

# Who Will Be There to Care? The Growing Gap between Caregiver Supply and Demand

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**OVERVIEW**—*This paper examines the increasing demand for long-term care services and the concurrent decrease in the supply of paid and unpaid caregivers. It considers workforce trends for paraprofessionals, such as certified nursing assistants, home health aides, and personal care attendants, as well as several public and private efforts to address staff shortages and quality-of-care. The paper explores the sociodemographic factors that have affected the demand for and supply of informal care provided by family and friends. It also reviews policy proposals designed to provide support for family caregivers and/or to give choices to consumers.*

# Who Will Be There to Care? The Growing Gap between Caregiver Supply and Demand

The numbers are dramatic. When the baby boom generation begins reaching retirement age in 2010, the number of older Americans will swell. The Census Bureau projects that by 2030 there will be about 70 million Americans aged 65 and older, more than twice their number in 1995. By 2040, one out of every five Americans will be over 65, and every state will have at least as high a proportion of elderly as Florida has now. The number of “old old,” aged 85 and older, is projected to triple or quadruple.

An older population will mean more people with health and personal care needs and greater use of health and long-term care services. As individuals age, their need increases for assistance with activities of daily living (ADLs), such as walking or dressing, and instrumental activities of daily living (IADLs), such as grocery shopping and money management. Currently, more than 40 percent of people over age 70 have at least one ADL or IADL limitation. Such demands are expected to grow significantly as the number of elderly increases. If the current rate of activity limitation stays the same, the number of elderly with activity limitations will more than double, from 8.5 million to 21 million by 2030. By 2050, over 25 million elderly will be limited in their activities and need assistance.<sup>1</sup>

At the very time the demand for long-term care services is increasing, the traditional supply of both paid caregivers and unpaid caregivers is shrinking. The majority of current long-term care workers (that is, home health aides, certified nursing assistants, and personal care attendants) are women between the ages of 25 and 54. While the population aged 85 and older is the fastest growing age group in the United States, the number of women aged 25 to 54 is expected to remain relatively unchanged from 2000 to 2030. Demographic data show a widening gap between the number of people likely to need care and the number of people who are most likely to provide the care. Beginning in 2025, the number of persons aged 65 and older will exceed the number of women aged 25-54 (Figure 1, page 3). Moreover, due to greater opportunities for education and workforce participation by women over the past four decades, fewer new workers are entering the long-term care workforce. In the past, women had many fewer avenues of employment; today, work opportunities less difficult and better-paying than long-term care are abundant.

These sociodemographic factors have affected the availability of informal caregivers as well. More women are working outside the home,

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making them less available to care for family members in need of assistance. Marriage and reproductive trends, such as an increased number of childless couples, smaller family sizes, and higher divorce rates, have also decreased the pool of potential family caregivers. According to the National Family Caregivers Association, the number of potential family caregivers for each person needing care will decrease from 11 in 1990 to an estimated 4 by 2050.<sup>2</sup>

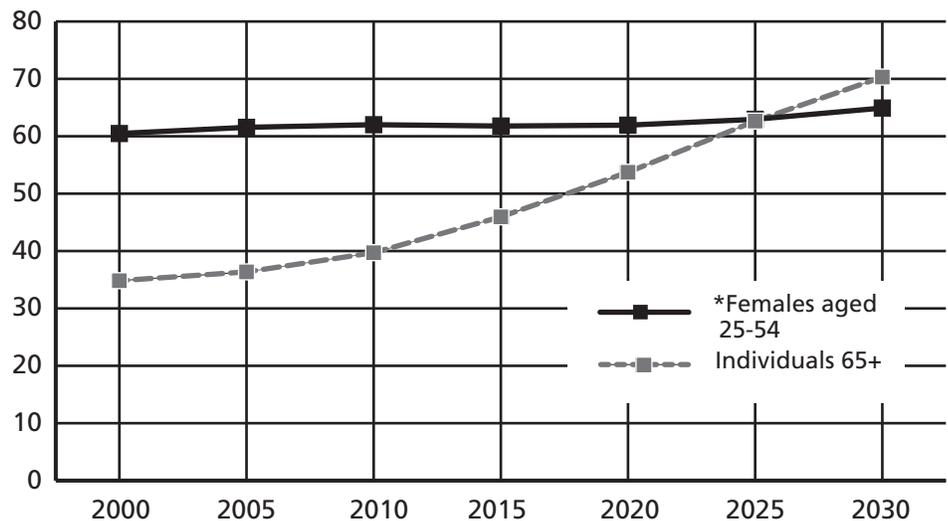
## FORMAL VERSUS INFORMAL CARE

In contrast to more medically oriented services, most long-term care is unpaid or informal assistance provided by family and friends. Although the use of paid care is growing, the vast majority (76 percent) of caregivers are unpaid. Family members comprise more than 70 percent of caregivers of elderly with activity limitations. Adult children constitute the largest proportion of caregivers (42 percent), followed by spouses (25 percent).<sup>3</sup> Assistance provided to elderly or disabled persons by friends or relatives may range from bill payment, transportation for medical appointments, and assistance with dressing to more complex personal care, such as administering medications or treatment plans. The proportion of long-term care users who reported using only informal care dropped from 51 percent in 1984 to 40 percent in 1994, while the proportion who reported using institutional care increased from approximately 26 percent to 30 percent during the same time period.<sup>4</sup> A significant proportion of those using informal care also use formal care as a supplement.

Most paid or formal caregivers are paraprofessional workers—certified nursing assistants (C.N.A.s) in the nursing home or home care workers—who deliver the largest share of the primarily low-tech personal care and assistance with managing daily life. Outside of acute care settings, paraprofessional workers are responsible for 70 to 90 percent of direct care to the elderly.<sup>5</sup>

The overwhelming majority of formal and informal caregivers are women. According to the most recent national survey of informal caregivers for

**FIGURE 1**  
**Women of Care-Giving Age\* and Individuals 65 and Over**  
**in the United States, 2000-2030**  
 (in millions)



Source: U.S. Census Bureau, National Population Projections, Summary Files, "Total Population by Age, Sex, Race, and Hispanic Origin."

the elderly, more than 75 percent of primary caregivers are female and their average age is 60. Recent studies show that nearly 90 percent of nursing home aides, 96 percent of home health aides employed by agencies, and virtually 100 percent of self-employed home health aides are female.<sup>6</sup>

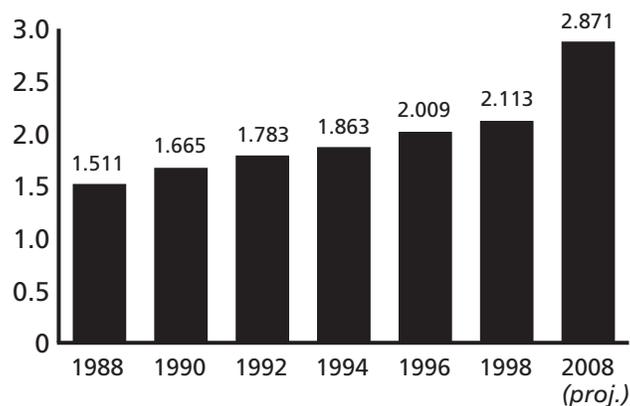
## DEMAND FOR PAID CAREGIVERS

With the aging of the population and corresponding increase in potential long-term care users, the demand for long-term care workers will sharply increase. In addition, the expansion of care delivery settings—such as home health care and community-based care—has increased the job opportunities available and the demand for these workers. Medical advances have permitted people with chronic illnesses and disabilities to live longer and to more often receive care in their homes or other community-based settings. Moreover, increased funding for in-home and community-based services, particularly by Medicare and Medicaid, has contributed to increased demand for nurse aide services.

The Bureau of Labor Statistics (BLS) projects that, through 2008, home health and personal care aides will be among the fastest-growing occupations in the nation. According to analysis by the U.S. General Accounting Office (GAO), between 1988 and 1998, nurse aide employment increased 40 percent, more than twice the rate of growth of the overall workforce. BLS projects that these trends will continue into the next decade. From 1998 to 2008, the overall number of nurse aide jobs is projected to grow an additional 36 percent—from 2.1 million to 2.9 million jobs—compared to an expected 14 percent increase in all jobs (Figure 2). Nurse aides working in home health are expected to be in even greater demand, with job growth projected to increase 58 percent, from 746,000 in 1998 to 1.2 million in 2008.<sup>7</sup>

Even today, nursing homes and other long-term care providers are experiencing severe shortages of nursing aides. Annual turnover rates in nursing homes are very high, in some cases exceeding 100 percent. In 1998, a survey sponsored by the American Health Care Association of 12 nursing home chains found 94 percent turnover of nurse aide positions. A recent national study of home health care agencies identified a 28 percent turnover rate among aides in 2000, up from 19 percent in 1994.<sup>8</sup> High turnover can contribute to both increased costs to the facility and significant problems with quality of care.

**FIGURE 2**  
**Growth in Aide\* Employment,**  
**1988-1998 and Projected to 2008**  
**(in millions)**



\* Includes nurse aides, orderlies, and attendants, as well as personal care and home health aides.

Source: U.S. General Accounting Office analysis of data from Bureau of Labor Statistics, U.S. Department of Labor, *Monthly Labor Review*.

## SUPPLY OF PAID CAREGIVERS

Nationwide, there were approximately 2.2 million nurse aides employed in 1999, most of whom worked in nursing homes, hospitals, or home health care. Nearly 90 percent of nurse aides working in nursing homes and home health care were women, and more than 40 percent were minorities. A significant percentage lived below the poverty line, with estimates ranging from 18 to 28 percent. The pool of likely entry-level workers—women in the civilian workforce within the age range of 25 to 44—is projected to decline, after three decades of significant expansion.<sup>9</sup> Thus, the labor supply of future workers will be profoundly different from what the long-term care system has experienced over the past 30 years.

Long-term care paraprofessionals are paid workers who provide direct and front-line care, primarily assistance with ADLs and IADLs. To become a paraprofessional, only the most rudimentary education, such as basic reading and writing skills, is typically required. Federal law requires that nurse aides who provide care in federally certified nursing homes and home health agencies complete a minimum of 75 hours of training and pass a competency evaluation within four months of employment. Approximately half of the states require more than 75 hours of training, with several requiring over 120 hours.<sup>10</sup> Federal law also requires states to maintain a registry of all C.N.A.s working in nursing homes who have passed their competency evaluations, but there is no such requirement for C.N.A.s working in home health. A variety of factors contribute to recruitment and retention problems for paraprofessionals, including low wages, few benefits, and difficult working conditions.

## Wages and Benefits

Most paraprofessionals are poorly paid and few receive employee benefits. According to GAO, in 1999, the national average hourly wage for aides working in nursing homes was \$8.29 compared to \$9.22 for service workers and \$15.29 for all workers. For aides working in home health care agencies, the average hourly wage was \$8.67; for aides working in hospitals, it was \$8.94. Moreover, the work in home-care settings is often unpredictable and part-time. Since home-care clients' needs frequently change and the Medicare program has changed reimbursement methods, home care agencies report that they have difficulty providing steady, full-time work.

Like most service workers, aides in nursing homes and home health care are less likely to have employer-provided health insurance or pension coverage than workers in general. According to GAO's analysis of the Census Bureau's Current Population Survey data, 25 percent of aides in nursing homes and 32 percent of aides in home health care are uninsured compared to 16 percent of all workers. A survey of Los Angeles County In-Home Supportive Services Providers found that nearly half (45 percent) of home care aides were uninsured.<sup>11</sup> Since most of the

## What Are ADLs & IADLs?

■ **ADLs** (*activities of daily living*)—Elemental activities, such as eating, dressing, ambulating, toileting, and hygiene, that are required at a minimum for individuals to care for themselves in a limited environment.

■ **IADLs** (*instrumental activities of daily living*)—Higher-level activities, such as shopping, housework, accounting, food preparation, and transportation, necessary to function in a community.

*Source: Mayo Clinic*

workers are poor or near poor, another 13 percent are enrolled in California's Medicaid program, Medi-Cal; 8 percent are Medicare enrollees; and 24 percent of the uninsured home workers rely on the county's Department of Health Services facilities for their care.

## Working Conditions

On top of low wages, few benefits, and little potential for career advancement, paraprofessionals work in difficult environments. The work itself can be physically and mentally grueling. The jobs often require moving patients in and out of bed, long hours of standing and walking, and dealing with patients or residents who may be disoriented or uncooperative. Nursing homes have one of the highest rates of workplace injury, 13 per 100 employees in 1999, compared to the construction industry, which had 8 per 100 employees.<sup>12</sup> Moreover, the work can be unpleasant; routine tasks include bathing, feeding, changing diapers, and cleaning the bedsores of elderly and disabled clients. While some researchers have acknowledged that these workers provide the "high touch" care that is essential to quality of life for chronically disabled individuals, most workers complain that the jobs lack respect, autonomy, or recognition.

Several studies have demonstrated that work settings and management are critical determinants of employee turnover for paraprofessionals. According to a report by the Institute of Medicine (IOM), turnover rates are related to the "adequacy of training, methods for managing workload and schedules, opportunities for career advancement, respect from administrators, organizational recognition, social climate and work level, staffing levels, clarity of roles, and participation in decision making."<sup>13</sup>

## POLICY OPTIONS

All of the factors listed above make it exceedingly difficult to attract workers who have other job opportunities. Supply of these workers is already scarce and demographic projections imply the problem will only get worse. While the cyclical nature of the economy could improve supply in the near term, most analysts agree that structural demographic shifts have taken place. The successful recruitment and retention of a high-quality paraprofessional workforce across a range of settings depends upon a variety of interactive factors that occur at different levels, according to researcher Robyn Stone. She states that,

at the most comprehensive level, demographics and economics interact with healthcare and long-term care policy (including reimbursement and regulation), labor policy (including "welfare to work" and unionization), education policy (training of professionals and paraprofessionals), and immigration policy to influence the character and availability of paraprofessional workers. At the workplace level, there are four major dimensions of influence: organizing arrangements, social factors, physical setting and environment, and technology.<sup>14</sup>

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To address workforce shortages and quality concerns, state and federal policymakers as well as long-term care providers have tried a variety of approaches, ranging from wage supplements to structural workplace changes. A study of state efforts to address recruitment and retention of nurse aides and other paraprofessionals found that 42 states reported that aide recruitment and retention is currently a major workforce issue.<sup>15</sup> Thirteen states reported that they have established or plan to establish a work group or task force to address nurse aide recruitment and retention issues. Major policy actions taken by states include the following:

- Wage and benefit pass-throughs.
- Performance-based reimbursement increases.
- Higher state reimbursement for shift differentials.
- Transportation reimbursements.
- Nurse aide career ladders.
- Nurse aide training.
- Training former welfare recipients.
- Expanding the use of volunteers.

### Wage Pass-Throughs

Several states have made efforts to increase wages for direct-care workers. The most common strategy has been to require long-term care providers to use some portion of their publicly funded reimbursement (primarily Medicaid) to increase wages and/or benefits for nurse aides. As of 2000, 26 states had established some form of wage pass-through, wage supplement, or related program for nurse aides and other direct care staff, according to GAO.<sup>16</sup> States have generally chosen two methods to implement wage pass-throughs: a set dollar amount for workers per hour or patient day or a percentage of the increased reimbursement rate. For example, Minnesota recently increased its long-term care reimbursement rates, two-thirds of which were earmarked for compensation-related costs. Most states surveyed said that monitoring providers' compliance with the wage and benefits requirement has not been, or is not expected to be, an undue burden for their agencies. However, implementing a wage pass-through system is still relatively new for the majority of states; most mandatory wage pass-throughs have only been in place over the last year or two.<sup>17</sup>

According to a 2000 survey by the North Carolina Division of Facility Services, 4 out of 12 states that had implemented a wage pass-through reported that it had had some positive effect on recruitment and retention of nurse aides.<sup>18</sup> Michigan and Kansas, in particular, have reported decreases in the aide turnover rates in facilities participating in wage pass-throughs. Beyond these two states, GAO analysis indicates that there "have been no evaluations examining short- or long-term effects on the wage pass-through strategy and differences in outcomes based

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on state variations in methodology.”<sup>19</sup> Given the significant amount of wage pass-through funds allocated over the past few years, future evaluations will be important.

### Nursing Home Staffing Ratios

Federal law requires nursing homes that participate in Medicare or Medicaid (over 95 percent) to provide “sufficient nursing staff to attain or maintain the highest practicable . . . well-being of each resident.” However, the law does not define “sufficient.” The majority of states have established some type of nursing home staffing requirements. According to a recent IOM report, there is growing evidence that inadequate staffing levels are linked to poor care in nursing homes. These findings have prompted many policymakers to demand that staff-to-patient ratios be mandated.

A landmark conference of experts convened by the John A. Hartford Foundation Institute for Geriatric Nursing in 1998 recommended that nursing home residents receive a minimum of 4.13 hours of direct care per day (licensed or unlicensed staff) and a total of 4.55 total hours per resident day. A congressionally mandated report released in 2000 by the Health Care Financing Administration (HCFA) said the Hartford recommendation would require 90 percent of facilities to increase staffing levels. More than 50 percent of facilities would have to increase staffing by 50 percent or more to be in compliance with this requirement.<sup>20</sup>

In its extensive report, HCFA demonstrated a direct relationship between nurse aide staffing levels and the quality of resident care.<sup>21</sup> According to the report, nursing home understaffing has contributed to cases of severe bedsores, malnutrition, and abnormal weight loss among residents, leaving many hospitalized for “life-threatening” infections, dehydration, congestive heart failure, and other preventable ailments. HCFA found that after preliminary efforts to control for case mix, staffing thresholds currently exist below a level at which quality of care may be seriously impaired. Using multivariate analysis and limited data from a few states, HCFA concluded that the minimum staffing level associated with optimizing quality is approximately 2.0 hours per resident day for nurse aides, regardless of facility case mix. The preferred minimum staffing levels for registered nursing and total licensed staff (R.N. and L.P.N.), which impacted all of the quality measures across the board, are .45 and 1.0 hours per resident day, respectively. HCFA conservatively estimated that, based on time-motion studies, the nurse aide staff necessary to provide optimal care is 2.9 hours per resident day or 58 minutes per 8-hour shift. This level of care is 18 minutes higher than the average amount provided to residents in 1999.

HCFA concluded that the general requirement that staffing must be “sufficient to meet resident needs” is difficult to enforce and that a more specific requirement makes the determination of compliance easier and

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more accurate. As a result, some federal lawmakers, supported by consumer and labor advocates, have called for the establishment of mandatory nurse staffing levels. A bill (H.R. 2677) introduced by Rep. Henry Waxman (D-Calif.) in 2001 would have required nursing homes to comply with the Hartford staffing standards, unless the health and human services secretary made a detailed finding that quality of care would not be compromised or that compliance was not feasible immediately. Staffing levels would not be permitted in any case, however, to fall below the minimum levels identified by HCFA in July 2000.

Provider group reactions to mandatory staffing ratios have been mixed. They point to the shortage of available workers and the difficulty of meeting these mandates if no workers are available to fill the jobs. They also emphasize the complexity of establishing ratios for different types of staff and levels of care. Most importantly, they complain that legislators demand higher staffing and quality levels while providing low reimbursement levels. An American Health Care Association study of nurse staffing in long-term care states that, "the call for greater staffing levels suggests that the present-day reduction in government funding of long-term care would have to be reversed, and funding increased, to enable long-term care providers to meet proposed staffing levels in a manner that maintains the fiscal soundness and viability of long-term care services."<sup>22</sup> Nevertheless, the report does concede that staffing is an important proxy to ensure that elements of quality are in place.

### Training and Career Advancement

To address workforce shortages and high turnover rates, states and private organizations have developed innovative approaches that focus on training, career advancement, and improved working conditions. Several states have implemented specific programs to establish a career path for paraprofessional direct care workers.<sup>23</sup> For example, Minnesota, Montana, and Nevada are developing training curricula that will enable C.N.A.s to qualify as licensed practical nurses (L.P.N.s). Delaware passed legislation in 1999 creating a new job level for C.N.A.s known as "Senior C.N.A.s." The Senior C.N.A. acts as a role model and resource person for entry-level C.N.A.s.

In the private sector, the Paraprofessional Healthcare Institute (PHI) has created several worker-owned home health agencies in the South Bronx, New Hampshire, Philadelphia, and Boston. The PHI network is based on the Cooperative Home Care Associates model in the Bronx, where wages and benefits are more than 20 percent above the industry average (not including time spent traveling to clients). They also provide health benefits and four weeks of training, far beyond the industry standard of 75 hours. Because PHI is worker-owned, employees have been periodically willing to forgo pay increases; since they share in the profits at the end of the year, their jobs and the long-term future of the company are directly linked. The model also emphasizes an investment

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in training and developing a worker-centered organizational culture exemplified by significant participation on the Board of Directors and a Worker Council. The agencies report job turnover of less than 20 percent.<sup>24</sup>

The nursing home industry has also stepped up efforts to improve retention in the C.N.A. workforce. Several studies have concluded that the organization's management style is the strongest predictor of lower turnover rates. In particular, the involvement of C.N.A.s in residents' care planning proved to be significant in reducing turnover. A study by Banaszak-Holl and Himes found turnover rates to be one-third lower in nursing homes in which mid-level managers were receptive to their nursing assistants' advice or at least discussed care plans with aides, compared with nursing homes that did not adopt this management philosophy. Nursing homes that involved C.N.A.s in care plan meetings experienced turnover rates 50 percent below those of other facilities.<sup>25</sup>

In Wisconsin, an alliance of 11 nonprofit nursing homes has decided to put these ideas into action. A model known as Wellspring Innovative Solutions, Inc., was founded in 1994 to collectively address quality-of-care concerns in nursing homes. The Wellspring model pays particular attention to the day-to-day work of frontline staff, especially C.N.A.s. The stated policy is that "top management sets policies for quality, and the workers who know the residents best decide how to implement those policies." For example, front-line workers may be given the authority to decide which equipment to purchase for residents within budget guidelines or how best to implement a fall-prevention plan. Staff members also receive permanent assignments so that they establish long-term relationships with the residents they care for.<sup>26</sup> These efforts have dramatically reduced turnover, with rates across the 11 facilities dropping from 110 percent in 1994, before implementation of the Wellspring program, to a current rate of 23 percent.

## DEMAND FOR INFORMAL CAREGIVING

Despite these efforts, the prospect of finding enough paid caregivers for future demand seems dim. Policymakers have begun to acknowledge family members as the critical link in assuring that those in need receive long-term care. Indeed, the majority of long-term care is provided by unpaid family caregivers to elderly and disabled individuals living either in their homes or with their families. Policymakers have begun to recognize the savings in public spending when relatives and friends provide long-term care. While much informal caregiving takes place alongside more formal arrangements, without the assistance of family and friends, many elderly and disabled individuals would be forced to enter institutions to receive care.

Informal caregiving is distinguished from care that is provided through formal agencies or institutions, paid for by the receiver, or provided by trained professionals or paraprofessionals. It may "precede, substitute

for, or take place along with formal caregiving arrangements."<sup>27</sup> The national economic value of informal caregiving was estimated to be \$196 billion in 1997—higher than national spending for formal home health care (\$32 billion) and nursing home care (\$83 billion) combined.<sup>28</sup>

Long-term care consumers have long showed a preference for caregivers whom they know and trust. A series of recent focus groups conducted by Barbara Schneider, an independent consultant with the Scripps Gerontology Center, found that consumers valued the following:

- Control—the ability to select workers and determine their schedules and tasks. They also reported that they valued having things done their way, the way they would do them, in contrast to care often provided by home health agency workers, over whom consumers generally have little control.
- Relationship—being treated with respect and knowing that their workers care about them and share their values.
- Security—being able to trust the worker and having peace of mind about the living and caring situation.
- Knowledge—having the information to make good decisions and sharing with others in similar situations.

The nature and extent of the demand for families to care for their elderly and disabled relatives has changed dramatically over the past decades. While individuals are living longer and therefore more likely to need long-term care, traditional family and support networks are no longer as readily available.

## SUPPLY OF INFORMAL CAREGIVERS

As stated earlier, demographic shifts have reduced the number of caregivers available. Fewer families, across generations, live in the same home or even in the same community. The family caregiver for the elderly is increasingly a spouse who is also an older adult.<sup>29</sup>

Women, who traditionally cared for their parents, are now more likely to be in the workforce, and are having children later in life. These individuals are popularly called the “sandwich generation,” because they are squeezed between parents and children. A recent AARP survey of baby boomers aged 45 to 55 found that 70 percent of this generation have at least one living parent, and nearly 4 of every 10 still have children living at home with them.<sup>30</sup>

A 1997 study by the National Alliance for Caregiving and AARP found that there were approximately 22 million adult caregivers in the United States. Thus, one in four households was involved in caring for a chronically ill or disabled family member or friend. Nearly three-fourths of these caregivers are women. The survey noted that the average family caregiver devotes 18 hours per week to caregiving activities. Nearly one in five (18 percent) provides at least 40 hours of care per week.

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While many family caregivers express fulfillment in providing care to their loved ones, they also face serious risk: high rates of depression, health problems, and role strain.<sup>31</sup> Caregiving clearly takes a well-documented toll on caregivers' physical and mental health. Studies have shown that stress and exhaustion may lead to increased health care utilization by the caregiver as well as the care recipient.<sup>32</sup>

Almost two-thirds of caregivers to older persons are working, mostly full time. The demands of caregiving often have a negative impact on these workers, ranging from missed work hours, decreased productivity, and lost job or career opportunities. Absenteeism and lost productivity negatively impact the economy and employer as well. A 1997 MetLife study estimated that the replacement costs for full-time workers who had to quit or take early retirement due to caregiving demands are almost \$5 billion a year.<sup>33</sup> Interruptions or distractions related to caregiving cost almost \$4 billion a year. Partial absenteeism costs employers approximately \$400 million a year.

## POLICY OPTIONS

Policymakers have developed a variety of programs to support family caregivers. These programs range from supportive services, such as respite care to provide time off from care responsibilities, to tax credits or cash vouchers to allow individuals and families to purchase their own services.

### Supportive Services

At the federal level, Congress authorized the new National Family Caregiver Support Program as part of the 2000 amendments to the federal Older Americans Act. For the first time in the history of the act, there is now national focus on caregivers as well as on care recipients.

The National Family Caregiver Support Program comprises five service categories: (a) information about services; (b) assistance with access to services; (c) individual counseling, organization of support groups, and caregiving training; (d) respite care; and (e) supplemental services, on a limited basis (for example, home modifications or assistive devices). On February 15, 2001, HHS Secretary Tommy Thompson authorized the release of \$113 million to states to begin implementation.

Many state efforts have already been underway for several years. These programs range from comprehensive packages of services available state-wide to smaller, targeted programs. Caregiver support services include respite, care planning, education and training, legal and financial counseling, information and referral services, and support groups (see Glossary of Caregiver Support Services, page 13).

A June 2000 report by the Public Policy Institute of AARP analyzed two surveys on state caregiver programs conducted in 1999 by the California Family

### Glossary of Caregiver Support Services

**Adult day services**—Structured and rehabilitative services for older adults that also provide respite care for caregivers.

**Counseling/support groups**—Emotional support given to caregivers coping with the strain of the caregiving role.

**Education and training**—Information on specific diseases and dementias and assistance in learning how to provide hands-on care.

**Family consultation/care planning**—Assistance in making a care plan and exploring care options.

**Financial support**—Vouchers or cash to purchase services or equipment.

**Information and referral**—Assistance in finding services for the care recipient or the caregiver.

**Legal and financial consultation**—Consultation on issues related to caregiving.

**Respite care**—Temporary break from caregiving responsibilities.

**Tax assistance**—State tax deductions or credits.

*Source: Barbara Coleman, "Helping the Helpers: State-Supported Services for Family Caregivers," Public Policy Institute/AARP, Washington, D.C., June 2000.*

Caregiver Alliance and the National Association of State Units on Aging.<sup>34</sup> Principle findings from the surveys include the following:

- Most state caregiver support programs serve families caring for persons with functional, developmental, and cognitive impairments (especially Alzheimer's disease).
- Caregiver support programs are generally funded through state general revenues. However, respite care is often funded as a specific service within a Medicaid or state-funded home and community-based package of services or separately as a state-funded program of respite services only.
- State eligibility criteria vary by diagnostic or functional level, age, and income. Most of the services aimed at the family caregiver have no income requirements and typically offer sliding fee-scale arrangements.
- State officials reported the most beneficial aspects of their programs as flexibility of services, broad eligibility to include middle-income families, and an emphasis on consumer-directed care. The biggest problems cited include inadequate funding, limited services or program scope, and lack of awareness of program services.

The majority of states provide respite care for family caregivers, making it the most prevalent service provided by states. The AARP report defines respite care as "temporary, short-term relief provided to

caregivers in or outside the home that is intended to help or alleviate the stress associated with constant or frequent caregiving responsibilities."<sup>35</sup> In 1998, Medicaid programs in 38 states covered annual respite care for an estimated 250,000 elderly, and Medicaid programs in 40 states covered adult day care.<sup>36</sup> Respite services are generally in great demand. For example, in fiscal year 1998, California had 2,500 families on a waiting list for respite care services. Yet, despite the overall importance of respite in community long-term care, there have been very few systematic evaluations of these programs. A recent review by Steven Zarit found that there is little evidence that respite services delay institutionalization or produce cost-savings. Benefits of respite services have been most clearly demonstrated for caregivers using adult day care.<sup>37</sup>

Several state models have tried to make access to caregiver support services easier by establishing multiple caregiver service centers throughout the state (California), providing financial assistance to a household to purchase services or supplies that assist in caring for a family member (Pennsylvania), or by bringing services such as adult day care to rural areas (Georgia).<sup>38</sup>

### Tax Incentives

More recently, lawmakers have looked to the tax code to address long-term care problems. During his last year in office, President Clinton proposed a \$3,000 income-related, nonrefundable tax credit for severely disabled persons and families helping to care for them. Although it was not enacted, the initiative raised awareness and appreciation of the efforts of family caregivers.

During the last session of Congress, lawmakers proposed expansion of tax credits aimed at families with dependent children to include long-term caregivers as well. A bill (S. 464) introduced by Sens. Evan Bayh (D-Ind.) and Hillary Rodham Clinton (D-N.Y.) would have renamed the child tax credit (Internal Revenue Code section 24) as the Family Care Credit and provided for an additional \$3,000 credit for long-term caregivers. A \$3,000 long-term care tax credit was also included in the Senate Democrats' tax relief bill (S. 9). Legislation (H.R. 2575) introduced by Rep. John Murtha (D-Pa.) in the House would have allowed a \$1,200 tax credit for caregivers. A bill (S. 384) introduced by Sen. Olympia Snowe (R-Maine) would have made the dependent care tax credit refundable and permit up to \$1,200 (\$2,400 in the case of more than one qualifying individual) of respite care expenses incurred in the care of (a) a dependent of the taxpayer who is at least 13 years old or (b) a spouse or other dependent who is physically or mentally incapable of self-care.

Legislation (S. 627 and H.R. 831) introduced by Sens. Charles Grassley (R-Iowa) and Bob Graham (D-Fla.) and Rep. Nancy Johnson (R-Conn.) also contained provisions that would have established a tax credit for caregivers, up to certain income limits. Under the bill, the maximum

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credit was \$1,000 for 2001, rising each year to reach \$3,000 by 2005 and thereafter. Similar legislation is expected to be introduced when Congress reconvenes in January 2002.

As of 1998, half of the states provided tax breaks for elder care to people who care for a family member in their own homes. These benefits are limited, however, since the relative must live with the caregiver and be financially dependent on the caregiver. Other states offer employers a tax credit for providing elder care assistance or establishing adult care programs.

Some analysts have criticized tax proposals to address long-term care as inadequate and designed primarily to benefit middle and upper-middle income taxpayers who are already caring for a disabled relative. They argue that funds would be better spent to increase public spending on Medicare, Medicaid, the Older Americans Act, or other direct service programs.<sup>39</sup> Caregiver advocacy groups have generally placed a priority on other policy initiatives, saying they would prefer “services to dollars.”<sup>40</sup>

### Consumer-Directed Programs

Advocacy for consumer direction in long-term care began in the United States during the 1970s with the Independent Living Movement for younger adults with disabilities. Advocates believe that people with disabilities have the ability and the right to make the decisions about the services that affect their lives. More recently, many federal and state policymakers have embraced the philosophy of consumer-directed care and applied it to services for elderly populations as well. Consumer-directed programs have also been put forward as a solution to the growing shortage of direct-care workers. In most consumer-directed models, consumers take on all worker management tasks, with the exception of paying the worker.

A newly developed inventory sponsored by the Office of the Assistant Secretary for Planning and Evaluation and the Centers for Medicare and Medicaid Services identified 139 state programs that use a consumer-directed approach to the delivery of support services.<sup>41</sup> Under these programs, consumers have a range of responsibilities, including recruiting and hiring their support service workers, hiring a relative to provide paid support services, and training the support service workers they hire. In 81 percent of the programs, certain categories of relatives (for example, spouses) were precluded from being paid as support service workers. Paying spouses to provide services is prohibited under Medicaid, although a few programs have received waivers to do so.

Nonetheless, informal caregivers play a major role in most consumer-directed programs. A study of four states by the Urban Institute found that half or more of consumer-directed beneficiaries hire friends or relatives to be their paid workers. According to the Urban Institute, “supporters of paid family caregivers argue that hiring family members sup-

ports the informal system, expands the labor pool, and results in high-quality care because of close family relationships."<sup>42</sup> Other research has shown advantages such as "easing worker shortages in difficult-to-serve areas and finding workers for 'hard-to-serve' clients."<sup>43</sup>

On the other hand, some policymakers and regulators have expressed concern about potential quality or fraud problems. If a relative caregiver does not perform adequately, it can be difficult for the long-term care consumer to fire a loved one, for example. Government agencies have reported more difficulty in training and monitoring paid family members.<sup>44</sup> In addition, lawmakers commonly express concern about the "woodwork" effect, whereby families not currently using institutional services would be more likely to apply for consumer-directed programs and subsequently increase the cost of the programs. Some state long-term care officials have requested that a demonstration project to study the woodwork effect be undertaken, since little data exist to document this effect.

One innovative, consumer-directed model that has shown promise is "cash and counseling," in which cash allowances, coupled with information services, are paid directly to elderly persons or those with disabilities, allowing them to purchase the services they feel best meet their needs. The Cash and Counseling Program consists of demonstrations and evaluations of programs in three states: Arkansas, Florida, and New Jersey. Arkansas and New Jersey are cashing out services from the Medicaid optional personal care benefit, while Florida is including services from the state's home and community-based services waivers.

Under the demonstration, consumers can use their monthly cash allowances to hire family members, friends, or anyone else to provide care or to provide equipment or devices to increase their independence. Preliminary results from an evaluation of the Arkansas demonstration by Mathematica Policy Research, Inc., found that enrollees almost always hired people they were already close to personally. Over three-fourths chose a family member and another 15 percent opted for a friend, neighbor, or church member. Two out of five enrollees used multiple caregivers to meet their needs. Enrollees also expressed satisfaction with the times of day they could get help, in contrast to care provided by agencies, which typically occurs whenever the paid caregiver works. So far, the program has been popular with participants and their families. A more extensive and conclusive evaluation for each of the sites will be completed at the end of the demonstration period.

## PREPARING FOR THE FUTURE

Assuring that caregivers will be available to care for the growing numbers of elderly and disabled individuals is a tremendous challenge. Worker shortages in the health care industry are pervasive, across many delivery sites and professions, and caused by a number of interrelated factors. The ability to recruit and retain quality paraprofessionals will depend on the

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intersection of health, labor, immigration, and welfare policy. Supportive services for family caregivers will need to be flexible and streamlined to recognize the diverse needs of a diverse population of caregivers who already face large demands on their time and energy.

Both the public and private sectors have developed a variety of approaches to address the impending shortage of caregivers. Many of these efforts have just begun and will require more evaluation to determine their effectiveness. To meet the increased demand for long-term care services, several options and innovations will need to be explored on a continuing basis.

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