# Older People, New Problems: Implications for Long-Term Health Care in Wisconsin

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#### **Foreword**

This report on the impact of an aging population on the provision of long-term health care in Wisconsin is the result of collaboration between the Robert M. La Follette School of Public Affairs at the University of Wisconsin–Madison and the state of Wisconsin Joint Legislative Council. Our objective is to provide graduate students at La Follette the opportunity to improve their policy analysis skills while contributing to the capacity of the Joint Legislative Council to provide the Legislature with high-quality analysis on issues of concern to the citizens of the state.

The La Follette School offers a two-year graduate program leading to a master's degree in public affairs. Students study policy analysis and public management, and pursue a concentration in a public policy area of their choice. They spend the first year and a half taking courses that provided them with the tools needed to analyze public policies. The authors of this report are all enrolled in Public Affairs 869, Workshop in Program and Policy Analysis, Domestic Issues. Although acquiring a set of policy analysis skills is important, there is no substitute for doing policy analysis as a means of learning policy analysis. Public Affairs 869 provides graduate students that opportunity.

The students were assigned to one of four project teams. One team worked on this project for the Legislative Council, while the other teams worked on projects for the Wisconsin Department of Revenue, the Budget and Management Division of the City of Milwaukee, and the Economic Development Commission and the Mayor's Office of the City of Madison. The topic of this report—the implications of demographic changes on the delivery of long-term health care services—was chosen by Terry C. Anderson, Director of the Legislative Council staff, from a list of topics proposed by his staff.

Demographers predict that by the year 2030, Wisconsin's population age 65 and older will increase 90 percent. Even though many older persons will remain in good health, there is little question that a growing number of Wisconsin residents will require long-term personal and health care. In this report, the authors explore a number of issues related to long-term care. First, given an increasingly mobile society, family members probably will deliver a smaller share of the long-term care of the elderly through informal caregiving. Second, the demand for publicly funded programs that provide long-term care services will grow. The state will need to determine the best way to support the long-term care needs of its citizens. And third, current trends suggest that the state may face a serious shortfall of individuals willing and able to provide long-term care services.

This report does not provide the final word on the complex issues the authors address. The graduate student authors are, after all, relatively inexperienced policy analysts, and the topic they have addressed is large and complex. Nevertheless, much has been accomplished, and I trust that the students, and the Joint Legislative Council and its staff have learned a great deal about the provision of long-term health care for Wisconsin's aging population. We hope the report will help define the issues and provide a foundation for further analysis and decision-making on this topic.

This report would not have been possible without Terry Anderson's support and encouragement. Legislative Council staff members John Stolzenberg and Russ Whitesel provided the authors with advice and guidance throughout the semester. A number of other people also contributed to the success of the report. Their names are listed in the acknowledgments.

The report also benefited greatly from the support of the staff of the La Follette School. Terry Shelton, the La Follette outreach director, along with Kari Reynolds, Elizabeth Hassemer, and Gregory Lynch contributed logistic and practical support for the project. Karen Faster, La Follette publications director, edited the report and shouldered the task of producing the final bound document.

I am very grateful to Wilbur R. Voigt whose generous gift to the La Follette School supports the La Follette School policy analysis workshop projects. With his support, we are able to finance the production of the final reports, plus other expenses associated with the projects.

By involving La Follette students in the tough issues faced by state government, I hope they not only have learned a great deal about doing policy analysis but have gained an appreciation of the complexities and challenges facing state and local governments in Wisconsin. I also hope that this report will contribute to the work of the Joint Legislative Council and to the ongoing public discussions on the challenges of meeting the long-term care needs of Wisconsin residents.

Andrew Reschovsky April 27, 2005

# **Acknowledgments**

We would like to thank Donna McDowell and Cynthia Ofstead of the Wisconsin Department of Health and Family Services for helping to explain the state programs and demographic projects related to aging in Wisconsin. Additionally, Dr. Stephanie Robert of the University of Wisconsin-Madison School of Social Work provided much appreciated insight into the Family Care pilot program. We are especially grateful to John Stolzenberg and Russ Whitesel of the Wisconsin Joint Legislative Council for their guidance and advice throughout the semester. Finally, we would like to thank Karen Faster for her editorial assistance and our professor, Andrew Reschovsky of the University of Wisconsin-Madison Robert M. La Follette School of Public Affairs. A special thank you to all friends, family, and classmates who provided helpful advice and great patience throughout the workshop process.

# **Executive Summary: Older People, New Problems**

The Wisconsin Joint Legislative Council asked the authors of this paper to study the impact of demographic trends on state policy implementation and development. Any demographic trend has the potential to affect policy; however, the most predictable and far-reaching demographic trend that Wisconsin faces is the aging of its population. For example, state demographics experts predict that there will be a 90 percent increase in the number of people 65 and older in Wisconsin from 2000 to 2030. This "graying of the population" will likely result in an increased demand for long-term health care.

In this report, the authors identify three policy areas driven by demographic trends and related to long-term health care that warrant the Legislative Council's attention:

1) the inadequacy of the current long-term care system's reliance on informal caregiving,

2) funding and quality-of-care discrepancies between the state's major community-based long-term care programs (Community Options Program and Family Care), and 3) the looming shortage of long-term health-care workers. Based on their research, the authors recommend the following topics for investigation by Legislative Council study committees:

- 1. Examine the current situation of informal caregiving for the elderly in Wisconsin. This study committee should evaluate Wisconsin's informal caregiver support programs, research informal caregiver policy and practices in other states, formulate economic development options to help keep families in Wisconsin, and propose legislation as the committee sees fit.
- 2. Evaluate, compare, and determine the future of the Community Options Program and Family Care. The study committee should specifically assess current long-term care use and predict future use patterns; evaluate the current funding levels and sources for the Community Options Program and Family Care; review implementation procedures in Family Care pilot counties; define adequate and sustainable levels of care with regard to state programs for the elderly, including tracking individuals on Community Options Program waiting lists; determine the program that meets the criteria; and propose legislation as the committee sees fit.
- 3. Evaluate options for alleviating the workforce shortage in long-term care. This study committee should formulate a plan for improved data collection about Wisconsin's health-care workforce, research legislation to create a more effective Medicaid "wage pass-through," determine how long-term care reimbursement policies could be altered to reward quality, evaluate educational opportunities for skilled caregivers, and propose legislation as the committee sees fit.

Demographic trends do not exist in a vacuum. The trends described in this report are converging to have wide-ranging effects on long-term care in Wisconsin. Wisconsin in 2030 will need different services than Wisconsin in 2005. The Legislature can use this knowledge about demographic trends to create long-term care policy that will have a positive effect on the people of Wisconsin, now and in the future.

# **Introduction: Older People, New Problems**

The most predicable and far-reaching demographic trend facing Wisconsin is the aging of its population (Voss, 2005). Wisconsin already has a population that is slightly older than that of the United States as a whole (Ofstead, n.d.). In 2005, 13 percent of Wisconsin's population was elderly, or age 65 or older (Egan-Robertson, Harrier, & Kale, 2004). According to predictions from the Demographic Services Center at the Wisconsin Department of Administration, the number of elderly in Wisconsin is expected to *increase 90 percent between 2000 and 2030*, from 702,553 in 2000 to 1,336,384 in 2030 (Egan-Robertson, Harrier, & Kale, 2004). Demographers predict that 21 percent of the state population will be 65 or older by 2030, increasing the proportion of the population that is elderly by a full 8 percent (Ofstead, n.d.).

These numbers are an example of demography, or the statistical study of human populations. "While demography is a descriptive and predictive science, demographics is an applied art and science" (Farlex, n.d., p.1). Demographics help people make informed policy decisions by providing information about current situations, predicting situations, and illuminating how problems could be linked in the future. Without understanding who makes up the state's population, policy-makers may create a program that does not allocate resources to the areas of greatest need. Demographic analysis also enables policy-makers to consider projected long-term needs and to plan accordingly.

The aging of Wisconsin's population has the potential to affect every corner of the state. The authors have identified three major topic areas related to long-term care that will be affected by the aging of Wisconsin's population: informal caregiving, or care provided by family and friends without monetary compensation; community care programs, including the Community Options Program and Family Care; and the shortage of trained health-care workers. We describe general demographic trends in the aging population, explain existing policies, make predictions based on what is known about Wisconsin's people today, and, in conclusion, make specific charges to the Joint Legislative Council for study committees to address these issues.

## What is Long-Term Care?

"Long-term care" refers to a broad range of help with daily activities that chronically disabled individuals need for a prolonged period of time (Stone, 2000). Such services include assistance with basic activities of daily living, such as eating, bathing, dressing, and toileting, as well as assistance with instrumental activities of daily living, including household chores, shopping, medication management, and transportation. People receiving long-term care may be physically able to perform these activities, but may need supervision or cueing to do so (Kessner & Bectel, 1998).

There are four types of long-term care:

• *Home health care*: An individual is paid to come into an elder's home and assist him or her with basic and instrumental activities of daily living, as well as small levels of nursing care.

- Assisted living: The most common type of assisted living facility is the residential care apartment complex, where an elderly person moves from her home into a setting that allows her to retain privacy while receiving skilled nursing care and assistance with basic and instrumental activities of daily living.
- *Skilled nursing care*: Received in skilled nursing facilities, commonly referred to as nursing homes, this is round-the-clock care for elders who are most frail.
- *Informal caregiving*: Unpaid relatives and friends help with basic and instrumental activities of daily living, including bathing, dressing, running errands, doing chores, and administering medications.

## Long-Term Care for Wisconsin's Elderly

The demographic trend of aging is important to note when considering that long-term care is increasingly expensive. Medicaid, the state-federal partnership to provide health care for individuals who are low-income or disabled, is the major source of long-term care financing in the United States. In 2003, Medicaid funded 40 percent of long-term care expenditures and 46 percent of nursing home expenditures nationally (Kaiser Family Foundation, 2005). Medicaid is the major source of long-term care financing in the United States.

Some elderly receive Medicaid services based on categorical eligibility, for example, by receiving Supplemental Security Income (Kaiser Family Foundation, 2005). Many elderly, however, "enter nursing homes as private pay clients, spend down their life savings, and become eligible for Medicaid once they have depleted their assets" (Kaiser Family Foundation, 2005). Long-term care insurance is one option consumers have in the marketplace, but "overall coverage levels remain very low, and long-term care is the greatest uninsured risk" faced by U.S. residents (Stapley, 2000). Therefore, Medicaid is expected to remain the primary funding source for long-term care in the near future.

Wisconsin is ranked fourth in the nation for Medicaid expenditures on long-term care as a percentage of its total Medicaid budget (Gibson, Gregory, Houser, & Fox-Grage, 2004). Since 1998, Wisconsin's payouts for nursing home care have increased 61 percent, versus the national average increase of 31 percent (Gibson, Gregory, Houser, & Fox-Grage, 2004). The number of Medicare beneficiaries receiving home health services in Wisconsin is below the national average, and home health-care services are typically more cost effective when compared with nursing home care (Gibson, Gregory, House, & Fox-Grage, 2004). If current policies are not altered to meet future needs, caring for the elderly could become one of Wisconsin's largest expenses, crowding out expenditures on public goods and services such as education, transportation, and non-elderly social services.

This project is not intended to project budgetary implications of aging and long-term care or to provide suggestions for reforming the health-care system. Instead, we use demographics to illustrate issues related to long-term care that have the potential to affect Wisconsin residents in the next 10 to 20 years. The issues described below have

been identified based on current situations, projected needs, and the available resources Wisconsin has to address these issues.

Current public policies in Wisconsin, which assume that families will care for their elderly, may be inadequate in the face of changing family structures. With more dual-earner households and family members living farther away from each other, informal care is expected to become even more complex and difficult. The authors address the following questions about informal caregiving:

- How will elderly people be affected by changes to informal caregiving?
- How will employers and the workforce cope with caregiving demands?
- Should the state of Wisconsin do more to support informal caregiving?

# Changing consumer choice and public budgetary constraints are creating a preference for community-based care, rather than nursing home care.

Social-work and health-care professionals generally recognize community-based care as preferable to nursing home care both for social and financial reasons. The authors address the following questions about programs designed to keep the elderly in the community:

- Why is community-based care important from a public policy perspective?
- How are the existing community-based care programs substantively different?
- What are the challenges of administering community-based care programs?

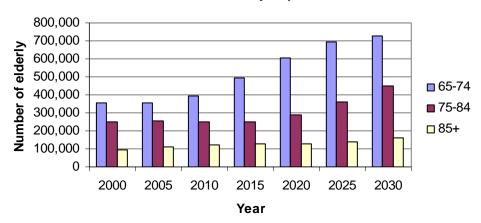
Wisconsin is experiencing a shortage of skilled caregivers. Health-care experts have long been warning policy-makers about the implications of this trend. More skilled caregivers will be important with an increasing elderly population. The authors address the following questions about the skilled caregiver shortage in Wisconsin:

- Is this a market problem that will correct itself, or is policy intervention necessary?
- What are the current public policies affecting the health-care workforce?
- How will changes in long-term care demands change the market for health-care workers?

# Who are Wisconsin's Elderly, Today and Tomorrow?

In the United States, 10 million people need long-term care, and 63 percent of those people are 65 and older (Georgetown University, 2003). Among people who are 85 and older, one-half need some kind of long-term care (Georgetown University, 2003). During the next 15 years, the number of people who need long-term care is expected to increase by 30 percent (Friedland, 2004). In Wisconsin, the number of elderly residents is expected to increase 90 percent between 2000 and 2030, while the entire population is expected to grow by 19 percent overall (Egan-Robertson, Harrier, & Kale, 2004). Figure 1 illustrates the growth in numbers of Wisconsin's elderly population from 2000 to 2030.

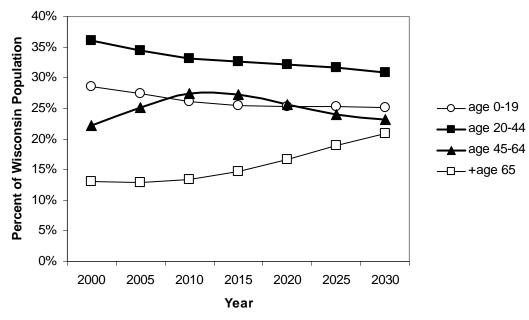
Figure 1
Growth in Wisconsin's Elderly Population, 2000-2030



Source: Data from Wisconsin Department of Administration, 2004

Furthermore, the number of old-old, or people 85 and older, has comprised Wisconsin's fastest growing age group since 1990, increasing 29 percent between 1990 and 2000, and "it will continue to grow faster than the total population or the 65-and-older population through 2010" (WDHFS, 2004, p. 6). As shown in Figure 2, the elderly are the only age group in Wisconsin's population that is expected to increase in the next 25 years.

Figure 2
Wisconsin's Population: 2000-2030



Source: Data from Wisconsin Department of Administration, 2004

Income and education levels among Wisconsin's elderly are also expected to increase. Wisconsin seniors are, on average, less poor and more educated than their national counterparts. Approximately 11 percent of Wisconsin's elderly were below the national poverty level in 2003, compared with 14 percent nationally (Kaiser Family Foundation, 2004). Wisconsin's lower levels of elderly poverty could be attributed to the education level of the state population. According to 2000 Census data, 66 percent of the elderly held a high school diploma, and 28 percent had some level of education beyond high school (WDHFS, 2004c). We expect these education levels to increase with future elderly, which could translate to a consumer base that is more discerning about long-term care options.

Northern Wisconsin will most acutely feel the effects of aging populations. Iron and Price counties are the only two Wisconsin counties expected to experience a decline in population between 2000 and 2030. Price County's population is expected to decline 4.8 percent in the next 25 years, and Iron County's population is expected to decline 4.5 percent (Egan-Robertson, Harrier, & Kale, 2004). Furthermore, counties that are growing in northern Wisconsin are growing due to in-migration of retiring individuals. Vilas County grew in population by more than 15 percent between 1990 and 2000, and 35 percent of this growth is attributed to in-migration of persons 60 years and older (Voss, Veroff, & Long, 2004). This shift of the young to the south and the old to the north is predicted to continue, presenting challenges for service provision to the elderly who remain in Wisconsin's remote areas.

While we can predict who will be old, we cannot predict exactly who will need long-term care services. National studies suggest that 14 percent of those ages 65 and older need long-term care (Georgetown University, 2003). In Wisconsin, 3 percent of those 65 to 74 years of age need nursing home care, a number that increases to 39 percent among those ages 85 and older (WDHFS, 2000). Several factors complicate predicting long-term care needs: most measures of long-term care demand do not account for the informal caregiving that family members and friends offer elderly relatives; many older adults deny their need for care or refuse care when offered; and it is difficult to predict medical advances and how those advances will affect the elderly. Barring the discovery of a cure for Alzheimer's, Parkinson's, and other debilitating diseases that often require older adults to move into long-term care facilities, we can predict that overall, the increasing number of elderly will demand higher amounts of long-term care.

# Whom Should Policy Support? Informal Caregiving for the Elderly

Throughout the United States, more than 6 million elderly had long-term care needs in 2000 (Georgetown University, 2003). Eight percent of the elderly rely solely upon paid care for assistance in performing activities of daily living (Brintnall-Peterson, 2003). The vast majority – 64 percent – relies completely on informal caregiving by family and friends for assistance (Brintnall-Peterson, 2003). The remaining 28 percent rely on some combination of informal and paid care (Brintnall-Peterson, 2003).

Informal caregiving is an important component of long-term care in the United States. The other three forms of long-term care – home health care, assisted living, and nursing home care – require monetary compensation to those providing services. Informal caregivers are usually uncompensated, and informal caregiving helps control formal long-term care costs. Studies have estimated the value of informal caregiving in the United States at \$257 billion annually (Arno, 2002); annual national spending for home health care and formal nursing home care is \$33 billion and \$83 billion respectively (Brintnall-Peterson, 2003).

Informal caregiving does not have an accepted definition, and it can take many forms, such as helping an elder write checks, clean house, buy groceries, attend medical appointments, and perform activities of daily living. Nearly 40 percent of informal caregivers administer medications; some administer 10 or more medications each day (Kaiser Family Foundation, 2002). The average informal caregiver provides 18 hours of care per week (Coleman, 2000).

Informal caregiving is one example of the demographic trend of Wisconsin's aging population interacting with demographic changes in family structures. An increasing number of elderly coupled with a decreasing number of available informal caregivers could have policy implications for long-term care. Consider that "50 percent of elderly people with long-term care needs who lack a family network live in nursing homes, compared to only 7 percent of those who do have family caregivers" (Stone, 2000, p. 10). In recent decades, informal caregiving has become increasingly difficult for numerous reasons detailed below (Brintnall-Peterson, 2003; Stone, 2000).

#### Family Structures

American families are much smaller than they used to be, resulting in fewer persons available to provide care for any given senior. In the mid-1950s, American families had an average of 3.7 children; by the mid-1970s, that figure had fallen to 1.9 children (Morrison, 2001). In 2000, families consisted of 2.1 children on average (Morrison, 2001). This trend leads to a situation where "[t]he average working couple has more living parents than children" (Grant, 2003). Divorce, remarriage, and out-of-wedlock childbearing also create complicated family structures with significant implications for informal caregiving. Adult children are often torn between allegiances to biological parents, stepparents, and estranged parents. As families grow more complicated and adult children find themselves unable to meet the growing demands of their elderly family members, the system of informal caregiving starts to break down, leaving some elderly without needed care.

### **Physical Distance**

An increase in employment-related mobility and cultural shifts have led to large geographic distances between family members, making it difficult to organize and provide consistent care to a family member. A 2004 national survey conducted by the MetLife Mature Market Institute and the National Alliance for Caregiving found that long-distance caregiving is common in many American families. The MetLife study defined "long-distance" as living one or more hours away from the care recipient. Survey respondents lived, on average, 450 miles or more than seven hours of travel time away from the person they were helping. Half of the caregivers visited the person for whom they cared a few times a month, and 23 percent of them described themselves as that person's sole caregiver (MetLife and National Alliance, 2004). The financial toll of physical distance adds up, with long-distance caregivers living between one and three hours away spending almost \$400 a month on travel; those who live more than three hours away average nearly \$700 each month (MetLife and National Alliance, 2004). Physical distance also increases long-distance telephone calls to "check up" on an elder, adding to the cost.

The five-hour drive from Madison to northern Wisconsin, for example, could exact heavy tolls on a caregiver's time and finances, assuming the caregiver could make the drive at all. Wisconsin winters are unpredictable; thus, inclement weather could limit a caregiver's ability to reach an elder in a time of need, placing that elder at greater risk of injury or death. As a result, counties with high proportions of elderly residents need to be especially cognizant of the risks of long-distance caregiving, because caring from afar is qualitatively different from care involving daily personal contact. When caregivers lack direct or easy access to care recipients, the opportunities to observe and respond to changes in health status or react quickly to an emergency decrease, which further places elderly persons at risk. These implications are important for those living in heavily rural counties with large older populations and few work opportunities for adult children.

As can be seen in Figure 3, most counties in northern Wisconsin are expected to have the lowest ratio of 25- to 29-year-olds to 60- to 64-year-olds. This trend indicates that many of Wisconsin's working age population choose to live in the southern counties, while our elderly continue to reside in northern Wisconsin. This has important implications for informal and formal caregiving, because there are both fewer family members to care informally for their elderly and fewer workers to fill long-term health-care positions.

Number of residents ages 25-29 per 100 residents ages 60-64.

Figure 3
Residents Ages 25-29 for Every 100 Residents Ages 60-64, by County, 2025

Source: Wisconsin Department of Administration's Demographic Services Center and the U.S. Census Bureau

### **Workplace Concerns**

50-74 residents75-99 residents

100-125 residents

Given the increase in the elderly population during the next two decades, some researchers assert that elderly caregiving could surpass child care as the 21st century's most pressing work-family issue (Smith, 2004). In the past, women — sisters, daughters, and daughters-in-law — tended to domestic affairs like child care and elderly caregiving. A typical caregiver is married, middle-aged (45 to 55), female, caring for a parent or grandparent, caring for a female elder with a serious health problem, and has a family income of less than \$35,000 (Kaiser Family Foundation, 2002). Women's participation in the labor force increased from 20 to 64 percent during the past four decades (Smith, 2004), making it more difficult for some women to maintain traditional roles as informal caregivers. In 2004, Wisconsin had one of the highest levels of female workforce participation in the country; more than two-thirds of Wisconsin women aged 16 and older hold jobs (Institute for Women's Policy Research, 2004).

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The MetLife (2004) survey also found that 80 percent of long-distance caregivers are employed full-time. Combining work and caregiving responsibilities can be challenging for many families. According to an AARP study, employed caregivers often modify their work schedules or activities to tend to the needs of their care recipient (Coleman & Pandya, 2001). For example, 84 percent of employed caregivers made personal calls on company time. Some of these calls were directly to the elder for whom they cared; others were to doctors, home health aides, and neighbors who might be looking after the elder during the day. More than two-thirds of survey respondents reported that they came in late or left early because of caregiving responsibilities; another two-thirds took time off during the workday (Coleman & Pandya, 2001).

Elder caregiving by employees can be costly to employers. Employees may be absent due to caregiving responsibilities or use work time to make phone calls. Distraction and anxiety about a loved one can impede concentration on workplace tasks. Productivity losses attributable to employees' elder care responsibilities are between \$11.4 billion and \$29 billion according to estimates by the National Alliance for Caregiving (Brintnall-Peterson, 2003; Grant, 2003). Figure 4 shows that replacing employees and workday interruptions are the costliest components of caregiving. This is the most recent study of its type that we were able to locate, and it is expected that these costs increased in the past eight years.

Figure 4: Costs of Informal Caregiving to Employers

All Costs to U.S. Employers, 1997						
Type of Cost	Cost per Employee*	<b>Total Employer Costs</b>				
Replacing Employees	Not available	\$4,933,816,305				
Absenteeism	\$69	\$397,596,918				
Partial Absenteeism	\$86	\$488,298,715				
Workday Interruptions	\$657	\$3,765,122,333				
Eldercare Crisis	\$189	\$1,084,355,232				
Supervisor's Time	\$141	\$805,133,760				
Total Annual Costs	\$1,142	\$11,474,323,263				

<sup>\*</sup>Total annual cost per employee does not include the cost of replacing an employee who may resign due to caregiving responsibilities.

Source: Brintnall-Peterson, 2003

The same study from Brintnall-Peterson (2003) found that some caregivers sacrifice nearly \$700,000 in lost wages and Social Security and pension benefits (Grant, 2003). Other studies show that caregivers often give up opportunities for promotion and work-related travel opportunities; some employed caregivers even go from full-time to part-time status in order to better care for their elderly kin (MetLife and National Alliance,

2004). The latter change in work arrangements is particularly important considering that part-time employees usually do not have access to full health benefits, and long-term caregivers are more likely to see their health suffer. Twenty percent of caregivers report that their physical health has suffered as a result of caregiving, and 30 to 59 percent of caregivers suffer depressive disorders or symptoms (Thompson, 2004).

One could argue that the increased prevalence of dual-earner families with fewer children would lead to greater opportunities for families to purchase long-term care services in the formal market, thus lessening the demand for informal care. However, this possibility does not mitigate the personal and emotional burdens of informal caregiving. Informal care, especially of one's parents or grandparents, is commonly viewed as a family duty—an act of love and respect. Consequently, when the Kaiser Family Foundation (2002) surveyed caregivers about why they perform caregiving services, the reasons were often both personal and financial. Forty percent of persons surveyed cited the inability of the care recipient to pay for private help as a major reason. Two emotional factors were almost as important: 43 percent felt that the care recipient did not need professional help, and 37 percent reported that the care recipient did not want strangers in her home (Kaiser Family Foundation, 2002). For the reasons indicated above, additional income may not necessarily reduce the desire to provide informal care services.

Productivity losses caused by informal caregiving reverberate through the economy. In order to maintain and increase their productive capabilities, employers are going to have to carefully consider how they define "family friendly" policies. Women's entrance into the paid workforce led to the development of such policies as flextime, on-site child care, the Family Medical Leave Act, and other workplace benefits. Most of these benefits, however, focus on an employee's parental commitments to dependent children. The population shift toward more elderly may require more public policies and private benefits that allow employees to care for their elders much like they care for their dependent children.

# **Demographics and Policy: Strengthening Informal Caregiving**

Based on our research, we propose that the Joint Legislative Council form a special committee to examine the current situation of informal caregiving for the elderly in Wisconsin. The special committee should specifically evaluate Wisconsin's caregiver support programs, research current state programs offering financial support to informal caregivers, consider options to help keep families in Wisconsin through economic development, and propose legislation where the committee sees fit. The specific topic areas for this study committee are outlined as follows:

#### **Evaluate Wisconsin's caregiver support programs**

Wisconsin's Alzheimer's Family and Caregiver Support Program provides financial benefits through county agencies to caregivers of financially eligible elders diagnosed with Alzheimer's or irreversible dementia. The program offers up to \$4,000 per person to cover the cost of services like in-home help, respite care, adult day-care programs, specialized clothing, and chair lifts

(WDHFS, 2005e). Counties may also use Alzheimer's Family and Caregiver Support Program funds to create community resources like libraries, support groups, and public awareness media about caregiving (WDHFS, 2005e). The program's total adjusted allocation for 2005 was just more than \$1.9 million. Little information exists about the program's effectiveness or the number of caregivers and elders it serves.

Wisconsin's Family Caregiver Support Program is also designed to provide support to family members caring for an elderly person at home. Like the Alzheimer's program, services and benefits provided through the program vary from county to county, but each county's program encompasses five components (WDHFS, 2004c): information to caregivers about available services; assistance to caregivers in gaining access to services; individual counseling, support groups, and training to caregivers; respite care to help caregivers take a break from providing care; and supplemental services. Information about the program is not well publicized.

An exploratory study committee could analyze usage trends and outcome data for caregivers using each of these programs. Specifically, a study would compile data on the number of families served by these programs, the types of services they have used, and the outcomes of elders involved in the programs. A more detailed study could compare the outcomes of caregivers and elders who utilize these programs to those who do not.

## Research options for financial support for informal caregivers

Several states have more than one option available to lessen the financial strain of caregiving. Legislation could provide a stipend or tax credit to informal caregivers, something other states provide, according to the National Governors Association (n.d.):

- *North Dakota*: Provides stipends of up to \$700 per month to individuals, including spouses, who bring an elder into their home and care for them, similar to how people bring children into the home as foster parents. The program also provides up to \$550 per month for respite services.
- *Arkansas, Florida, and New Jersey*: Provide cash transfers to consumers to purchase care services. The program is scheduled to expand to 10 other states due to early success.
- Delaware, Iowa, Michigan, Pennsylvania, and West Virginia: Provide cash payments to family caregivers through alternative funding sources such as the lottery or tobacco settlements.
- *California and Pennsylvania*: Provide cash payments to caregivers from general revenue funds.
- *The District of Columbia and 26 states:* Provide tax deductions or tax credits to family caregivers.

Many states offer caregivers in-kind transfers or vouchers that they can exchange for respite care or the services of home health aides. Respite care allows a family member to take a break from caregiving duties. States usually pay for respite services through their budgets, but the National Family Caregiver Support Program enacted in 2000 allows states to use federal funds to improve upon and expand their existing respite program options (Feinberg et al., n.d.).

Financial benefits could cover personal assistive devices like canes, walkers, and wheelchairs, or be directed toward home improvements like installing handrails in showers, building ramps, and widening doorways (Thompson, 2004). Some states provide these services under their existing Family Caregiver Support programs, but many more have yet to expand their offerings in this way.

# Review economic development programs to help keep young people in Wisconsin

Employment-related mobility is expected to affect elderly individuals living in rural Wisconsin. Perhaps one of the best ways to support elders is to encourage economic development and shape Wisconsin communities in ways that will attract and retain younger workers and families. Some young people may choose to leave rural areas, but the option to remain or return as family members grow older could be more alluring with healthy, robust communities.

# **Community-Based Options: The Next Wave of Long-Term Care**

Although the majority of the elderly rely on informal caregiving, public policies traditionally focus on institutional care, such as nursing homes. Financial support through Medicare and Medicaid has also been geared to paying for nursing home care (WCLTCR, 2002).

According to the Wisconsin Department of Health and Family Services, in state fiscal year 2004, \$1.2 billion was spent on primary, acute, and long-term community care for the aged (WDHFS, 2005d). Of this, \$761 million was spent on nursing home care for the elderly (WDHFS, 2005d). The total Medicaid expenditure in Wisconsin on nursing home care for the elderly and disabled in state fiscal year 2004 was \$1.1 billion, or 25 percent of the total Wisconsin Medicaid budget (WDHFS, 2005d). "In 2003-2004, the state spent approximately \$2.1 billion (all funds) to provide long-term care services to Wisconsin residents" (LFB, 2005, p. 50).

Wisconsin is ranked fourth in the nation for Medicaid expenditures on long-term care as a percentage of its total Medicaid budget (Gibson, Gregory, Houser, & Fox-Grage, 2004). From 1998 to 2003, however, Wisconsin witnessed a 15 percent decline in the nursing home utilization rate for people aged 65 and older and a 21 percent decline for those aged 85 and older (WDHFS, 2004e).

While nursing home rates may continue to decline, the demographics of aging indicate that the need for formal long-term care will only continue to grow. Government estimates suggest that the number of people using paid long-term care services could increase from 15 million in 2000 to 27 million in 2050 (Friedland, 2004). The fastest-growing group of Wisconsin's elderly is the old-old, those who are 85 and older. In 2000, this group numbers more than 95,000. This number is expected to increase 66 percent by 2030 (Farley, 2004).

This trend holds important implications for health-care policy, as the old-old have the highest rates of disability and are most likely to spend their last years with chronic debilitating conditions, such as dementia or paralysis following a stroke (Kessner & Bectel, 1998; Cooper, 1998). Individuals who are 85 and older are likely to require more hands-on care than most families or friends are equipped to provide, leading to higher health-care costs and the need for institutionalized care (Cooper, 1998). It is possible that medical science will improve to mitigate the debilitating results of these illnesses, but the Legislature should not rely upon this idea.

# Where is Care Provided, Today and Tomorrow?

Figure 5 shows the number of nursing home beds available in 2005 on a per capita basis according to a county's current 65 and older population. While there are exceptions, in general, Wisconsin's rural counties have more nursing home beds per capita than urban counties. Nationally, the supply of nursing homes and nursing home beds is nearly 43 percent greater in non-metropolitan than in metropolitan areas (Coburn, 2002).

Because of the public expense associated with nursing home care, the Legislature should be concerned if individuals go to nursing homes due to constrained choices instead of severe care needs. Medicaid generally covers nursing home stays, while alternative forms of long-term care are generally paid for through private sources. Non-metropolitan elderly have lower incomes, rely more heavily on Medicare and Medicaid, and are less likely to have supplemental coverage than their urban counterparts (Coburn, 2002). If there are no options between staying in one's own home and receiving Medicaid-funded nursing home care, it would be expected that rural elderly nursing home residents are less disabled than their urban counterparts. A study of Kansas elderly supported this conclusion (Rowles, 1996). The same kinds of choice constraints may be expected for low-income urban elderly.

Number of skilled nursing home beds per 100 residents age 65 and older:

0-19.99 beds
20-29.99 beds
30-39.99 beds
40-59.99 beds
60+ beds

Figure 5
Nursing Home Beds per 100 Residents Age 65 and Older, by County, 2005

Source: Wisconsin Department of Health and Family Services, February 2005, and Wisconsin Department of Administration's Prediction Data

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Figure 6 presents the predictions for the number of nursing home beds per capita according to the population 65 and older in 2025, assuming that the number of nursing home beds currently available does not increase by that time. The number of nursing home beds available is generally expected to decrease. We cannot predict, however, if this decrease is a negative or positive phenomenon. It may be positive if elderly have more access to care options, but it could be negative if people are being denied care because of a lack of space.

Number of skilled nursing home beds per 100 residents age 65 and older:

0-19.99 beds
20-29.99 beds
30-39.99 beds
40-59.99 beds
60+ beds

Figure 6
Nursing Home Beds per 100 Residents Age 65 and Older, by County, 2025

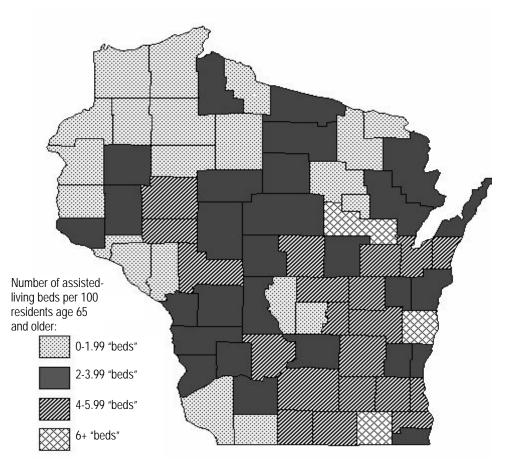
Source: Wisconsin Department of Health and Family Services, February 2005, and Wisconsin Department of Administration's Prediction Data

Assisted living facilities are one way elders and their families negotiate the gap between complete independence and full-time skilled care. Access to these facilities is in high demand and often depends on an elder's ability to pay. Almost half of the assisted living facilities in Wisconsin do not accept public payment sources, and these facilities have either a minimum income or minimum asset requirement for new residents (Dieringer Research Group, 2003). Of these, most require that the new resident must be able to afford a minimum length of stay varying from one year to four years, with the median minimum length of stay being two years (Dieringer Research Group, 2003).

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Figure 7 illustrates the per-capita rate of assisted-living beds per county, based on the county's population of individuals who are 65 and older. This map shows the lowest per-capita rates of assisted living facilities are, generally, in the northern counties of Wisconsin. As discussed, the elderly in these non-metropolitan areas are generally poorer than their urban counterparts. The use of assisted-living facilities is a market-driven phenomenon, and without buying power, non-metropolitan elderly do not have the option of assisted living.

Figure 7
Assisted Living Beds per 100 Residents
Age 65 and Older, by County, 2005



Source: Wisconsin Department of Health and Family Services, February 2005, and Wisconsin Department of Administration's Prediction Data

Figure 8 displays the availability of assisted living facilities in 2025 on a 65-and-older per-capita basis, assuming that no additional assisted living facilities are built between now and then. The number of assisted living beds per capita in rural counties, especially in northern Wisconsin, is predicted to decrease, an expected result based on lower expected incomes in non-metropolitan areas, as discussed. When Figure 8 is compared with Figure 6, it appears that elderly residents of northern Wisconsin are expected to lose both nursing home and assisted living options by 2025.

Number of assisted-living beds per 100 residents age 65 and older:

0-1.99 beds
2-3.99 beds
4-5.99 beds
6+ beds

Figure 8
Assisted Living Beds per 100 Residents
Age 65 and Older, by County, 2025

Source: Wisconsin Department of Health and Family Services, February 2005, and Wisconsin Department of Administration's Prediction Data

We cannot predict exactly what will happen with elderly migration in the next 25 years. Adult children working in metropolitan areas may move their parents from rural counties to more urban counties if they are financially able. This may not matter, however, if a parent insists on remaining in a community near her home. What is clear, however, is that leaving intermediate care – care between complete

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independence and round-the-clock skilled care in nursing homes – completely up to market forces leads to overuse of nursing home care or under-provision of necessary services to the elderly. Community-based options for long-term care are necessary to keep Medicaid nursing home costs under control.

## **Providing Care in the Community: Wisconsin's Program Options**

Two Wisconsin programs are directly targeted at helping the elderly and people with disabilities remain in the home: the Community Options Program and Family Care. The Community Options Program, or COP, was enacted in 1981. COP helps individuals who need long-term care services remain in their homes with cost-effective alternatives to institutionalized long-term care (WDHFS, 2004a). The COP waiver, approved in 1987, is a Medicaid waiver that pays for COP-eligible care. COP is available to any person who would be eligible for nursing home care under Medical Assistance, but COP helps that individual remain in his or her own home (WDHFS, 2004a).

COP provides comprehensive care, but there are waiting lists and budgetary constraints on participation. The total COP budget of federal and state funds in fiscal year 2003-2004 was \$145 million, and \$106.5 million of that was earmarked for elder care services (LFB, 2005). In 2004, 3,389 people ages 65 and older were placed on COP waiting lists (WDHFS, 2005b). Of the 9,352 elders COP served in 2003, 38 percent were ages 75 to 84. Waiting time for COP services can be up to nine years in some cases (WDHFS, 2004d). This should be cause for concern, given that elders must spend down their assets and become Medicaid-eligible to be placed on the COP waiting list. There is no formal tracking of individuals on COP waiting lists, so it is unknown if these individuals move into nursing homes, receive inadequate care, or die before they are served by the COP program.

While COP is an important program for elderly people, most people who are served by COP are disabled and younger than 65, as can be seen in Figure 9:

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<sup>&</sup>lt;sup>1</sup> Please see Appendix A for additional information about these two programs.

30,000 25.000 **Number of Participants** 9,351 9,918 20,000 11,863 10,380 ■ Elderly 15,000 □ Disabled 10,000 15,922 15,513 13,926 13.760 5,000 0 2000 2001 2002 2003

Figure 9
Community Options Program Participants by Year

Source: Department of Health and Family Services, 2005

Year

The second program, Family Care, was developed to address many of the concerns with other community-based waiver and fee-for-services programs. The goals of Family Care are to increase access to long-term care by eliminating the waiting lists, to have a consumer-oriented approach by giving seniors more choices about their needed services and supports, to increase quality by focusing both on health and social outcomes, and to provide cost-effective alternatives to nursing home care (WDHFS, 2005a). Family Care provides one flexible benefit for all long-term care services, including medical supplies, home-delivered meals, nursing services, in-home personal care, and residential services (WDHFS, 2004d).

Family Care is being piloted in nine Wisconsin counties: Fond du Lac, Jackson, Kenosha, La Crosse, Marathon, Milwaukee, Portage, Richland, and Trempealeau (WDHFS, 2003a). Figure 10 shows the locations of these counties.



Source: Wisconsin Department of Health and Family Services http://www.dhfs.state.wi.us/LTCare/Generalinfo/FCMap.htm

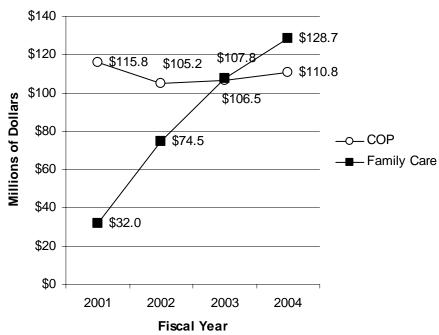
Five of the nine counties – Fond du Lac, La Crosse, Milwaukee, Portage, and Richland – have the Care Management Organization component of the program, which arranges and manages health-care services and is the most expensive part. The other four counties have the Resource Center only, which provides a single point of entry for information about receiving publicly funded long-term care services (WDHFS, 2003b). The Resource Centers are typically housed in the county Human Services Department or county Department on Aging (WDHFS, 2003b).

Family Care helps individuals with the same needs as those who participate in COP, but the major difference is that Family Care is an entitlement, so no one who is eligible is placed on a waiting list. To be eligible for Family Care, a person must have long-term care service needs, be an older adult or an adult with a disability, live in a Family Care pilot county, and meet financial requirements (WDHFS, 2005c). Medicaid-eligible individuals automatically meet the financial eligibility criteria for Family Care (WDHFS, 2005c). Individuals who are not financially eligible for Medicaid may still qualify for Family Care based on their cost of care (WDHFS, 2005c).

According to Donna McDowell, director of the Bureau of Aging and Long-Term Care Resources at the Wisconsin Department of Health and Family Services, Family Care requires a social worker and a nurse to make care arrangements for the client to ensure appropriate care for that person's needs (personal communication, March 30, 2005). The Family Care program received \$209 million in state and federal funds in fiscal year 2003-2004 for use in the nine Family Care pilot counties, including \$107.8 million for elder care and \$101.7 million for care for individuals with disabilities (LFB, 2005).

Because Family Care is an entitlement and a comprehensive program, it is more expensive than COP. Enrollments of elderly have grown rapidly, from 1,318 individuals in 2000 to 7,680 in 2004 (WDHFS, 2005b). This is a 483 percent increase over four years. Costs for the Family Care program have increased steadily since the program began, and Family Care expenditures for the elderly now exceed COP expenditures for the elderly, as can be seen in Figure 11:

Figure 11 Costs of Community Options Program and Costs of Family Care for the Elderly, in Millions



Source: Department of Health and Family Services, 2005

The Wisconsin Legislative Audit Bureau subcontracted with The Lewin Group for an evaluation of the Family Care pilot program in June 2003. This evaluation found that Family Care increased the choices available to those receiving services, eliminated waiting lists, and improved quality through a focus on social outcomes (The Lewin Group, n.d.). The program did not, however, demonstrate increased quality of care as related to health outcomes, and it was still too early to determine the ability to create a cost-effective program for the whole state (The Lewin Group, n.d.).

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The Lewin Group's conclusion that there was a lack of evidence regarding quality of care outcomes may have been related to the newness of Family Care. Still, social-work professionals continue to disagree about how the quality of care varies between Community Options Program and Family Care. We interviewed a social worker [name withheld upon request] who administers the COP in a rural county in western Wisconsin. She stated, "COP is a great program, and it works, if it's funded" (personal communication, March 4, 2005). She asserted that COP in her county lost money in its budget to help increase the budget for an adjacent county's Family Care program. She did not believe there was a substantial difference in the care received by those participating in COP versus those in Family Care; the major difference she saw was that those in Family Care counties do not face waiting lists.

In contrast, McDowell had positive comments about the Family Care program. She believes that Family Care is more effective at keeping people in their homes for a longer period of time because a nurse is directly involved in case management (personal communication, March 30, 2005). Similarly, Stephanie Robert, a researcher from the University of Wisconsin-Madison School of Social Work, feels that Family Care is more effective because it is consistent. Unlike COP, Family Care does not vary across counties in its services or waiting periods. Robert also suggested that Family Care is beneficial to families since it offers the flexibility to compensate family members and friends for their caregiving (personal communication, April 19, 2005).

This disagreement among professionals is important when considering the demographic trend of an aging population and the costs associated with long-term care. While costs for Family Care now surpass those of Community Options Program, as can be seen in Figure 11, Family Care serves far fewer individuals. The total package of Family Care services is available in only five Wisconsin counties, whereas COP is expected to serve all eligible individuals in the remaining 67 counties. Family Care is already more expensive than COP, calling into question whether this program can be extended to all Wisconsin counties.

## **Cost Estimates: Expanding Family Care**

While there is no way to estimate how many seniors will be eligible for specific services and levels of care in the years to come, an average daily cost comparison between COP waivers and Family Care illustrates the level of expense. According to the Wisconsin Department of Health and Family Services, COP costs average from \$62 to \$62.32 per elder per day while Family Care costs average \$59.38 to \$68.47 to pay for the daily services of frail elders (WDHFS, 2005a). The Family Care range is larger because costs are based, in part, on the cost of care in each region of the state (LFB, 2005). While COP is more expensive per day in some cases, the Family Care program could be more expensive in total because it is an entitlement.

The authors have made several estimates of expanding Family Care to the entire state if the program remains an entitlement and all eligible elderly are covered. The authors are aware that Family Care costs are different in each county, due to costs of care varying

in each region as well as with the level of care required. A study committee could take these differences into account more accurately.

First, based on numbers from the Wisconsin Department of Health and Family Services and the Legislative Fiscal Bureau, the authors calculated that 85 percent of Family Care enrollees statewide were elderly. This figure was calculated based on total enrollment numbers of 9,056 in November 2004, as reported by Legislative Fiscal Bureau (2005). The Wisconsin Department of Health and Family Services reported a 2004 enrollment of 7,680 elderly individuals in Family Care. Figure 12 shows the Family Care enrollments by county for pilot counties with the Care Management Organizations.

Figure 12
Family Care Enrollment by County

County	Number of People Ages 65 +	Total Family Care Enrollment	85 percent Family Care Enrollment	Percent of Elderly Population Enrolled
Milwaukee	117,954	5,446	4,629	3.92%
Fond du Lac	14,075	959	815	5.79%
La Crosse	13,788	1,598	1,358	9.85%
Richland	3,055	293	249	8.15%
Portage	7,892	760	646	8.19%
Total	156,764	9,056	7,697	
Average				7.18%

Source: Calculations based on figures from Wisconsin Department of Health and Family Services and Legislative Fiscal Bureau

Using the average calculated in Figure 12, of 7.18 percent of Wisconsin's 719,262 elderly, 51,643 individuals would be enrolled in Family Care.

The average yearly cost of care for an elder enrolled in Family Care, based on the 2004 numbers from Wisconsin's Department of Health and Family Services described above, was calculated to be \$16,758. This number was calculated by taking the \$128.7 million allocated to Family Care for the elderly, and dividing it by 7,680, the number of elderly enrolled in Family Care in 2004. If the 85 percent estimate of 7,697 calculated in the table above was used, the average yearly cost would be \$16,721. Yearly cost calculations could equal:

Low:  $$16,721/\text{year} \times 51,643 = $863 \text{ million}$ 

High:  $$16,758/year \times 51,643 = $865$  million

A calculation based on the high and low daily costs of care is also estimated. As noted above, daily Family Care costs range from \$59.38 per diem to \$68.47 per diem, according to WDHFS. Total yearly costs of care, assuming that all program participants are enrolled for one year, could equal:

Low: \$59.38/daily x 365 days x 51,643 individuals = \$1.12 billion

High: 68.47/daily x 365 days x 51,643 individuals = 1.29 billion

Again, these are rough calculations, as we are unable to determine the costs of care and reasons why coverage rates differ in the pilot counties. We recommend that a study committee commission a more in-depth study, evaluating average length of participation in Family Care as well as costs of care in differing regions of the state.

What does all this mean for programs? Community-based care options are preferred to institutional care, both from a social and a financial perspective. It is important to again note that the state spent \$761 million on nursing home care for the elderly – 63 percent of the total \$1.2 billion spent on all long-term care options for the elderly (WDHFS, 2005d). Demographics indicate that the number of people who will need long-term care will only increase. Financially, it is advantageous to the state to keep people out of nursing homes for as long as possible. The question is then about what is appropriate and adequate care. The qualitative differences in care should be assessed to determine if COP is adequate to meet the needs of an increasing elderly population, or if the positive benefits of Family Care warrant statewide investment in this program.

### **Demographics and Policy: Evaluating Community Care**

Based on our research, we propose that the Joint Legislative Council form a study committee to evaluate, compare, and determine the future of the Community Options Program and Family Care. The study committee should specifically assess current use of long-term care and predict future use patterns; evaluate the current funding levels and sources for COP and Family Care; review implementation procedures in Family Care pilot counties; define adequate and sustainable levels of care with regard to state programs for the elderly, including tracking those individuals on COP waiting lists; determine the program that meets the criteria; and propose legislation as the committee sees fit. The specific topics are outlined as follows:

#### **Assess current long-term care use and predict use patterns**

The maps in Figures 5, 6, 7, and 8 illustrate what appears to be a reduction in several long-term care options for elderly in northern Wisconsin. An assessment to determine if this is indeed the case could be helpful to determining which public policy interventions are necessary to ensure that these elderly receive adequate care. Some effort to survey the elderly who have migrated to this area may be necessary to determine whether those individuals will be seeking long-term care options in their new counties of residence.

# **Evaluate current funding for the Community Options Program and Family Care**

Governor Jim Doyle's budget proposal calls for an additional 1,440 openings in the state's Community Options Program. This COP expansion will reduce but not eliminate waiting lists. This expansion should be evaluated in terms of whether the cost budgeted is enough to cover the cost of services (WCLTCR, 2002). The cost of scaling Family Care up to the state level should also be evaluated. The two programs have already been evaluated separately; a joint evaluation comparing the programs may be useful.

# Review implementation procedures currently used in Family Care counties

Donna McDowell, director of the Bureau of Aging and Long-Term Care Resources at the Wisconsin Department of Health and Family Services, stated that the Family Care care maintenance organizations in Milwaukee and La Crosse counties are running deficits because there is no technical support available to help counties negotiate the complicated federal requirements associated with the waivers. There are also wide variations in the cost per person in the Family Care pilot counties. The implementation procedures in each county should be reviewed to determine best practices and areas for improvement.

# Determine which community care program offers an adequate and sustainable level of care

If the study committee determines that Community Options Program meets satisfactory goals but needs additional funding, it might be preferable to the very comprehensive but expensive Family Care. On the other hand, if care under the COP is inadequate, Family Care should be refined and expanded with the understanding that it will be expensive. In the current situation, it appears that those who reside in Family Care counties are receiving "Cadillac" long-term care at the expense of those on the COP waiting list.

# Research the outcomes for those individuals on Community Options Program waiting lists

The lack of formal tracking of those who are placed on Community Options Program waiting lists makes it difficult to determine if the wait actually causes decreased health outcomes. Tracking these outcomes is necessary to determine if COP or Family Care is the preferable community care program.

# A Crisis in Care: The Looming Health-Care Workforce Shortage

Demographics can help policy-makers predict what may be the most serious impending problem in long-term care policy: the lack of an adequately trained health-care workforce (Stone, 2001). Increased demand for formal care, inadequate labor supply, and a fragmented payment system that is too inflexible to respond sufficiently to market forces are all factors that may contribute to a potential long-term care workforce shortage, skyrocketing health-care costs, or both. Indeed, the problem is not simply one of supply; it involves a more fundamental, long-term dilemma of how to develop "a committed, stable pool of frontline workers who are willing, able and prepared to provide quality care to people with long-term care needs" (Stone & Wiener, 2001, p. 13). The following section outlines the causes of the impending shortage, as well as a number of policy options that may be exercised to alleviate it.

# **Increased Demand for Long-Term Care**

Although it is difficult to predict exactly how many elderly Wisconsinites will need formal long-term care, demographic information suggests that demand for such services will increase. While not all elderly people require long-term care, the probability of needing such care increases with age (Stone, 2001). In addition, although the prevalence of disability among the elderly has been decreasing, those requiring assistance for basic activities of daily living and instrumental activities of daily living has stayed constant. Not being able to perform these activities is associated with a higher level of disability, and thus requires a higher level of person-to-person assistance (Citizens for Long-Term Care, 2003).

Other demographic factors may increase the demand for formal long-term care. For example, assuming reasonable rates of economic growth, baby boomers are likely to have higher real incomes during their retirement years than today's retirees. Those facing long-term care decisions may be more willing and able to purchase formal services as opposed to relying solely on informal care (Stone, 2001). As noted, families may have no other option than to pay for care, as informal care will likely be less available.

#### The Supply of Health-Care Workers

Whether an adequate supply of frontline health-care workers will be available to meet this demand is a serious concern. Additional registered nurses, licensed practical nurses, and paraprofessional health-care (or direct-care) workers are needed to help provide care for elderly and disabled people. The majority of hands-on care within the long-term care system is provided by the certified nursing assistants, home health aides, and personal attendants who are part of the direct-care workforce (Direct Care Alliance, 2004). The Wisconsin Department of Workforce Development (2002) predicts workforce shortages in each of those occupations within the next 10 years.

Demographics explains part of the potential shortage. While the number of people older than 65 will increase 89 percent by 2030, the number of potential workers ages 18-44 will *decrease* by 1 percent (Governor's Health Care Workforce Shortage Committee, 2002).

Figure 13 illustrates how the population distribution in Wisconsin is expected to change between 2005 and 2030. The largest rates of population growth will be in the age groups that are 60 and older.

500,000 450,000 350,000 300,000 250,000 150,000 100,000 50,000 50,000 100,000 50,000 100,000 50,000

Figure 13
Changes in Age Distribution Among Wisconsin's Population, 2005 and 2030

Source: Wisconsin Department of Administration's Demographic Services Center

Age Groups

In addition, the traditional pool of long-term health-care workers continues to shrink and change in other ways. Long-term health-care paraprofessionals have traditionally been middle-aged women. By 2010, this group of workers will be substantially smaller, and is predicted to increase by only 7 percent during the next 30 years. Perhaps more importantly, the pool of potential female entry-level workers (age 25-44) is projected to decline by 1.4 percent during the next six years. In addition, the educational level of minority women—those most likely to enter the paraprofessional workforce—is improving. These more educated women may be less willing to work in the types of low-wage, low-benefit jobs that make up the base of the formal long-term health-care system. Women in transition from welfare to work make up a potential untapped labor market; however, many of these women have already been absorbed into the economy or possess multiple barriers to employment (Stone, 2001).

For each of the occupations crucial to long-term care delivery, the Wisconsin Department of Workforce Development (2002) predicts rapid rates of job growth that far outpace the growth of the labor market in general. For example, between 2002 and 2012, the department predicts that the state will need 31.4 percent more registered nurses; 20.3 percent more licensed practical nurses; and 24.6 more certified nursing assistants, orderlies, and attendants. The largest rate of job growth, 50.4 percent, will occur in the

field of home health aides. In addition, surveys of long-term facilities continue to report overall turnover rates as high 100 percent (Stone, 2001).

National research suggests that low wages are associated with high turnover rates among frontline caregivers, and in some cases, benefits may be even more important than wages (Direct Care Workforce Issues Committee, 2005). Researchers suggest that shortages in long-term health-care occupations occur for a variety of other reasons as well, including poor working conditions, inadequate training, few opportunities for career advancement, and the emotional and physical demands of the job.<sup>2</sup>

### Why Wages Won't Respond: The Role of Medicaid

Economists might view this situation as a boon for future health-care workers who will reap the benefits from increased demand; however, the way long-term care is funded makes it difficult for the system to respond adequately to the emerging staffing crisis.

As noted in the introduction, Medicaid is the largest source of funding for long-term care services. Figure 14 illustrates the sources of long-term care financing in the United States. Nationally, nearly 41 percent of people rely on Medicaid to pay for long-term care; 64 percent of Wisconsin nursing home residents rely on Medicaid as a payment source (WDHFS, 2004e). Of these payments, 50 to 70 percent are used for direct labor costs (Direct Care Workforce Issues Committee, 2005). As a result, reimbursement by Medicaid programs creates the framework within which employers set wages for many direct-care workers.

Other 7.3%

Insurance
12.1%

Medicaid
40.5%

Out-of-Pocket
25%

Figure 14
Long-Term Care Financing Sources

Source: Paraprofessional Healthcare Institute, 2003

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<sup>&</sup>lt;sup>2</sup> A more detailed discussion of factors affecting each occupation is available in Appendix B.

Medicaid underfunds the true costs of long-term care, and, as a result, states implement cost-containment measures that restrict the amount of money providers can spend per client, per episode, or per visit. Since labor typically accounts for the majority of costs in long-term care, these measures often dictate the amount of money available for wages, benefits, and hours of work (Citizens for Long-Term Care, 2003).

Although reimbursement rates are "prospective" in that they determine in advance a set amount of dollars for each health-care event, the formulas are really "retrospective" because they are based on historic costs. As a result, reimbursement rates allow little flexibility for providers to respond to rapid changes in market forces (Citizens for Long-Term Care, 2003).

It is difficult to say whether Wisconsin's future elderly population will be more or less reliant on Medicaid than today's elderly population, although current caseload numbers suggest an upward trend. If Medicaid continues to play a crucial role in long-term care financing, however, its payment system sets up a situation in which staffing shortages will occur during both good and bad economic times. During times of economic growth, potential direct-care workers will be lured to more attractive employment that offers higher wages. When the economy stagnates, tax revenues plummet, threatening cutbacks in Medicaid funding, thus hampering efforts to improve reimbursement for long-term care staffing. The Legislature should consider re-evaluating and adjusting the system to better reflect actual and future costs of attracting and retaining direct-care workers in an increasingly competitive marketplace (Citizens for Long-Term Care, 2003).

### **Implications of Long-Term Care Workforce Shortages**

High rates of staff turnover and vacancies could have serious implications for families, providers, consumers, and employees. For example, families and informal caregivers often must bear the brunt of worker shortages, causing added stress and financial burden. Inadequate staffing can affect workers, who may experience higher levels of stress, frustration, and injury (Stone, 2001). Ultimately, shortages drive up health-care costs for all those involved, including Wisconsin taxpayers.

Turnover is particularly expensive for providers. Studies suggest that recruitment, training, increased management expenses, and lost productivity add up to \$1,400 to \$3,900 in losses per direct-care worker (Stone, 2001). Using temporary agencies or temporary workers to combat shortages is common practice in the long-term care industry. These workers earn \$20-\$25 per hour—almost triple the average wage for permanent workers. Facilities may also employ temporary or "traveling" nurses, who often earn between two and two-and-one-half times more than a staff nurse. Other nurse recruitment efforts, including signing bonuses and tuition reimbursement, may increase costs (National Governors Association Center for Best Practices, 2004).

In addition, increased costs often lead to higher Medicaid reimbursement rates, which are passed onto the state, or higher private payer costs, which are passed on to individuals and their families (Stone, 2001). As mentioned in the previous section, if Medicaid

reimbursement rates fail to keep up with the "true cost" of providing services, providers have less flexibility to offer competitive wages and benefits (Stone, 2001).

Labor shortages and high turnover rates also affect the continuity and quality of long-term care, as well as access to formal services. For example, among nursing home residents, staffing shortages contribute to malnutrition and dehydration among nearly a third of residents (National Governors Association Center for Best Practices, 2004). Several studies suggest that inadequate staffing is associated with preventable hospitalizations among nursing home residents (Stone, 2001). Rapid turnover of frontline workers may affect the mental functioning of patients because continuity of care is continuously disrupted (National Governors Association Center for Best Practices, 2004). Finally, there is concern that overworked, frustrated staffers may be more likely to mentally or physically abuse patients (National Governors Association Center for Best Practices, 2004).

### **Expanding Access to Health-Care Education**

State policy and budgeting for health-care education initiatives should reflect growing needs. The state education system for kindergarten through 12th grade is one pipeline for enhancing youth interest in health-care fields. Some Wisconsin programs include youth apprenticeships, health-care skill training, and advertising of health-related careers within the K-12 education system (WDHFS, n.d.c). Budgetary cuts, however, have already reduced the number of students served by the state's Youth Apprenticeship Program by 50 percent (Abdul-Alim, 2004). The magnitude of the impending problem calls for increasing, not decreasing, investments in the future workforce.

Investment in education will be necessary to recruit minority workers. For example, despite the fact that Latinos constitute the fastest growing population in the state, their presence in the nursing field hovers around 1 percent. Language barriers and lack of education appear to be the most prevalent factors that prevent Latinos from gaining a foothold in the field (Lalwani, 2005). Tuition reimbursement programs may help bring in workers who cannot afford post-secondary training (Stone, 2001).

The state's education system lacks the capacity to train the number of workers needed to sustain Wisconsin's long-term health-care needs. Although state technical schools and universities have increased enrollments in health-care education programs, long waiting lists still exist, and interested learners are turned away. The Wisconsin Hospital Association (2004) predicts that current efforts will not be sufficient to create the number of workers needed in the near future.

An aging faculty presents an additional complication; for example, the average age of nursing faculty members at technical training schools in Wisconsin is 57. At the University of Wisconsin-Milwaukee's College of Nursing, the largest nursing school in the state, half of the faculty will retire or be eligible for retirement in 2008-2010. No one on the UW-Milwaukee nursing faculty is younger than 40 (Hajewski, 2005). Requirements for teaching may also need to be

re-evaluated. Donna McDowell, director of the Bureau of Aging and Long-Term Care Resources at the Wisconsin Department of Health and Family Services, pointed out that a master's degree in nursing is required to teach certified nursing assistant courses in Wisconsin technical colleges. Requiring a bachelor's degree only may increase the number of individuals who are interested in teaching.

### **Demographics and Policy: Alleviating Workforce Shortages**

Based on our research, we propose that the Joint Legislative Council form a study committee to evaluate the options for alleviating the workforce shortage in long-term care. The study committee should specifically formulate a plan for improved data collection about Wisconsin's health-care workforce; examine Medicaid "wage pass-through" and create legislation to improve the system if necessary; determine how long-term care reimbursement policies could be altered to reward quality; evaluate educational opportunities for skilled caregivers; and propose legislation as the committee sees fit. The specific topics are outlined as follows:

### Improve the data collected about Wisconsin's health-care workforce

Effective implementation of policy recommendations related to long-term care will require better, more specific workforce information than is currently available in Wisconsin. Although the Wisconsin Department of Health and Family Services collects information about frontline workers for its annual nursing home survey and Medicaid cost reports, the state has limited knowledge about workers in other residential and community-based settings (Direct Care Workforce Issues Committee, 2005).

Throughout this report, we illustrate how demographic information can serve as a useful tool for policy-makers. If the trend toward community-based long-term care continues, it will be important to systematically collect information about these workers in order to pinpoint problem areas, focus public and private efforts to improve sufficiency and stability of the direct care workforce, and test the extent to which these efforts have a real impact (Direct Care Workforce Issues Committee, 2005).

Other states, such as North Carolina, already collect and analyze data from a variety of providers, including nursing homes, adult-care homes, and homecare agencies, using a standard set of questions (Direct Care Workforce Issues Committee, 2005).

## Examine Medicaid "wage pass-through"

More than 20 states, including Wisconsin, use Medicaid "wage pass-through" programs that provide reimbursements for increased compensation for direct-care workers (USDHHS, 2002). Formal assessment of the efficacy of such programs remains scarce, and evaluation results are ambiguous (Direct Care Workforce Issues Committee, 2005). Some state programs, however,

successfully reduce turnover and increase direct-care worker wages (Paraprofessional Healthcare Institute, 2003).

Again, demographics can serve as a tool for legislators to better target this intervention. Wisconsin's wage pass-through program currently applies only to workers in skilled nursing facilities, but it could be expanded to include community care programs. Program administrators can also use demographics to identify areas of the state that suffer from low wages or inadequate workforce supply, or that serve a higher proportion of elderly Medicaid recipients. Documentation that funds are being used for wages and benefits should also be required (Direct Care Workforce Issues Committee, 2005).

### Change current long-term care reimbursement policies

Currently, Wisconsin's nursing home reimbursement formula contains no factors directly related to the adequacy or stability of direct care staff (Direct Care Workforce Issues Committee, 2005). The direct-care allowance factor in the formula is based on historic costs, creating a disincentive to hire more staff or increase wages and benefits. In addition, according to the Direct Care Workforce Issues Committee (2005), "reimbursement rates for initial nurse aide training and testing have not been increased since the early 1990s and there is no reimbursement for in-service training."

Several states, including Iowa, Minnesota, and Michigan, tie quality measures to their nursing home formulas. Other states, including California and South Carolina, provide "bonus" payments for nursing homes that meet certain quality criteria. Wisconsin policy-makers could re-evaluate reimbursement rates and incorporate such mechanisms to encourage sufficient and stable staffing, and reward high retention and low turnover rates. State rates could incorporate funding for initial and ongoing training efforts.

### **Evaluate education opportunities for skilled caregivers**

There is a need to increase interest in skilled care fields, as well as to expand the number of instructors available to teach interested students. Expansion of youth apprenticeship and career shadowing experiences, changes in current degree requirements for teaching at different levels of post-secondary instruction, and implementation of more technology-based instruction may help expand the pool of workers. New educational strategies may be required to recruit and nurture future long-term health-care workers and teachers. For example, investments in online or video conference learning, weekend, and evening programs would help meet the needs of potential long-term health-care workers who work full-time, live in rural communities, or have other family obligations. The state education system must also have the resources to provide incentives for health-care professionals to enter teaching (Wisconsin Hospital Association, 2004).

## Conclusion: Changing Trends, Changing Needs – Recommendations for Future Study Committees

The Wisconsin Joint Legislative Council asked the authors of this paper to study the impact of state demographic trends on state policy implementation and development. Any given demographic trend has the potential to affect policy; however, the aging of Wisconsin's population will affect many policy areas in the 21st century. "This 'graying of the population' is a trend that speaks clearly regarding some of the challenges the state will face in coming years in the areas of social, health and housing policy" (Voss, Verhoff, & Long, 2004, p.117). Long-term care intersects all three of those policy areas, creating major tests for state policy in the years to come.

If trends continue, Wisconsin could see the crowding out of public services not related to caring for elderly people; high-quality care available to some individuals, but inadequate care available to others; fiscal hardships faced by parts of the state with high numbers of elderly individuals; job changes due to informal caregiving demands; increased shortages of skilled caregivers; and a range of other problems related to long-term care for the elderly.

To address these situations, we propose the following study committees for the Joint Legislative Council:

# Examine the current situation of informal caregiving for elderly people in Wisconsin

The special committee should specifically evaluate Wisconsin's caregiver support programs, research current state programs offering financial support to informal caregivers, and consider options to help keep families in Wisconsin through economic development, and propose legislation as the committee sees fit.

## Evaluate, compare, and determine the future of the Community Options Program and Family Care

The study committee should specifically assess current use of long-term care and predict use patterns; evaluate the current funding levels and sources for the Community Options Program and Family Care; review implementation procedures in Family Care pilot counties; define adequate and sustainable levels of care with regards to state programs for the elderly, including tracking those individuals on COP waiting lists; determine the program that meets the criteria; and propose legislation as the committee sees fit.

## **Evaluate the options for alleviating the workforce shortage in long-term care**

The study committee should formulate a plan for improved data collection about Wisconsin's health-care workforce; examine Medicaid "wage pass-through" and propose necessary changes; determine how long-term care reimbursement policies could be altered to reward quality; evaluate educational opportunities for skilled caregivers; and propose legislation as the committee sees fit.

Demographic trends do not exist in a vacuum. The demographic trends described in this report are converging to have wide-ranging effects on long-term care in Wisconsin. Wisconsin in 2030 will need different services than Wisconsin in 2005. The Legislature can use this knowledge about demographic trends to create long-term care policy that will have a positive effect on the people of Wisconsin, now and in the future.

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# Appendix A: Detail on Community Options Program and Family Care

The Community Options Program (COP) and Family Care are the two major programs available to Wisconsin elderly for assistance in remaining in their homes when living completely independently is no longer possible. COP is available in every county throughout Wisconsin, but there are waiting lists to receive services. Family Care, on the other hand, is a pilot program in nine counties throughout the state. Family Care is an entitlement, which means that individuals determined eligible through an evaluation receive services immediately.

COP is administered by county human services agencies and governed by the Wisconsin Department of Health and Family Services (WDHFS, 2004a). COP services are paid for by state general purpose revenue and the COP Waiver (WDHFS, 2004a). A set amount of COP funding is provided to each county, which can serve people based on the cost of nursing home care in that area (LFB, 2005). There are no income limits to have a COP assessment and care plan created, but income limits are used to decide if COP will pay for all or part of the services (WDHFS, 2004a). Individuals who may not be eligible for the COP waiver but who are eligible for COP services are those with early stage Alzheimer's disease and individuals with chronic mental illness.

Four federal Medicaid waivers fund Family Care (LFB, 2005). These waivers are combined into a single "pot of money" to make funding easier (Donna McDowell, personal communication, March 30, 2005). Family Care is made up of two major components: resource care centers and care maintenance organizations (CMOs). Only five counties have both the resource centers and CMOs; the other four counties have only resource centers. CMOs are the most expensive component of the Family Care program.

The resource centers provide information, assessments and eligibility determinations, and the CMOs that manage and provide the Family Care benefit (LFB, 2005). Eligible individuals enroll in their county CMO, similar to how individuals enroll in an HMO. The CMOs are generally part of the county aging department or human services department.

# Appendix B: Specific Situations Contributing to Workforce Shortages

The core of the long-term health-care workforce is made up of registered nurses (14 percent of workforce), licensed practical nurses (14 percent of workforce), and paraprofessionals (72 percent of workforce) including: certified nursing assistants, nursing assistants, orderlies, personal care workers, personal care attendants, personal aides, home health and home care aides. Several supply-side factors particular to the long-term health-care industry may be converging to constrain the supply of and increase the turnover rate of these workers (USDHHS, 2003). Some of these factors, specific to profession, are detailed below.

### **Registered Nurses**

In addition to supply-and-demand problems, 40 percent of register nurses (RNs) are dissatisfied with their jobs, making recruitment and retention difficult. The nursing workforce is also aging; 66 percent of all nurses are 41 to 60 years old (USDHHS, 2003). RNs in long-term care settings face a complex regulatory environment, have few training and education opportunities related to long-term care populations, and earn lower salaries and face decreased benefits compared to nurses in hospital settings (USDHHS, 2003). The professional nursing labor market is different from the paraprofessional "direct care" market in that there is a "time lag to entry" caused by higher educational requirements (i.e., in Wisconsin, a two-year associate's degree or four-year bachelor's degree). Therefore, in the nursing professions, even if job competitiveness improves, new candidates still must apply for, enter, and graduate from one of these programs (Citizens for Long-Term Care, 2003).

#### **Licensed Practical Nurses**

Licensed practical nurses (LPNs) provide basic bedside care under the direction of registered nurses or physicians and often serve as charge nurses (USDHHS, 2003). Their major responsibilities include supervising nursing assistants, dispensing medications, providing treatments, and monitoring residents' conditions (Stone, 2000). LPNs take on educational roles in residential settings by supervising home health-care aides and providing basic nursing instruction to informal caregivers. Factors contributing to constrain the supply of LPNs in long-term care settings are similar to those for RNs, including pipeline and educational facility shortages, inadequate training, and lack of benefits compared to LPNs in other care settings (DHHS, 2003).

### **Certified Nursing Assistants**

The median hourly wage for certified nursing assistants (CNAs) in Wisconsin is \$10.44, 22 percent less than median hourly wage for all occupations in the state. Most CNAs do not work full time; statewide, about half of nursing home workers are part-time (Direct Care Workforce Issues Committee, 2005). Benefits are not standard in these positions. These jobs involve strenuous physical labor and have high injury rates. Turnover rates for CNAs have been estimated as high as 76 percent, and shortages abound, aggravating problem conditions by reducing the amount of time that can be spent with each patient.

#### **Home Health Aides**

The state does not have comprehensive information about home health aides. Estimates suggest that home health aides constitute two-thirds of long-term paraprofessional workers; however, this estimate undercounts the number of home health workers because it excludes hospital-based workers, independent providers, and public agency workers (USDHHS, 2003).

Home health aides are particularly vulnerable to low wages and lack of benefits because of the nature of their employment; for example, many work part-time and independently. In Wisconsin, the median wage for home health aides is \$9.49 (Direct Care Workforce Issues Committee, 2005). In addition, unlike RNs, LPNs, and some CNAs, there are no standards within the home health-care industry for workers' wages and benefits. Other constraining factors are similar to those faced by other health-care paraprofessionals, including lack of training and the stigma of being perceived as an extension of domestic worker. It is also difficult for home health-care workers to emigrate from other countries due to work permitting issues, further limiting supply (USDHHS, 2003).