

ISSUE BRIEF

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TRENDS IN LONG-TERM CARE

Shoring Up the Infrastructure for Long-Term Care: What Do Vulnerable Adults Know About Their Options?

by William Black and Randall Brown

Improving the ability of the long-term care system to meet the needs of an aging population is at the top of the nation's policy agenda. The Robert Wood Johnson Foundation's Community Partnerships for Older Adults Program is helping 13 communities develop strategies to improve awareness about long-term care issues and to increase access to related services. To identify older adults at risk of needing long-term care in the next few years and assess gaps in their knowledge about their options, Mathematica conducted a telephone survey in mid-2002 of adults age 50 and over in these 13 communities. We used these data to describe their demographic characteristics, education, and health status; knowledge of long-term care coverage and service availability; and sources of information used to address their long-term care questions.

The Long-Term Care Challenge

Over the next several decades, the number of Americans needing long-term care will reach unprecedented levels. How easily they will be able to secure this care will depend on their ability to navigate the complex mosaic of services, providers, coverage types, and benefit and payment options that

make up the long-term care system. Confusing by any measure, the process of obtaining long-term care is further complicated by two overriding factors: (1) most Americans do not begin to explore long-term care choices until their need is urgent; and (2) there is no single, authoritative source of information on this care.

The situation is especially critical for “vulnerable” adults—those at significant risk of needing long-term care services in the near future. Absent an understanding of what services are available and how to access and finance them, these individuals might make less-than-optimal long-term care decisions—especially if they do so at a time of crisis, when there is little opportunity to investigate alternatives. Doing so could lead to reduced quality of life, unnecessary health problems, and greater caregiver burden.

Who Are Vulnerable Adults?

We define vulnerable adults as all those age 75 or older, or those age 60 to 74 who meet at least one of the following criteria: (1) say they are in fair or poor health; or (2) have one or more chronic illnesses (congestive heart failure, coronary artery disease, diabetes, stroke, or lung disease). On average across the 13 communities, 40 percent of our target population meet these criteria. More than half of these vulnerable adults (54 percent) are age 75 and over. In addition, 40 percent describe their health as fair or poor, compared to 24 percent of all older adults in these communities. The vulnerable adults in our sample also have lower education and income levels—only 39 percent have any education beyond

high school and half have annual incomes below \$20,000 (compared to 50 percent and one-third respectively for the older adults as a whole in these communities).

Over one-fourth of vulnerable adults (28 percent) either receive assistance or expect to need it within five years to continue living independently. About 13 percent have problems or need help with at least one personal care activity of daily living, such as bathing or dressing. About one-quarter (26 percent) have problems or need help with at least one instrumental activity of daily living, such as preparing meals or doing light housework. For the most part, unpaid family members and friends provide the personal assistance vulnerable adults receive.

Many Lack Knowledge of Long-Term Care

In the 13 communities we studied, vulnerable adults typically do not know much about coverage for long-term care costs. Only 8 percent have private long-term care insurance, and 71 percent of the remainder do not know how much such coverage would cost for someone their age. In fact, 31 percent of vulnerable adults have never even heard of long-term care insurance. More than half do not know that Medicare does not cover personal assistance (62 percent) or that Medicaid does cover it (70 percent). About 23 percent are currently on Medicaid.

Financial constraints put long-term care beyond the reach of many. Nearly 6 in 10 vulnerable adults say they would be unable to afford \$100 per week for help with personal care. Furthermore, many of these individuals probably are unable to afford *any* assistance—3 in 10 have a yearly income under \$20,000 and are not on Medicaid. Furthermore, almost one-quarter report being unable to afford some basic need, such as food or prescription drugs, at some time during the past 12 months.

A sizable minority of vulnerable adults lack information about long-term care services that are available in their community. Between 15 and 25 percent of vulnerable adults are unaware that nursing homes, visiting nurse services, home-delivered meals, and senior centers—programs that are well-established and generally visible in the community—are available to them (Figure 1). About one-third report being unaware that personal assistance services and door-to-door transportation services—two key factors that could help them remain in the community—are available (Figure 2). Similarly, nearly 4 in 10

Figure 1: Percent Unaware of Services Available

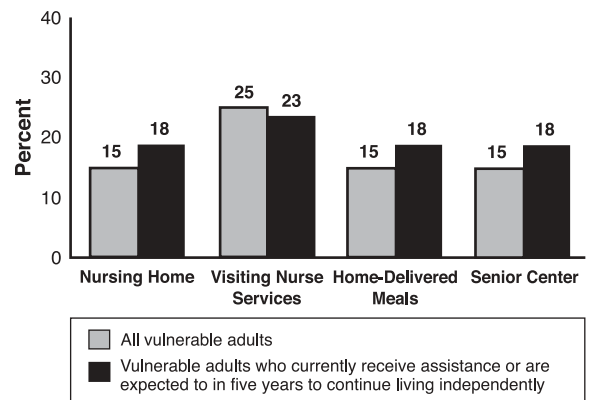
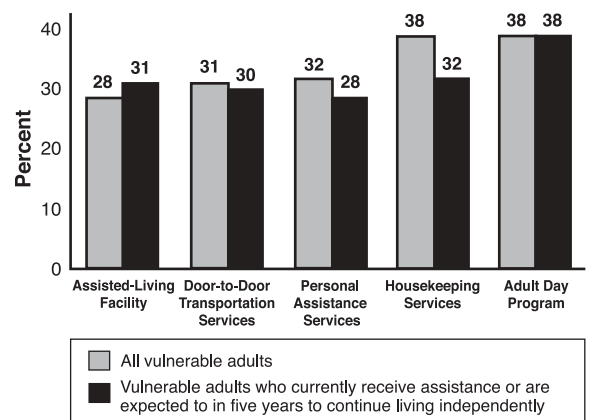


Figure 2: Percent Unaware of Key Long-Term Care Services



vulnerable adults are unaware that adult day programs are available, and about 3 in 10 do not know of assisted-living facilities in their area. It is noteworthy that, despite their greater need for information about long-term care, vulnerable adults who either receive personal assistance or expect to need it within five years are no more likely to be aware of the availability of long-term care services than are vulnerable adults generally.

Knowledge of long-term care services varies substantially by community. For example, the proportion of vulnerable adults who are unaware of assisted-living facilities available in their community ranges from 12 to 39 percent (Figure 3). It is important for each community to tailor its plan to disseminate long-term care information to the needs of its residents.

Consulting Reliable Sources

Vulnerable adults say they would get information on long-term care from a variety of sources. For information on personal care, they would go to family and friends, health care providers, and community sources (such as a senior center or an Area Agency on Aging—Figure 4). However, nearly one-fifth (18 percent) would not know where to go. About half report that they would turn to their doctor (23 percent), another health care provider (21 percent), or hospital staff (11 percent). Family

Figure 3: Knowledge Varies Across Sites

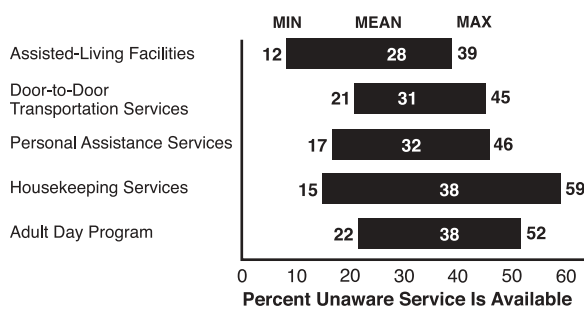
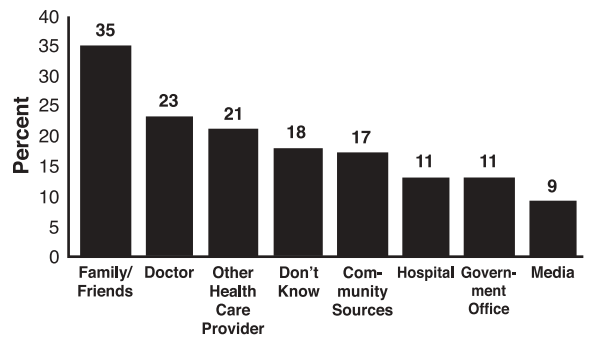


Figure 4: Sources of Information



and friends are the most commonly cited source—about one-third (35 percent) would go there first.

The study shows that many adults who are likely to need long-term care information in the next few years have substantial gaps in their knowledge. Communities seeking to bridge these gaps are likely to face challenges in improving vulnerable adults’ awareness of long-term care issues, particularly since this population turns to a wide range of sources for information. Some of the strategies that the individual partnerships are currently implementing include:

- Developing and promoting the use of a telephone helpline that seniors can use to access information about long-term care services
- Conducting a media campaign to promote awareness of long-term care issues
- Conducting a door-to-door outreach campaign to reach isolated older adults
- Improving communication and collaboration among long-term care service providers and senior services organizations to promote a “no wrong door” approach, which facilitates access to long-term care services and information by allowing seniors to enter the long-term care system through multiple channels in the community

Community strategies show promise for tackling the growing need for long-term care in America. The Community Partnerships for Older Adults Program provided grants to 13 communities to develop creative strategies for improving their residents' awareness about long-term care issues and increasing their access to long-term care services. Eight of the original 13 communities received additional funding to implement the strategies they developed. Mathematica's five-year evaluation is documenting changes resulting from the program to help enhance community-based long-term care systems nationwide.

The survey sample consisted of approximately 400 adults age 50 and over in each community. The average survey response rate was 63 percent across all 13 sites and ranged from 53 to 71 percent in individual communities. To enhance the precision of the estimates for vulnerable adults, who make up approximately 40 percent of the population age 50 and over, we oversampled this group so that they accounted for about half of the total sample in each community. For more information on this study, which was funded by the Robert Wood Johnson Foundation, contact William Black, (202) 264-3462, wblack@mathematica-mpr.com.

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