state money.

There are some trends that can be viewed as enhancing the state's ability to deal with future challenges with respect to long-term care and fiscal resources. Polos noted that life expectancy continues to increase despite challenges of chronic diseases such as diabetes, hypertension, and obesity. The "baby boomers" will be the best educated and

most affluent population in U.S. history, which may translate into better planning, more savings and greater care for their health and well-being. In addition, new medical technology, advancing medical genetics, and new therapeutics are likely to improve health and reduce disability among aging baby boomers. Baby boomers are likely to demand – and will likely attain – better health and quality of life than prior generations. Finally, Polos pointed out that both the federal and state governments know what is coming, so the issues surrounding long-term care, though pressing, will not be a surprise.

“You Can Run, but You Can't Hide: Problems and Policy in Long-Term Care”

Dr. Joshua Wiener (*below*) discussed four major components of long-term care: (1) demand; (2) finance; (3) institutional-community care balance; and (4) caregivers. Wiener stressed that the rising demand for long-term care is fundamentally the result of demographic transitions and, therefore, is not a transitory phenomenon that might be safe-



ly ignored. From 2000 to 2050, the share of the population 65 or older is projected to grow by 147 percent and the share that is 85 or older is projected to rise by 386 percent. The proportion under 65 is projected to grow by only 35 percent. This shift in the population distribution toward the “old-old” has major implications for long-term care, because this group's disability rate is highest of all. The paltry growth of the population under 65 (half of which is due to immigration) is the more unexpected demographic development. Thus, the looming crisis of insufficient numbers of workers and caregivers is at least as much a problem of decreased supply as of increased demand.

Money to pay for this care is clearly of paramount interest to policymakers. Worldwide, long-term care consumes about 1.33 percent of GDP, most of which is publicly provided. By 2050, long-term care demand in the United States will consume about 2.5 percent of GDP, up from 1.4 percent. Wiener noted that long-term care is “overwhelmingly a public responsibility” even in the United States. Almost 60 percent of elder care is paid through Medicaid and Medicare, while only 4 percent is financed by private

insurance. The remainder is paid out-of-pocket and from other private funds. This latter figure illustrates the difficulty in establishing a robust market in long-term care insurance, which many policymakers had hoped would relieve demand pressures on government programs. Wiener doubts that long-term care insurance will ever finance the typical household's long-term care needs. His research suggests that currently only 10 percent of the aged can afford a good long-term care plan, while in 10-20 years, this figure will rise to just 20 percent. Wiener also discussed problems with long-term care insurance regulation, especially the lack of requirements to provide inflation-protected policies to consumers.

Much long-term care in the United States is still delivered through nursing homes. While home care and other community-based care are becoming more prominent, Wiener argues that "funding is not up to the rhetoric" at this point, with less than one-third of Medicaid spending going to home and other community-based care (including assisted living) for the elderly in recent years. While community-based care holds out the promise of cost savings, a universal increase in the availability of home care would likely be expensive. Given a choice between no care and an institution, people choose no care; given a choice between community-based services and no care, people choose community-based care. Therefore, states that wish to use the expansion of community-based options as a cost-control measure are being careful to target individuals at risk of institutionalization.

Finally, Wiener turned to "the elephant in the room," the problem of finding and keeping long-term care workers in the field. Even at the highest skill levels, there is little specialization in fields related to long-term care (for example, less than 1 percent of physicians are geriatricians). Most long-term-care workers are not highly skilled and lack specialized training, so they receive low pay and few if any benefits, including health insurance. In turn, the sector is marked by high turnover, lower quality care, and discontinuity of care for clients. Possible solutions to this vicious cycle might include bringing new workers into the long-term care field (for example, increasing the number of men), or technological advances that would increase the productivity of caregivers or even serve as substitutes.

Some Views from the General Assembly

Rep. Daniel Beiser, D-Alton, offered a personal perspective, relating how long-term care needs have affected his own family. He cited three lessons from this experience. First, there is a shortage of geriatric physicians and professional staff to give care and guidance. Without projections on the levels of care that might be needed, attempts to plan intelligently for the future are short-circuited. Second, even though his relative bought long-term care insurance coverage and believed it would be adequate, it was not. Beiser expressed concern that his relative may not have fully understood the plan she purchased. The policy proved insufficient, and over the next year, in order for her to stay in her present nursing home, his relative will have to consume her assets to qualify for Medicaid coverage. Finally, Beiser said

Illinois families need guidance on how to integrate into the long-term health care system while aging members are still in their homes. Many families feel helpless because they do not have enough information to prepare for the future.

Rep. Julie Hamos, D-Evanston, also believes Illinois is not yet prepared. She said the state is rebalancing its long-term care system by adding community resources and changing the culture in communities and the nursing home industry. In her view, the state must offer services that respond to the specific needs of our aging population so more are able to live at home. She said Illinois is developing a single point of entry, which would include a comprehensive assessment of future long-term care needs for families as they plan. Hamos concluded by noting that three class-action lawsuits against Illinois are pending, and that the courts may force the state to shift its paradigm of long-term care even if the legislature fails or refuses to do so.

While Sen. Dale Righter, R-Mattoon, noted that Illinois is making some progress in long-term care, he described the gains as very uneven, and the system as a whole as disorganized. He complimented the efforts of those who provide seniors with long-term care in the communities, but argued that Illinois lacks a much-needed comprehensive strategy to provide this type of care. Regarding fiscal responsibility, Righter noted that if the General Assembly were to approve the governor's recommended increase for the Department on Aging, the department's budget would have increased 117 percent over the past six years, which makes it the fastest growing part of the general revenue fund. In his view, families will need to take an even greater role as long-term caregivers; as the state reprioritizes its allocation of resources for this purpose, he does not anticipate significant funding increases under current fiscal conditions.

Rep. Elizabeth Coulson, R-Glenview, focused on the professional and non-professional work force in long-term care. She pointed to work force shortages in Illinois, for example, in nursing and physical therapy. Although Illinois has taken a few steps to address these shortages, we need to do more, including providing career ladders and higher education so that nurse's aides can move up to become nurses. Coulson acknowledged the need for a single point of entry into long-term care that is available statewide, and



a need to build on existing models of excellence to move Illinois forward more quickly. She concluded by lamenting that most people equate "long-term care" to nursing homes, a regrettable fact, since most people want to avoid and, in fact, do not need nursing-home care. She urged that we rethink long-term care as a part of a "continuum of care" that emphasizes wellness and preventive medical care that will be attractive to the next generation of seniors.

Rep. Don Moffitt, R-Galesburg, said that while Illinois is probably not prepared for the long-term care needs of its citizens, we are not avoiding the issue. However, other crises and priorities have slowed our response. As an example of a legislative initiative in long-term care, Moffitt referred to Senate Bill 2112 introduced by Sen. David Koehler, D-Peoria, that passed the Senate in April 2008. The bill, sponsored by Moffitt in the House, would require the Department of Human Services and the Department of Healthcare and Family Services to develop a demonstration project within the Home Services Program under which spouses may be reimbursed for providing care. Findings and recommendations from this pilot program (limited to just 100 clients) would be reported back to the General Assembly. Panelists were divided on whether the bill con-

tains adequate safeguards against exploitation, fraud, and abuse.

Conclusion

Experts and legislators agree that the burgeoning demand for long-term care will force the state to revamp policy in this area. Barring regulatory reform, long-term care insurance will not become a financially realistic option for most families. For the foreseeable future, the large majority of those needing care will thus continue to turn to the state. Policies that permit people to stay in their own homes or communities hold some promise of providing adequate care while controlling costs. These are also the policies that most individuals prefer. At present, Illinois lags behind in establishing "one-stop shops" or "portals" that link families to appropriate services. The state is also behind in introducing self-directed models in which individuals exercise meaningful choice about services and caregivers. While there are pilot programs in Illinois in these areas, no major policy efforts are currently under way. These are among the many issues that will need to be addressed once long-term care finally comes to the attention of the General Assembly as a first-order crisis.



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